COMMUNICATION BETWEEN CHILDREN WITH CANCER AND THEIR CARETAKERS

by

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We accept this thesis as conforming to the required standard

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ABSTRACT

The study examines interactions between children with cancer, their parents and hospital staff. Participant observation and interviewing techniques were used to gain insight into the perspectives of the three groups of persons involved. Various hospital staff members were followed through their daily routines and parents were extensively observed and interviewed. Children were observed during their first phase of the treatment in hospital using a case study approach.

Extensive examples of interactions and scenes from the hospital setting are presented and analyzed. The changing role of participant observation is discussed and examined from the personal perspective of the observer.

The understanding of the communication of each group which was generated showed many failures in mutual understanding during interactions. Well-meaning staff were often caught in organizational and hierarchical issues of the hospital setting and interpreted parent's and children's behaviour according to its usefulness for the application of treatment procedures. Parents tried to comply with hospital requirements, which seemed to represent their only hope for the well-being of their child, while at the same time they had to cope with their feelings in face of the suffering of their child. Children seemed to suffer from the direct consequences of the treatment as well as from the lack of meaningful explanations of the events, which led them to distrust communications.

It is concluded that caring persons frequently fail to relate to the world of children with cancer, impeding a cooperative effort in the fight against the illness.
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Björn Ratjen
INTRODUCTION

It is not an easy task to communicate the complexity of a particular setting to someone else. Personal experiences are involved and sometimes moods and emotions express more than the spoken word. Structure is a necessary element in transmission of information and various ways have been chosen in an effort to reflect the processes of the hospital setting and the persons in it.

A brief overview may help as a guide through the information: The First Chapter provides background and focus of the study which is followed by review of appropriate literature in Issues Concerning the Child with Cancer in the Literature. The next chapter Conceptualizations highlights the underlying theoretical concepts. Conducting the Inquiry explains the methodological approach of this study in general terms. A closer look at methodological issues arising from the observations of the individual groups is given in conjunction with the accounts of staff, parents, and children. This is in line with the process oriented character of the study and places issues in their proper context. The chapter Participant Observations - A Personal Account provides a personal view of the experiences which the researcher has made during the conduct of the study. Since the researcher has been the major instrument for data collection, this chapter informs about the processes which were involved in the conduct of the study and highlights personal experiences. It should also help to shed some light on the researcher's viewpoint when viewed comparatively with similar studies.

Three groups of persons form the focus of the next three chapters: Hospital Staff, Parents and Families, and Children. These chapters - in the case of the hospital staff it also involves subchapters about the various subgroups are organized in a somewhat parallel way in order to facilitate comparisons between
the different groups of persons. Patterns of information gathering and relationships as well as the perspectives of individual groups are already reflected in the structure of these accounts through respective subchapters. Actual scenes describe events in the hospital and illustrate interactions, however the names of the person have been changed in order to ensure their anonymity. Every one of those chapters and subchapters is concluded by a reflective account highlighting some issues concerning the observations of the persons involved. This should make the conduct of the study somewhat more transparent. It can also show some details about the atmosphere and the problems which arose during individual observation periods.

_The Last Chapter_ sums up the study, its concerns and its findings. The findings of the respective subchapters are reflected and analyzed in the context of the study as a whole and its theoretical background.

The whole report is interspersed with scenes (*Images*) from the setting and other relevant sources, which hopefully help to communicate some additional aspects of the atmosphere on the hospital ward. These scenes are direct accounts or quotations which are placed into a context without further comment. They are like windows and enable the reader to look at some issues which are important for the understanding of the context of interactions.
# TABLE OF CONTENTS

Abstract ........................................................................................................... ii

Acknowledgements ....................................................................................... iii

Introduction ...................................................................................................... iv

1. The First Chapter ................................................................. 1
   1.1. The Beginning ................................................................. 1
   1.2. The Search for Meaning .................................................... 2
   1.3. Interacting When a Child Has Cancer .............................. 3
   1.4. Focus of the Study ............................................................. 4

2. Issues Concerning the Child with Cancer in the Literature ............. 10
   2.1. Terminal, Life-Threatening, or Chronic Illness .................. 10
   2.2. Attitudes Toward Death and Dying ................................. 10
   2.3. Children and Death .......................................................... 15
   2.4. Reactions to the Diagnosis .............................................. 17
      2.4.1. Impact on Parents ...................................................... 18
      2.4.2. Impact on Children .................................................. 21
      2.4.3. Impact on Siblings .................................................... 22
   2.5. Awareness Context and Knowledge About Illness ............ 22
   2.6. 'Protective' and 'Open' Approach .................................... 25
   2.7. Children's Awareness and Information ........................... 29
   2.8. Hospitalization ................................................................. 33
      2.8.1. Being in Hospital ...................................................... 33
      2.8.2. Impact of Illness and Hospitalization on Children ....... 34
      2.8.3. The Roles of Health Professionals ......................... 36
   2.9. The Various Perspectives ................................................. 40

3. Conceptualizations ................................................................................. 42

4. Conducting the Inquiry ................................................................. 51
   4.1. Context of the Study ........................................................ 52
      4.1.1. Phases of the Illness .................................................. 52
      4.1.2. The Persons Involved ................................................. 53
   4.2. An Anthropological Approach: Participant Observation .... 55
   4.3. Access ................................................................................. 62
   4.4. Fieldwork ............................................................................ 64
      4.4.1. The Setting ................................................................. 65
      4.4.2. First Phase: Hospital Staff ......................................... 65
      4.4.3. Second Phase: Parents and Children ....................... 67
         4.4.3.1. Parents ................................................................. 68
         4.4.3.2. Children ............................................................. 71
   4.5. Recording Procedures ...................................................... 72
   4.6. Post Fieldwork Analysis ................................................... 75

5. Participant Observation: A Personal Account .............................. 79
   5.1. Stage 1: Preparations ......................................................... 79
<table>
<thead>
<tr>
<th>Section</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.2.</td>
<td>Stage 2: The Preliminary Field Work</td>
<td>81</td>
</tr>
<tr>
<td>5.3.</td>
<td>Stage 3: The Formal Proposal</td>
<td>91</td>
</tr>
<tr>
<td>5.4.</td>
<td>Stage 4: The Fieldwork</td>
<td>93</td>
</tr>
<tr>
<td>5.5.</td>
<td>Stage 5: Analysis</td>
<td>101</td>
</tr>
<tr>
<td>6.</td>
<td>Hospital Staff</td>
<td>102</td>
</tr>
<tr>
<td>6.1.</td>
<td>Introduction</td>
<td>102</td>
</tr>
<tr>
<td>6.1.1.</td>
<td>The Social Setting</td>
<td>102</td>
</tr>
<tr>
<td>6.1.2.</td>
<td>Observational Approach</td>
<td>105</td>
</tr>
<tr>
<td>6.1.3.</td>
<td>The Structure of Analysis</td>
<td>106</td>
</tr>
<tr>
<td>6.2.</td>
<td>Hospital Teachers</td>
<td>106</td>
</tr>
<tr>
<td>6.2.1.</td>
<td>The School Setting</td>
<td>107</td>
</tr>
<tr>
<td>6.2.2.</td>
<td>Teaching Aims</td>
<td>108</td>
</tr>
<tr>
<td>6.2.3.</td>
<td>Rewards</td>
<td>109</td>
</tr>
<tr>
<td>6.2.4.</td>
<td>Teachers' Position in the Hospitals</td>
<td>110</td>
</tr>
<tr>
<td>6.2.5.</td>
<td>Information</td>
<td>111</td>
</tr>
<tr>
<td>6.2.6.</td>
<td>Teacher and Children</td>
<td>115</td>
</tr>
<tr>
<td>6.2.7.</td>
<td>Children's Attitudes</td>
<td>120</td>
</tr>
<tr>
<td>6.2.8.</td>
<td>The Teachers' Perspective</td>
<td>120</td>
</tr>
<tr>
<td>6.2.9.</td>
<td>Observing the Teachers</td>
<td>123</td>
</tr>
<tr>
<td>6.3.</td>
<td>Nurses</td>
<td>126</td>
</tr>
<tr>
<td>6.3.1.</td>
<td>The Nurses' Setting</td>
<td>126</td>
</tr>
<tr>
<td>6.3.2.</td>
<td>Nursing Aims</td>
<td>130</td>
</tr>
<tr>
<td>6.3.2.1.</td>
<td>Nurses' Rewards</td>
<td>133</td>
</tr>
<tr>
<td>6.3.3.</td>
<td>Information</td>
<td>134</td>
</tr>
<tr>
<td>6.3.4.</td>
<td>Nurses' Position in the Hospital</td>
<td>141</td>
</tr>
<tr>
<td>6.3.5.</td>
<td>Nurses and Parents</td>
<td>145</td>
</tr>
<tr>
<td>6.3.6.</td>
<td>Nurses and Children</td>
<td>146</td>
</tr>
<tr>
<td>6.3.6.1.</td>
<td>Treatments</td>
<td>146</td>
</tr>
<tr>
<td>6.3.6.2.</td>
<td>Casual Interactions</td>
<td>148</td>
</tr>
<tr>
<td>6.3.6.3.</td>
<td>Understanding Children</td>
<td>154</td>
</tr>
<tr>
<td>6.3.7.</td>
<td>The Perspective of Nurses</td>
<td>158</td>
</tr>
<tr>
<td>6.3.8.</td>
<td>Observing the Nurses</td>
<td>161</td>
</tr>
<tr>
<td>6.4.</td>
<td>Child Life</td>
<td>164</td>
</tr>
<tr>
<td>6.4.1.</td>
<td>Child Life Workers in the Hospital</td>
<td>164</td>
</tr>
<tr>
<td>6.4.2.</td>
<td>Aims</td>
<td>165</td>
</tr>
<tr>
<td>6.4.3.</td>
<td>Rewards</td>
<td>167</td>
</tr>
<tr>
<td>6.4.4.</td>
<td>Information</td>
<td>167</td>
</tr>
<tr>
<td>6.4.5.</td>
<td>Relating to Other Hospital Staff</td>
<td>168</td>
</tr>
<tr>
<td>6.4.6.</td>
<td>Child Life Worker and Parents</td>
<td>171</td>
</tr>
<tr>
<td>6.4.7.</td>
<td>Child Life Worker and Children</td>
<td>173</td>
</tr>
<tr>
<td>6.4.8.</td>
<td>The Perspective of a Child Life Worker</td>
<td>177</td>
</tr>
<tr>
<td>6.4.9.</td>
<td>Observing the Child Life Worker</td>
<td>179</td>
</tr>
<tr>
<td>6.5.</td>
<td>Physicians</td>
<td>182</td>
</tr>
<tr>
<td>6.5.1.</td>
<td>Aims</td>
<td>182</td>
</tr>
<tr>
<td>6.5.2.</td>
<td>Information</td>
<td>183</td>
</tr>
<tr>
<td>6.5.3.</td>
<td>Physicians Relating to Other Physicians</td>
<td>186</td>
</tr>
<tr>
<td>6.5.4.</td>
<td>Physicians and Nurses</td>
<td>187</td>
</tr>
<tr>
<td>6.5.5.</td>
<td>Physicians and Parents</td>
<td>188</td>
</tr>
<tr>
<td>Section</td>
<td>Page</td>
<td></td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>------</td>
<td></td>
</tr>
<tr>
<td>6.5.6. Physicians and Children</td>
<td>191</td>
<td></td>
</tr>
<tr>
<td>6.5.7. The Perspective of a Physician</td>
<td>192</td>
<td></td>
</tr>
<tr>
<td>6.5.8. Observing the Physicians</td>
<td>195</td>
<td></td>
</tr>
<tr>
<td>6.6. Therapists</td>
<td>198</td>
<td></td>
</tr>
<tr>
<td>6.6.1. Occupational Therapist</td>
<td>198</td>
<td></td>
</tr>
<tr>
<td>6.6.1.1. Aims</td>
<td>198</td>
<td></td>
</tr>
<tr>
<td>6.6.1.2. Information</td>
<td>199</td>
<td></td>
</tr>
<tr>
<td>6.6.1.3. Occupational Therapist and Children</td>
<td>199</td>
<td></td>
</tr>
<tr>
<td>6.6.1.4. Occupational Therapist and Parents</td>
<td>202</td>
<td></td>
</tr>
<tr>
<td>6.6.1.5. Relationship with other Staff</td>
<td>203</td>
<td></td>
</tr>
<tr>
<td>6.6.1.6. The Perspective of the Occupational Therapist</td>
<td>205</td>
<td></td>
</tr>
<tr>
<td>6.6.1.7. Observing the Occupational Therapist</td>
<td>206</td>
<td></td>
</tr>
<tr>
<td>6.6.2. Physiotherapist</td>
<td>208</td>
<td></td>
</tr>
<tr>
<td>6.6.2.1. Aims</td>
<td>208</td>
<td></td>
</tr>
<tr>
<td>6.6.2.2. Information</td>
<td>209</td>
<td></td>
</tr>
<tr>
<td>6.6.2.3. Physiotherapist and Children</td>
<td>209</td>
<td></td>
</tr>
<tr>
<td>6.6.2.4. Physiotherapist and Parents</td>
<td>211</td>
<td></td>
</tr>
<tr>
<td>6.6.2.5. Relationship with other Staff</td>
<td>212</td>
<td></td>
</tr>
<tr>
<td>6.6.2.6. The Perspective of the Physiotherapist</td>
<td>212</td>
<td></td>
</tr>
<tr>
<td>6.6.2.7. Observing the Physiotherapist</td>
<td>213</td>
<td></td>
</tr>
<tr>
<td>6.6.3. The Perspectives of Therapists</td>
<td>215</td>
<td></td>
</tr>
<tr>
<td>6.7. Social Workers</td>
<td>216</td>
<td></td>
</tr>
<tr>
<td>6.7.1. Aims</td>
<td>216</td>
<td></td>
</tr>
<tr>
<td>6.7.2. Information</td>
<td>218</td>
<td></td>
</tr>
<tr>
<td>6.7.3. Social Worker and Parents</td>
<td>219</td>
<td></td>
</tr>
<tr>
<td>6.7.4. Social Worker and Children</td>
<td>225</td>
<td></td>
</tr>
<tr>
<td>6.7.5. Social Worker Relating to other Staff</td>
<td>227</td>
<td></td>
</tr>
<tr>
<td>6.7.6. The Perspective of the Social Worker</td>
<td>229</td>
<td></td>
</tr>
<tr>
<td>6.7.7. Observing the Social Worker</td>
<td>230</td>
<td></td>
</tr>
<tr>
<td>6.8. Other Staff</td>
<td>233</td>
<td></td>
</tr>
<tr>
<td>6.8.1. Technicians</td>
<td>233</td>
<td></td>
</tr>
<tr>
<td>6.8.2. Housekeeping Personnel</td>
<td>234</td>
<td></td>
</tr>
<tr>
<td>6.8.3. Psychologist</td>
<td>234</td>
<td></td>
</tr>
<tr>
<td>6.8.4. Dietitian</td>
<td>235</td>
<td></td>
</tr>
<tr>
<td>6.8.5. Volunteers</td>
<td>235</td>
<td></td>
</tr>
<tr>
<td>6.9. Staff Perspectives</td>
<td>237</td>
<td></td>
</tr>
<tr>
<td>6.9.1. The Medical Line of Authority</td>
<td>237</td>
<td></td>
</tr>
<tr>
<td>6.9.2. The Administrative Line of Authority</td>
<td>238</td>
<td></td>
</tr>
<tr>
<td>6.9.3. Complementary Line of Authority</td>
<td>239</td>
<td></td>
</tr>
<tr>
<td>6.9.4. Issues</td>
<td>239</td>
<td></td>
</tr>
<tr>
<td>7. Parents and Family</td>
<td>243</td>
<td></td>
</tr>
<tr>
<td>7.1. Introduction</td>
<td>243</td>
<td></td>
</tr>
<tr>
<td>7.1.1. The Case Studies</td>
<td>243</td>
<td></td>
</tr>
<tr>
<td>7.1.2. Observational Approach</td>
<td>249</td>
<td></td>
</tr>
<tr>
<td>7.2. Discovering the Illness</td>
<td>252</td>
<td></td>
</tr>
<tr>
<td>7.3. Reactions to the Diagnosis</td>
<td>254</td>
<td></td>
</tr>
<tr>
<td>7.4. Parents in Hospital</td>
<td>259</td>
<td></td>
</tr>
<tr>
<td>Section</td>
<td>Page</td>
<td></td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>------</td>
<td></td>
</tr>
<tr>
<td>7.5. Information</td>
<td>263</td>
<td></td>
</tr>
<tr>
<td>7.6. Parents and Hospital Staff</td>
<td>266</td>
<td></td>
</tr>
<tr>
<td>7.6.1. Parents and Physicians</td>
<td>268</td>
<td></td>
</tr>
<tr>
<td>7.6.2. Parents and Nurses</td>
<td>271</td>
<td></td>
</tr>
<tr>
<td>7.6.3. Parents and Social Worker</td>
<td>274</td>
<td></td>
</tr>
<tr>
<td>7.7. Parents Relating to other Parents</td>
<td>275</td>
<td></td>
</tr>
<tr>
<td>7.8. Parents and their Children</td>
<td>278</td>
<td></td>
</tr>
<tr>
<td>7.8.1. In Hospital</td>
<td>278</td>
<td></td>
</tr>
<tr>
<td>7.8.2. After Treatment</td>
<td>281</td>
<td></td>
</tr>
<tr>
<td>7.9. Impact on the Family System</td>
<td>282</td>
<td></td>
</tr>
<tr>
<td>7.9.1. Grandparents</td>
<td>283</td>
<td></td>
</tr>
<tr>
<td>7.9.2. Siblings</td>
<td>284</td>
<td></td>
</tr>
<tr>
<td>7.10. Parental Perspectives</td>
<td>286</td>
<td></td>
</tr>
<tr>
<td>7.11. Observing the Parents</td>
<td>290</td>
<td></td>
</tr>
<tr>
<td>8. Children</td>
<td>293</td>
<td></td>
</tr>
<tr>
<td>8.1. Introduction</td>
<td>293</td>
<td></td>
</tr>
<tr>
<td>8.1.1. The Case Studies</td>
<td>293</td>
<td></td>
</tr>
<tr>
<td>8.1.2. Observational Approach</td>
<td>295</td>
<td></td>
</tr>
<tr>
<td>8.2. The Scenario</td>
<td>296</td>
<td></td>
</tr>
<tr>
<td>8.2.1. Diagnosis and Treatment</td>
<td>296</td>
<td></td>
</tr>
<tr>
<td>8.2.2. A Child’s View</td>
<td>298</td>
<td></td>
</tr>
<tr>
<td>8.3. Children’s Communications</td>
<td>300</td>
<td></td>
</tr>
<tr>
<td>8.3.1. Nonverbal Symbols</td>
<td>300</td>
<td></td>
</tr>
<tr>
<td>8.3.2. Verbal Symbols</td>
<td>304</td>
<td></td>
</tr>
<tr>
<td>8.4. Children’s Understanding</td>
<td>306</td>
<td></td>
</tr>
<tr>
<td>8.5. Information</td>
<td>309</td>
<td></td>
</tr>
<tr>
<td>8.6. Procedures</td>
<td>319</td>
<td></td>
</tr>
<tr>
<td>8.6.1. Getting an IV</td>
<td>323</td>
<td></td>
</tr>
<tr>
<td>8.6.2. Lumbar Puncture (LP)</td>
<td>326</td>
<td></td>
</tr>
<tr>
<td>8.7. Children and Their Parents</td>
<td>336</td>
<td></td>
</tr>
<tr>
<td>8.8. Children and Hospital Staff</td>
<td>338</td>
<td></td>
</tr>
<tr>
<td>8.8.1. Children Relating to Nurses</td>
<td>339</td>
<td></td>
</tr>
<tr>
<td>8.8.2. Children and Physicians</td>
<td>341</td>
<td></td>
</tr>
<tr>
<td>8.8.3. Children and Child Life Worker</td>
<td>343</td>
<td></td>
</tr>
<tr>
<td>8.8.4. Other Staff</td>
<td>344</td>
<td></td>
</tr>
<tr>
<td>8.9. Children and School</td>
<td>345</td>
<td></td>
</tr>
<tr>
<td>8.10. Children Relating to Children</td>
<td>349</td>
<td></td>
</tr>
<tr>
<td>8.11. The Perspective of Children with Cancer</td>
<td>352</td>
<td></td>
</tr>
<tr>
<td>8.12. Observing the Children</td>
<td>358</td>
<td></td>
</tr>
<tr>
<td>9. The Last Chapter</td>
<td>365</td>
<td></td>
</tr>
<tr>
<td>9.1. Interacting in a Hospital Setting</td>
<td>368</td>
<td></td>
</tr>
<tr>
<td>9.2. Interpretation of Meaning</td>
<td>374</td>
<td></td>
</tr>
<tr>
<td>9.3. Coping Processes</td>
<td>379</td>
<td></td>
</tr>
<tr>
<td>9.4. Adapting to the Suffering</td>
<td>382</td>
<td></td>
</tr>
<tr>
<td>9.4.1. Implications</td>
<td>389</td>
<td></td>
</tr>
<tr>
<td>10. Appendices</td>
<td>392</td>
<td></td>
</tr>
<tr>
<td>Section</td>
<td>Page</td>
<td></td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>------</td>
<td></td>
</tr>
<tr>
<td>10.1. References</td>
<td>392</td>
<td></td>
</tr>
<tr>
<td>10.2. Consent Letter Physicians</td>
<td>426</td>
<td></td>
</tr>
<tr>
<td>10.3. Consent Letter for Parents</td>
<td>429</td>
<td></td>
</tr>
<tr>
<td>10.4. Children's Consent</td>
<td>431</td>
<td></td>
</tr>
<tr>
<td>10.5. Acronyms and Medical Expressions</td>
<td>432</td>
<td></td>
</tr>
</tbody>
</table>
LIST OF IMAGES

<table>
<thead>
<tr>
<th>IMAGE</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>The Five Stages of Grief</td>
<td>13</td>
</tr>
<tr>
<td>2</td>
<td>To the Children</td>
<td>31</td>
</tr>
<tr>
<td>3</td>
<td>Professional Attitudes</td>
<td>142</td>
</tr>
<tr>
<td>4</td>
<td>Not a Good Morning</td>
<td>159</td>
</tr>
<tr>
<td>5</td>
<td>Do You Really Think They Are Alright?</td>
<td>172</td>
</tr>
<tr>
<td>6</td>
<td>In the Special Care Nursery</td>
<td>200</td>
</tr>
<tr>
<td>7</td>
<td>Telling Mother</td>
<td>262</td>
</tr>
<tr>
<td>8</td>
<td>Lullaby for My Dead Child</td>
<td>289</td>
</tr>
<tr>
<td>9</td>
<td>Children’s Talk</td>
<td>299</td>
</tr>
</tbody>
</table>
1. THE FIRST CHAPTER

1.1. THE BEGINNING

At first there was only the personal experience with cancer. It was the experience of an close observer, because I did not suffer from the disease myself but it was my brother who eventually died from it. Nevertheless there were the emotions, the agony, the feelings of sadness and helplessness. I recall the death verdict by the surgeon who nevertheless erred two years in his prognosis, which confused me enough to trigger a search for answers. I witnessed the effects of treatment and hospital environment. I experienced changes in family relations. Then I began to look for explanations and started to read about the experiences of people in similar situations. Two main issues really stood out. One was the search for meaning, an answer to the question why, and to find some way of coping with the situation and the other was the interaction of a family with the medical community, especially within the hospital. Both issues changed profoundly my thinking and behaviour.

The search for meaning meant that one had to come to grips with concepts of the illness and the fears which they evoked. The fear of loss triggered grieving processes while at the same time new information had to be digested. Death was something I had never experienced as closely although I had seen people die before. I remember that at times I thought it was all a bad dream and in the next moment I wished to see my brother dead to save him from the suffering. The search for meaning became a circular motion. Often the individual parts did not seem to make sense, but nevertheless procedures were established and implemented in hope for the best outcome.
There was heavy reliance on sometimes conflicting medical advice. Medical technology seemed to be the last straw. Medical terminology and treatment procedures began to preoccupy thinking and dominate family routines. Advice from physicians was considered carefully and hospital routines often dictated personal choices.

1.2. THE SEARCH FOR MEANING

The experiences catalyzed my investigative interest. At first I looked at the threat of death and dying which is something all those involved with cancer have to come to grips with. The threat of death evokes thoughts about dying which are embedded in personal beliefs and cultural interpretations. I noticed that grieving does not only take place after the event, but begins with the perceived threat of death, which comes with the diagnosis. I remember reading "On Death and Dying" (Kübler-Ross, 1969) and waiting for signs of different phases. The actual experiences as an observer of illness and treatment, however, were usually stronger than theoretical considerations.

In the end, when it actually happened and my brother died, everything was there at once: relief, sadness, anger, and confusion. I also felt troubled because I was unable to understand him and his wishes during the last hours.

After the dust had settled and I had begun to continue my life, I happened to see some children with Leukemia during a presentation in a medical seminar at the university. The search for meaning was on again and I wrote my masters thesis about children's death and dying. I investigated cultural and pedagogical aspects which influenced attitudes to their fate. I found that they were very often wrapped into communicative blankets which in fact seemed to
leave them alone with their coping processes.

All this pointed even more strongly at the unsettled question: what really happens with communication and relationships under the strong influence of medical authority in a hospital setting?

1.3. INTERACTING WHEN A CHILD HAS CANCER

Communicating and achieving mutual understanding is a complex issue which has been in the focus of an ever increasing amount of publications on communication. The added complexities of childhood cancer complicate interactions by individual emotional overlays as well as differences in perception which relate to the various roles of the people involved.

Initially I wanted to distinguish between three different groups of persons who are usually involved in interactions when children have cancer, medical staff, their parents and family, and of course the children themselves. Interactions between these groups build the framework for coping.

As we will see in the next chapter the literature examines interactions from various viewpoints. Some parents wrote very personal and illustrative accounts of their experiences (e.g. Becker, 1977; Ludwig-Klein, 1980) The bulk of the literature, however, is written by professionals who emphasize several issues. On the one hand attempts have been made to interpret children's behaviour and their reactions to the illness (e.g. Bürgin, 1978; Spinetta, 1977; Kellerman, 1980) and others have looked at family issues (e.g. Mann, 1974; Desmond, 1977; Pearse, 1977; Christ and Flomenhaft, 1984). Considerable thought has also been given to the question of information and the adjustment to it (e.g. Share, 1972; Slavin et al., 1982) However, rarely have researchers looked at the ongoing
dynamic interactions during the treatment and the degree of mutual understanding which is achieved on the basis of the perception of those involved. What is actually communicated between families, their children with cancer and the hospital staff, and how is it understood? How are messages actually perceived by the different persons involved? These questions centered around the child led to the current research.

1.4. FOCUS OF THE STUDY

It is the view of symbolic interactionism that persons possess a self which is expressed in interaction with others and enables the individual to organize own behaviour toward others (Blumer, 1969; Denzin, 1973). This study focuses on the expressions of self in the context of pediatric cancer. Those expressions vary according to the setting where interactions take place, the situational roles and functions of the persons involved, and the emotional context. The symbols used to communicate meaning are analyzed on the basis of those variables.

The context of meaning involves the interactions of three groups of persons: hospital staff, parents, and children. This study strives to analyze the evolution of understanding between those three groups as dynamic and interactional processes from an inside and outside perspective. The inside perspective refers to the understanding which persons develop and express during interactions. The outside perspective addresses an analysis from an observer's viewpoint which can generate an additional understanding on a meta-level.

This exploratory study also acknowledges the dynamic character of interactional processes in its methodology. The researcher follows the whole way from the development of personal understanding to the expressions of meaning
which take place during interactions. The processes of data collection, which have an influence on interpretations, are themselves subject to analysis.

The first phase of the illness (between diagnosis and first remission) is chosen as the primary target, because it is the initial contact with the illness. This evokes many reactions in parents and children which require the development of appropriate coping mechanisms. It has also been reported to be a time of extreme stress for children and their families (Fife, 1980; Christ et al., 1984; Northouse, 1984).

The interest in communication involving children with cancer stems from the experience of the researcher and others that mutual understanding can have a great impact on the coping processes. Mutual understanding means that two or more persons achieve a common basis of understanding by relating to each other with communicative means which they are able to interpret in the same way. This may also be explained with reference to the awareness context where mutual understanding may be created if persons can relate to their respective awareness context.¹ The literature about the psychosocial effects of childhood cancer often refers to a functional context of understanding, i.e. whether or not parents understand the diagnosis. However, communication is a dynamic process which involves different personalities, role relationships, and situational context. It involves the transfer of meaning with the help of interpretable symbols. Therefore communication and the interpretation of meaning must be understood in relationship to the perspectives of the three groups involved: hospital staff, parents and family, and the children with cancer. An analysis of their communication must relate to their perspectives and include a careful exploration

¹ See chapter "2.5. Awareness Context and Knowledge About Illness".
of the interactive processes within the hospital setting.

This leads to three general questions:

1. **How do persons involved with children with cancer in a hospital setting interact with each other?**
2. **What is the mutual understanding of meaning among the participants in interactions?**
3. **How does communication in the hospital setting relate to the coping processes?**

These general exploratory questions involve different persons and can be broken down into several components which leads to a set of more specific questions.

**Question 1:** The time span of interactions in this study covers the period of hospitalization after a diagnosis has been established until a first remission is achieved. It has been mentioned that an interpretation of communication must involve knowledge about the interactive context. The influence of the setting with its behavioural rules has to be taken into account as well as the various means of expression which the interacting persons choose to communicate. The question "how" relates to form and content of interactions.

It is important to study the means of communication of all persons involved - hospital staff, parents (and family), and children - because they form the framework of interactions. This can be addressed with the following question:

- **How do persons in a hospital setting express themselves?**

This question addresses the kind of symbols which are used in relation to the context of interactions. It is of interest which means are used for communicating with each other and how those are being utilized. In order to understand their communication one has to analyze expressions and their intentions. This leads to
another question, which is applicable to those three groups:

- **What levels of communication are used in interactions in the hospital setting?**

Different levels of communication may communicate different messages, i.e. voice and gestures may communicate anxiety while words try to convey factual information. This may be illustrated by focusing on a particular information, which can be pursued as it is passed on from one person to another. Illness related communication is of particular interest because it is the revolving point of many activities in this context.

- **How is information illness related communicated?**

This question refers to communication among members of one group and between one group and another, e.g. nurses and parents.

The constellation of interactions may also change the content of communications and it is of interest to learn more about the focus of interactions and where they take place.

- **What is the focus of communications in interactions among members of one group and in relation to the other persons involved?**

The answer to this question may help to illustrate where and how important information is being passed on to others. Additional understanding may be achieved if the approaches toward an interaction and intentions which influence the behaviour are clarified. In other words:

- **What is the intention of communication within a specific group and in communication with others?**

This question addresses the relationships of persons within one group and to other persons outside. The intention has to be examined from the perspectives of the parties involved, which may then generate an understanding of their
viewpoint and how it relates to the interpretation of meaning by another group.

Question 2: Successful communication results in mutual understanding. This requires a good perception of the symbols which are used to communicate meaning. Meaning is attached to symbols within a personal and situational context. Understanding the meaning of communicated messages requires knowing how to interpret other's symbols. After one has looked at the different means of communication which are used among the persons involved, it would be interesting to learn more about the levels of mutual understanding. This relates to the degree of understanding members of one group develop of members of another group as well as to the awareness they have of each others interpretations. On the one hand one would like to know:

- What are the levels of understanding between the different groups?
The levels of understanding cannot be measured in absolute terms. The question rather refers to a comparison between the understanding which one group has of itself and the interpretation of another group. In addition the question arises:

- What is the awareness of each others interpretation of meaning?
The answers to these questions may produce insight into the relationships between the different persons in a hospital setting.

It is of special interest when lack of mutual understanding may lead to a breakdown of communication.

- If there is misinterpretation of communications, how and why does it happen?
Information about misinterpretations can only be gathered when a thorough knowledge of the perceptions of the persons involved can be achieved.

Question 3: Part of the literature indicates that communication can have

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2 See also the considerations in chapter "3. Conceptualizations".
considerable impact on coping, i.e. "open" versus "protected" approach. Although some effects (i.e. isolation) have been mentioned the direct impact of communication on coping has yet to be assessed.

- **What are the effects of communication on coping for children, parents and hospital staff?**

Coping has individual and role components. Coping relates on the one hand to the personal management of difficult situations and on the other it relates to the performance according to a specific role. Coping of hospital staff for example may be regarded as adapting according to professional requirements. The hospital organization may also prescribe certain ways of coping (Menzies, 1970) which influence communication. There is a mutual influence and one may also ask:

- **How do coping strategies influence communication?**

Since coping with the situation is very important the study may also reveal strategies for improvements.

- **What are the improvements which can be made to facilitate coping with the situation?**

This addresses implications for individual behaviour as well as for the organizational constitution of the setting. In addition it may point out directions for future research.

The main concern in this study centers around the well-being of the child. It is the aim to generate a more thorough understanding of the interactive processes in a hospital setting. If understanding prevails then beneficial adaptations for individual needs can hopefully be found. Before the investigation can be conducted we should take a look at present knowledge about some of the important issues in the environment of children with cancer.
2. ISSUES CONCERNING THE CHILD WITH CANCER IN THE LITERATURE

2.1. TERMINAL, LIFE-THREATENING, OR CHRONIC ILLNESS

Literature on children with cancer is found under different headings. This is a reflection of the progress in medical treatment, which has increased the survival rates of many forms of the disease. The focus of research about the psychological impact of the illness has also shifted toward a more long term strategy of coping, preparing to live with cancer (Spinetta et al., 1981).

Nevertheless the issue of death is relevant because many still die from cancer. As Dongen-Melman and Sanders-Woudstra (1986a: 166) note:

"As long as cancer is not a completely curable disease, and it is unpredictable whether a child will die or will be cured, aspects directly related to the loss of the child will be present."

A confrontation with death is created, not only when someone is actually dying from cancer, but also in a perceived sense when a diagnosis of cancer is regarded as a real or possible death threat. It is part of the stigma (Goffman, 1963) of the illness which establishes a link to personal and cultural attitudes toward death and dying.

2.2. ATTITUDES TOWARD DEATH AND DYING

Attitudes toward death depend on cultural and individual backgrounds (Ariès, 1974; Fremantle and Trungpa, 1975). Death cannot be considered as a purely individual event. The dying person is a social being with many interrelations with the social environment, relations to individual persons and relations to
society with respect to social functions (Fuchs, 1979). The personal confrontation with a dying person is minimized for the general public, because it mostly takes place in hospital. David Sudnow (1967) described how health professionals avoid the confrontation with death. In the hospital setting death is again dealt with by specialists who, therefore are attached with a certain stigma in the health care setting.

When Elisabeth Kübler-Ross started her work on death and dying she faced unforeseen problems (Kübler-Ross, 1971):

"How naive I was: I discovered that there was not a single dying patient in a 600-bed hospital! I went from ward to ward and told the nurses and the doctors that I would like to talk to a terminally ill patient. "What about?"
"About dying."
"Oh, we have nobody dying."
If I pushed, they said, "He's too weak" or "too sick" or "too tired" or "he doesn't feel like talking". A lot of not only denial and rationalization but also hostility and some very aggressive behaviour emerged. One nurse asked me, "Do you get a kick out of telling a 20-year-old that he has one week to live?" And, of course, there was much well-meant protectiveness for the patients."

Although death seems to be put aside as a taboo in a medically oriented world, an increasing amount of literature about many aspects of death and dying can be found (Fulton, 1977; Simpson, 1979). This amount makes Michael Simpson (1979) in his annotated bibliography even wonder if death really is a taboo topic. Even though there is an increasing amount of information available in literature and other media, it cannot replace the personal experience. For most people death seems to be happening somewhere else. Thus a diagnosis of cancer provides a sudden realization of the imminence of death.

After the initial phase of shock, reactions like disbelief, denial, anger,
bargaining (guilt), and depression have been observed. These feelings have been
described as a form of anticipatory grief. Erich Lindeman (1944) first used this
term, when he described the reactions of parents to the threat of the loss of
their child after a major accident in which several children of a community were
killed. Later studies revealed that the expectation of a loss can also produce
these reactions (Friedman et al., 1963; Green and Solnit, 1964; Chodoff et al.,
1964; Schoenberg, 1970) as a preparation for the threatening incident. One can
also assume that most of the people involved with someone who has a life
threatening illness or seems to be dying go through similar reactions, including
the health professionals involved in the care (Teyber and Littlehales, 1981).

The reactions involved are very similar to the ones Elisabeth Kübler-Ross
described in her studies with persons who are actually dying. She described five
different stages (1968):

1. Denial and Isolation: "not me, it cannot be true."
2. Anger: "Why me?"
3. Bargaining: "If God has decided to take us from earth and he did not
   respond to my angry pleas, he may be more favourable if I ask nicely."
4. Depression: reactive depression, preparatory depression.
5. Acceptance: final rest before the long journey.

Kübler-Ross herself and others have noticed that these stages do not necessarily
appear as a consistent sequence of reactions (Kübler-Ross, 1969) and some of the
research concerning stages of dying seems to show inconsistencies (Schulz and
Aderman, 1974). Others have added additional stages and substages and thus
expanded the scope of reactions, e.g. Sporken (1973), who divided stage one into
implicit and explicit denial. In addition it has to be considered if these stages
The Five Stages of Grief

The night I lost you
someone pointed me towards
the Five Stages of Grief.
Go that way, they said,
it's easy, like learning to climb
stairs after the amputation.
And so I climbed.
Denial was first.
I sat down at breakfast
carefully setting the table
for two. I passed you the toast
you sat there. I passed
you the paper - you hid
behind it.
Anger seemed more familiar.
I burned the toast, snatched
the paper and read the headlines myself.
But then they mentioned your departure,
and so I moved on to
Bargaining. What could I exchange
for you? The silence
after storms? My typing fingers?
Before I could decide, Depression
came puffing up, a poor relation
its suitcase tied together
with string. In the suitcase
were bandages for the eyes
and bottles of sleep. I slid
all the way down the stairs
feeling nothing.
And all the time Hope
flashed on and off
in defective neon.
Hope was a signpost pointing
straight in the air.
Hope was my uncle's middle name,
he died of it.
After a year I am still climbing,
though my feet slip
on your stone face.

Linda Pastan
The treeline
has long since disappeared;
green is a color
I have forgotten.
But now I see what I am climbing
towards: *Acceptance*
written in capital letters,
a special headline:
*Acceptance*, its name in lights.
I struggle on,
waving and shouting.
Below, my whole life spreads its surf,
all the landscapes I've ever known
or dreamed of. Below
a fish jumps: the pulse
in your neck.
*Acceptance*. I finally
reach it.
But something is wrong.
Grief is a circular staircase.
I have lost you.

(in Moffat, 1982)
are really typical for dying persons only or if they represent responses to other threatening incidents as well.

2.3. CHILDREN AND DEATH

Children react to fears and threats to their lives very differently according to their age. Death is a different issue for them and might not even be a concern at the first stages of cancer. Maria Nagy (1948) observed a number of children in 1946 and concluded from her interactions with them three stages in the development of the understanding of death:

1. There is no death (0 - 4 years).
2. Death is a man (5 - 9 years).
3. Death is the cessation of corporal activities (older than 10 years).

Although her conclusions rely on some unclear methodological measures, and it has to be taken into account that her research took place just after the second world war when experiences might have influenced children's perceptions of death considerably, she has been quoted very frequently and later authors came to similar conclusions. A modified version according to Wolfgang Larbig (1974) including the results of numerous studies conducted by Heuyer et al. (1955), E. Stern (1957), etc. looks as follows:

1. 4-6 years: no emotional attitude toward death. No idea of life after death or why people die.
2. 6-11 years: rare emotional attitude toward death (i.e. sorrow, fear).
3. 10-14 years: attitudes toward death approach adult levels.

Research in this area is mainly based on Piaget’s theories of development.

Richard Lonetto (1980) described three different stages as a result of his
research in which a large amount of the existing literature is included:

1. Children from three through five years:

"The drawings of these three-to-five year olds show their concerns about the physical features of death and the dead, the condition of the dead, and separation and abandonment. They are generally supportive of earlier research findings. The drawings seem to suggest ways of dealing with aging and death, and show a tendency toward humanizing the unknown, especially if the unknown takes the form of a monster. Also recorded in their drawings is a good deal of confusion of "the dead" with "death". The drawings of children between the ages of three and five indicate that methods of dying (by shooting or stabbing are not as frequently perceived as the methods of separation (kidnapping, hiding, and so forth) or the condition of the dead (standing or lying down)." (p. 78)

2. Children from six through eight years:

"Death for a child from six to eight years old is personified, externalized, and can be avoided if one sees death in time. Death is not yet finalized; rather, it assumes various external forms (skeletons, ghosts, the death-man). The child is expressing a conceptual belief that places emphasis on the separation of internal and external agents. During these years, the child also shows concern about the ceremonial rites associated with the dead. Interest and anxiety appear about funerals and burials." (p. 100)

3. Children from nine through twelve years:

"The drawings and comments of 9-to-12 year olds display both uniqueness and common concerns. In terms of the unique elements associated with each age level, we find the 9 year olds show concern over the deaths of particular people, with emphasis upon the deaths of the grandparents. These children are able to incorporate their experiences into their interpretations of death; thus, death becomes related to old age, illness, and disease. These children also show an interest in the condition of the dead. The 10 year olds are troubled about the gloom, doom and pain imposed by death. ... Eleven year olds know that death is inevitable and desire a painless death. Some 12 year olds represent death in abstract terms and show a distinct lack of activity in their drawings of death. The common concerns shown across the age groups are seen in children's expressed awareness of self-mortality, in their distinct fears of death, in their interests in the rituals of burial, and in their feelings about the inevitability of death." (p. 156-157)
Although cancer does not necessarily result in death, it does bring up powerful feelings about death. This is especially true for some parents. Natterson and Knudson (1960) state about the mother-child relationship: "The threat of death to the child poses a symbolic threat of death to the mother ... In a sense, the mother faces death, experiences it, and survives (p. 461)." Children seem to react initially more to the immediate threats of the treatment and have to experience the progress of the illness in themselves and others before they link their state to dying (Bluebond-Langner, 1978). With their experiences they seem to understand the implications very well. It can create a gap in communication when adults think that younger children are not concerned about death because they do not understand its implications anyway. As John Spinetta (1974) notes:

"The general argument is as follows: Children under 10 do not speak overtly of death; besides, they are not yet old enough to be capable of understanding the concept of death so they must not be worried about the fatal nature of their illness."

The attitudes towards death which surround the child nevertheless have an impact on the communication which takes place once the diagnosis has been established.

2.4. REACTIONS TO THE DIAGNOSIS

The diagnosis of cancer in a child has a strong impact on the family, especially the parents. Parents are usually the first members of the family who are told by a physician about the diagnostic findings. Their reaction filters down to their children and other relatives.
2.4.1. Impact on Parents

Parents have described the diagnosis "as the hardest blow they had to bear throughout the course of illness" (Binger et al., 1969: 114). Many things that they have heard about cancer will come into their minds and the fear of losing their child will arise. Their first reaction is a state of shock (Solnit and Green, 1959; Burgert, 1972), which is followed by disbelief, anger, denial, guilt, etc. This state of shock means that their capacity of receiving new information is very limited (Myers, 1983). Sometimes parents do not remember anything else but the diagnosis of cancer from this communication with a physician. As Donald Brunnquell and Maria Hall (1980: 42) have noted:

"Parents have reported recalling not a word from long meetings, aside from diagnosis, even though points were frequently repeated."

The information requires time to "sink in". They need time to be able to adjust. The way in which the interaction takes place and the amount of empathy of the informing physician can also have a great influence on the understanding (Myers, 1983).

Parents find their lives are suddenly changed. The expectation that their relationship with their child will go on forever is threatened and feelings of loss and separation anxiety lead to a crisis situation (Mann, 1974; Sourkes, 1977). They have to cope with this new situation. Coping involves all the strategies necessary to keep one's psychological stability and, as Chodoff et al. (1964: 744) note:

"Coping can be thought of as consisting of two aspects, an externally directed one, judged for effectiveness in social terms, ... and an internally directed or defensive aspect, which serves to protect the individual from disruptive degrees of anxiety and which is judged for
These two aspects can be a source of conflict when there is a contradiction between internal coping requirements and demands for specific external behaviour. It is often overlooked that successful coping also requires a relaxation and a positive attitude in order to recharge energy (Powell, 1974; Zevon et al., 1981).

Reactions toward the diagnosis can vary not only due to individual differences, but also due to the cultural context which influences the view of the illness (Anderson, 1981; Friedman, 1985; Vilaro, 1985). The initial shock and the closure against more information also has a denying function (Chodoff et al., 1964) and can lead to behaviors such as keeping oneself busy, isolated socially, etc. Denial, however, can also have an isolating effect on their child. If the parents are not able to acknowledge their child's reality, they have little in common.

Their reactions might be part of an anticipatory grieving process. This is an adaptation process which takes place in the parents after they have been told the diagnosis. It has been mentioned above that this can influence parental perception of communication as they are unable to digest much information. It also can have an isolating effect on the child because it means that the parents are more preoccupied with their own feelings and in addition they seem to advance the possible loss of their child into their present reality.

Green and Solnit (1964) have described a reaction to the threatened loss of a child as a 

**vulnerable child syndrome.** This involves symptoms of:

1. **Difficulty with separation:** This frequently includes sleep problems, when the parent is afraid the child might die during his sleep.

2. **Infantilization:** the overprotective and overindulgent parents are unable to set disciplinary limits; the child in return becomes overdependent, disobedient,
irritable, and uncooperative.

3. **Bodily overconcerns:** the parents become overconcerned with minor infections, color of the skin, and keep a close check on the child, who shows headaches, infantile fears, and hypochondrihal complaints.

4. **School underachievement:** child and mother share an unspoken agreement that the child is only safe when the mother is present.

Hospitalization of their child with cancer poses a threat to the parental role. Care seems to be taken out of their hands and they seem to lose control over the well being of their child (Brunnquell, Hall, 1980), which increases their feelings of helplessness and incompetence. Their self-esteem is seriously challenged and their child seems already be taken away by the new hospital environment.

Dorothy Marlow (1977: 86) lists seven causes of parental anxiety:

1. Fear of strange environment in the hospital;

2. Fear of separation from the child and fear that the nurses may be unloving or that they are able to do so much for him, that they will take his love from them;

3. Fear of the unknown and what will happen to the child immediately and in the future;

4. Fear that the child will suffer;

5. Fear that the condition is infectious and may spread to other family members;

6. Fear of unbearable financial obligations incurred through the illness;

7. Fear that society will look upon the illness as a reflection of something wrong with the child’s parents.

Some authors have tried to deal with aspects of parental needs; however, the reports have mostly been written by health professionals, often on an anecdotal basis. The few reports written by parents provide very personal and often dramatic accounts (e.g. Becker, 1974; Ludwig-Klein, 1980). In addition some efforts have been made to involve parents in the teamwork of care (Adams,
Issues Concerning the Child with Cancer in the Literature / 21

1979) and integrate some of their reactions (Friedman et al., 1963; Kreuger et al., 1981; Blau et al. 1983).

Parents are emotionally involved, find it difficult to express themselves and "are sensitive to study for study's sake and "emotional vultures", a term used by a mother to describe persons only interested in her reactions to the child's leukemia" (Mann, 1974: 87). It has been noted that parents have their own viewpoint and may view issues quite differently from medical staff (Chesler and Barbarin, 1984).

Parents have various needs for support during the course of the illness, as many authors have noticed (Ross, 1978; Kreuger et al., 1981; Pichler et al., 1982b; Dongen-Melman et al., 1986b). Good communication seems to be essential, especially within the family. Verwoerd (1966: 135) concluded:

"During the time of such a crisis, effective communication between husband and wife are particularly essential. A great deal of support is needed by each spouse, one from the other ...the stability of the entire family unit depends upon the strength of the parental relationship."

The difficulties in coping with own feelings are likely to be passed on to the child and have an effect on the communication and relationship.

2.4.2. Impact on Children

Initially the child is only indirectly concerned with the diagnosis, but its impact is perceived through parental reactions and through its consequences: medical treatment and hospitalization, which will be discussed later.³ It is important to note, however, that a discrepancy can be created at this point between parents

who react to information and their sick child, who experiences the physical and emotional impact much more directly. The parental coping behaviour and their distress may also have an impact on the coping response of the child (Blotcky et al., 1985).

2.4.3. Impact on Siblings
Siblings experience the consequences of the diagnosis indirectly. They perceive the reaction of their parents and can see that their brother or sister is suddenly taken away. Siblings may also experience role changes in the family when they are more on their own or have to assume more caretaking roles within the household. In addition everythings seems to revolve around the sick child which can make them feel left out, especially if they do not receive sufficient information. The possibility of own illness or death is highlighted which may create fears, but also the wish to be able to do something like trade places (Koch-Hattem, 1986). The adaptive responses of siblings have become a focus for research only in recent years (Cohen, 1985; Richmond, 1985; Cimini, 1986; Perez-Ortega, 1986; Asada, 1987; Walker, 1987).

All this highlights the needs of support for all family members and the importance of open communication between all who are involved (Adams-Greenly et al., 1986; Bush, 1987).

2.5. AWARENESS CONTEXT AND KNOWLEDGE ABOUT ILLNESS
Communication also has to be seen in the awareness context which Barney Glaser and Anselm Strauss have described. They defined this term (1965):

"By the term awareness context we mean the total combination of
what each interactant in a situation knows about the identity of the other and his own identity in the eyes of the other."

They distinguished four different types of awareness (1964):

"An open awareness context obtains when each interactant is aware of the other’s true identity and his own identity in the eyes of the other. A closed awareness context obtains when one of the interactants does not know either the other’s identity or the other’s view of identity. A suspicion awareness context is a modification of the closed one: one interactant suspects the true identity of the other or the other’s view of his own identity, or both. A pretense awareness context is a modification of the open one: both interactants are fully aware but pretend not to be."

Strauss and Glaser (1970) looked at the different awareness contexts with dying patients. They found five structural conditions for the closed awareness context:

"First, most patients have little or no experience in recognizing the signs of impending death. A second structural condition is that American physicians ordinarily do not tell patients outright that death is probable or inevitable. ... A third structural condition is that families tend to guard the secret, thereby confirming what the physician has announced. ... A fourth structural condition is that of the organization of hospitals and the commitments of personnel who work within them by which medical information is concealed from patients. ... A fifth structural condition, perhaps somewhat less apparent, is that ordinarily the patient has no allies who reveal or help him discover the fact of his impending death."

There are some differences of course which have to be noted with regard to children with cancer. The progress of medical treatment does not justify to look at every child as if he was dying. This can also lead to a strengthening of the closed awareness context because there always seem to be chances which nourish hope, even when reality tells a different story.

Another factor, which Myra Bluebond-Langner (1978) has described, is the flow of information on the ward. Children seem to get a considerable amount of
information from their peers, and the death of another patient gains special attention. This has already been noted by Emma Plank (1971). As Waechter (1971), Spinetta et al. (1973) and others have shown, children are aware of the illness and its impact although the topic may be avoided in communications. Thus the closed awareness soon becomes suspected or pretense awareness. Myra Bluebond-Langner (1978) described the efforts which have to be made to stay at the mutual pretense awareness level which seems to be the most common with children who have cancer. Glaser and Strauss (1965: 72ff) noticed a set of rules which have to be applied to keep the interactions at this level:

"One rule is that dangerous topics should generally be avoided. There is, however, a qualifying rule: Talk about dangerous topics is permissible as long as neither party breaks down. A third rule, complementing the first two, is that each actor should focus determinedly on appropriately safe topics. A fourth interactional rule is that when something happens, or is said, that tends to expose the fiction that both parties are attempting to sustain, then each must pretend that nothing has gone awry."

In addition the parties must strive to keep the interaction normal and brief. And as Myra Bluebond-Langner (1978: 206) stated:

"When the rules become impossible to follow and the breakdown of the mutual pretense appears imminent, avoid or terminate the interaction."

This means that there is a constant threat to isolation. The mutual pretense awareness may also lead to a double-bind communication (Erickson, Hyerstay, 1975), when different messages come across at the same time. A person might say: "you are doing fine", which can also mean: "I don't want to talk about your illness". Verbal and nonverbal messages can be contradictory and therefore create a double-bind situation. The child as a patient, however, might have to
communicate in this way with the adults if s/he wants to communicate at all. It also has been shown that commonly used phrases in a hospital can be interpreted very differently (Wile, 1981), and if no communication is allowed to clarify the matter, then it will only increase the isolation.

2.6. 'PROTECTIVE' AND 'OPEN' APPROACH

Basically two approaches have been described in the literature: the protective approach, favours shielding the children from knowledge of the disease, and the open approach, which means the diagnosis should be communicated to the children in an appropriate way as soon as possible (Share 1972). A concept of hope seems to be the driving force behind the protective approach when Emma Plank (1964) stated for example:

"Life but not death is children's business. When a child who may conceivably die during hospitalization brings up the question of the possibility of his own death, we assure him with great conviction and help him to deny the possibility."

Three different reasons seem to form the rationale of the protective approach:

1. The child does not have enough understanding of the impact.
2. The child shall not be burdened with the knowledge of the limitations of his life.
3. Dealing with the implications of the illness only means a higher level of anxiety for the child.

An approach with controlled emotions means the safest way to ensure the well-being of the child. Howell (1966) stated for example:

"One of the ways that this (helping the family to control emotions) can be done is by challenging the family to protect their child from
the knowledge that his life span is limited. There is no need for a child to bear the burden of knowingly facing death: the parents can save him this (p. 3)."

This approach also helps to protect a defense mechanism against a unmanageable anxiety as Evans (1968) stated:

"One often deals with fears (about death) by suppressing or rejection and this can be very effective. By open discussion, this excellent defense mechanism is destroyed (p. 138)."

However, it has to be considered that the child is well aware that something serious is happening, although s/he might not know the name of the illness immediately. Vernick and Karon (1965) state:

"When the physician gives the fateful news to the parents, the child immediately "knows" that s/he has something very serious because his/her entire environment changes. His/her parents, no matter how hard they try, cannot conceal their own grave concern. The child quickly senses that the people whom s/he had come to trust and love are now keeping something from him, something frightening (p. 395)."

Emma Plank acknowledged in a later book (1971), in which she gave examples of communication with children about death on a hospital ward, that the news about a death spreads faster then the staff was aware off. Vernick and Karon (1965) had already argued for a better communication with respect to the illness to reduce fear and anxiety. They stated that considerable effort had to be expended to keep the diagnosis secret, and they noticed relief when communication about the illness could finally take place. Thus they shifted the focus of the question if a child shall be told s/he has leukemia:

"Such a proposition merely begs the question for the basic issue is not whether to talk to the child about his serious concerns but how to talk to him (p. 393)."
Soon afterwards concern was expressed about the aftermath of telling the diagnosis, and about the impact on the relationships of children with parents, relatives, and friends (Agranoff, Mauer, 1965). However, Eugenia Waechter (1971) contradicted the protective approach and showed with projective tests that children are in fact aware of the closeness of their death. Spinetta, Rigler, and Karon (1973) came to similar conclusions when they transformed Eugenia Waechter's approach into a three-dimensional study of space the children gave to the persons around them. Other studies even found a positive long-term effect of the open approach in the adjustment of cancer survivors, which becomes more and more important with the increasing successes of medical treatment (Binger et al., 1969; Slavin et al. 1980). However, the term adjustment is not always clarified sufficiently. Does it mean the visible absence of extreme behaviors, or does it include the internal coping processes of the individual according to his/her situation?

The protective approach seems to have a very serious impact on the child's relationships. Rather than giving comfort it means that suspicion about communication in general is increased, because the child senses something is wrong, but the people s/he trusts are withholding important information. This reduces trust in the relationship between the child and the persons s/he communicates with. Martin (1968) stated:

"The obvious paradox in verbally stating that there is nothing to worry about while non-verbally denying this statement with anxious facial expressions or body gestures not only undermines the child's confidence in the communicator but may also undermine his confidence in his own vulnerability....When this type of paradoxical and evasive communication is given to the child by significant adults in his environment, all communication soon becomes suspect in the eyes of the child (p. 41, 71)."
The child finally has to draw his/her own conclusions about illness and his/her experiences (Vernick and Karon, 1965; Bluebond-Langner, 1978). S/he might consider it as a punishment for something s/he has done wrong (Schowalter, 1970), or his/her interpretations about medical and other procedures might only increase his/her general anxiety (Prugh et al., 1953).

It is no surprise that adults develop their own rationalization and try to "protect" the child from the information which decreases the amount of meaningful communication. Binger et al. (1969: 115) state about the impact of the effort to protect the child:

"As the parents attempted to protect their children from the concerns of the illness, older leukemic attempted similarly to protect their parents; the children who were perhaps the loneliest of all were those who were aware of their diagnosis but at the same time recognized that their parents did not wish them to know. As a result, there was little or no meaningful communication. No one was left to whom the child could openly express his feelings of sadness, fear or anxiety."

As Lynda Share (1972: 198) concluded:

"The adult, as a result of lack of meaningful communication with his child, becomes increasingly unable to accurately perceive, assess, and respond to the child's inner experience. The child, in turn, responds to the adult's apparent "unawareness" with further withdrawal, accompanied by feelings of loneliness and increasing anxiety."

This may be compounded by the medical treatment of cancer which usually involves a series of anxiety provoking procedures.

The child's anxiety itself is difficult to measure and is highly dependent on the development of the child. Katz et al. (1980) tried to develop a measuring system for anxiety. However, their study shows the problems of dealing with a construct in which a number of different factors are involved, such as pain,
individual sensations, circumstances etc.

If a child is unable to cope with anxiety then it becomes an further burden in addition to experiences created directly through the illness. Thus, the open approach argues, communication is important to help to relieve anxiety. Binger et al. (1969: 115) state in their studies on the effects of an open approach:

"There was no evidence during the course of the illness or in interviews with the families after death that these children had greater difficulty coping than their counterparts to whom nothing had been said directly. Both these families reported a more meaningful relationship with the child than they had ever experienced before. They thought this change was largely due to the frank discussion of the diagnosis and the open communication within the families (p. 115)."

The open approach may help to reduce the general level of anxiety because it is possible to communicate about it. The feelings are not locked in and less energy is spent to keeping up the protective attitude.

The discussion about various approaches has to take the children into account because their awareness level basically determines the possibilities of communication about the illness.

2.7. CHILDREN'S AWARENESS AND INFORMATION

Myra Bluebond-Langner's (1978) interesting studies on dying children used an ethnomethodological approach. She studied their awareness and information gathering process by spending a longer period of time with them. She found that leukemic children acquire factual information about their disease in five stages (1978: 166). Each stage meant that more information about the disease was acquired. The knowledge which was acquired in one stage was necessary for the
interpretation of information in the next stage. Children moved from concrete levels to higher stages of abstraction. The had to know the names and purposes of the drugs before they could relate them to the treatment and the illness. Children received a considerable amount of information from other children on the ward. Especially the passage from stage 4 to 5 depended on the news of another child’s death. When a death occurred on the ward all children who were in stage 4 passed to stage 5. A very important factor is experience. Myra Bluebond-Langner (1978: 169) noted:

"Some three- and four-year-olds of average intelligence knew more about their prognosis than some very intelligent nine-year-olds, who were still in their first remission, had fewer clinic visits, and hence less experience. They were only aware of the fact that they had a serious illness."

This finding is consistent with other studies who also noted that direct experience influences conceptualizations (Jay et al., 1987).

Other authors (Brunnquell and Hall, 1982) have noted that information is sometimes passed on through conversations between staff or staff and parents which take place in the child’s room or nearby so that the child can understand the words. This, however, can also be a source for misunderstanding, because children frequently misinterpret technical or jargon terms and develop their own
To the Children’s Hospital

Instruments beep and shudder
with a long pale body
in the midst of the clutter

The body lies motionless
with a pillow beneath her head
while doctors huddle quietly
without a notion of what’s ahead

Suddenly the face of the patient turns blue
and all the doctor’s eyes widen
as they look at one another
wondering what to do
one switches the machine off
and says, we’ll let her sleep
she’s been through enough
and with that went the last beep

The doctors and nurses crowd
around the patient
praying silently amongst themselves
tears run down the faces
of those who knew her best
feeling sorrow and relief
that she is now at rest

This poem is dedicated to my friend Toni who died April 13, 1983 after spending one year recovering from Aplastic Anemia.

On October 19, 1983, Debbie Gutz, the authoress of the poem went to join her friend Toni. It is a better life she has gone to.

(Plaque on Hospital Ward)
explanations, which can create a great deal of anxiety.

Myra Bluebond-Langner (1978: 169) observed that the children while passing through the different stages of acquisition of information also passed through five different stages of self-concept.

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The child receives the information necessary to pass from one stage to the other from his/her observations. Myra Bluebond-Langner (1978: 170ff.) described these passages:

* Passage to stage 1: The child realizes from the behavior of others, i.e. crying of his parents, receiving many presents suddenly, etc., that it is serious.

* Passage from stage 1 to stage 2: The child receives information from his peers and has the experience of remission.

* Passage from stage 2 to stage 3: The first relapse is experienced as a shock; the parents cry more and the hospital staff is less open.

* Passage from stage 3 to stage 4: More relapses are experienced and the child’s world is rapidly being deformed by the disease.

* Passage from stage 4 to stage 5: The child learns about the death of another person in a similar situation.

Her anthropological study has produced some insight into the coping processes of children involved in such a situation. It also provides detailed information about the communication processes. However, the important link with the perspective of all persons involved, parents and especially health professionals, seems to be
2.8. HOSPITALIZATION

2.8.1. Being in Hospital

Severe illnesses are usually handled within a hospital setting which has its own dynamics. Hospitals are oriented according to medical and administrative needs. Accordingly two lines of authority can be found within the setting. The medical authority structures treatments and sets professional hierarchies, and the administrative authority set rules for professional conduct and manages the financial resources.

Hospitals have been criticized as becoming increasingly unresponsive to individual needs and setting their own agenda instead. Norman Cousins wrote about his experiences while he suffered from a life threatening illness (1979: 29):

"I had the fast-growing conviction that a hospital is no place for a person who is seriously ill. The surprising lack of respect for basic sanitation; the rapidity with which staphylococci and other pathogenic organisms can run through an entire hospital; the extensive and sometimes promiscuous use of X-ray equipment; the seemingly indiscriminate administration of tranquilizers and powerful painkillers, sometimes more for the convenience of hospital staff in managing patients than for therapeutic needs; and the regularity with which hospital routine takes precedence over the rest of the requirements of the patient (slumber, when it comes for an ill person, is a common blessing and is not to be wantonly interrupted) - all these and other practices seemed to me be critical shortcomings of the modern hospital."

He decided to leave the hospital setting and adopted his own successful strategy for recovery. Not everyone will agree with Cousins, but it shows that the modern hospital has many shortcomings which may in fact be counterproductive.
for recovery from an illness. However, it is difficult for someone who does not see any choice to do anything but cope with the situation. This is the case with children who are usually not given any choice in this matter.

2.8.2. Impact of Illness and Hospitalization on Children

Hospitalization is a major step for children. An extensive literature describes the many issues and anxieties which are generated due to the separation from parents and the familiar environment (Stacey et al, 1970; Oremland and Oremland, 1973; Robinson and Clarke, 1980).

There is agreement that hospitalization has an effect on every child (Prugh et al., 1953; King and Ziegler, 1981), but the impact varies according to the developmental age of the child. Hospitalization is more difficult to understand for the young children. Separation can be seen as loss although the parent is only temporarily gone. Robertson (1958) found three phases of responses to the absence of mother and the strange hospital environment: After an initial phase of protest and distraught in which the toddler is crying for his mother, he enters into a phase of distrust and despair, which is followed by denial where he or she passively accepts the care and holding of other people. Teyber and Littlehales (1981: 58) note that "it is with this stage of denial that many hospital staff may be deceived; the toddlers denial is often misinterpreted as a "positive hospital adjustment". Despair and anger are commonly expressed in preschool-age and school-age children. Anger can be directed against parents and/or staff. Prugh et al. (1953) found the most extreme reactions between two and five years.

Many young hospitalized children develop separation anxiety and become
preoccupied with themes of death, especially when there are only limited opportunities for communication available (Teyber and Littlehales, 1981; Grollman, 1970). With respect to adolescents Oremland and Oremland (1973) reported feelings of being trapped, imprisoned, humiliated, helpless, as well as anger and frustration. Frustration and despair can lead to regression and social withdrawal (Vernon et al. 1965). If an impulse is too strong then withdrawal is quite a common reaction. King and Ziegler (1981) concluded in a review article on the literature of the behavioral effects of hospitalization on children that the presence of mother or mother substitute has positive effects on the child. This, however, requires that the mother can be there for the child, which is a difficult task if there are siblings, or if she herself is preoccupied with her own feelings about the illness.

With increasing age children become more aware of their body. Their body sensations can be seriously disturbed by the intrusive measures which take place during the treatment of cancer. This creates a great deal of anxiety which can even increase with the frequency of the procedures as Spinetta and Maloney (1975) have found in their observations of bone marrow transplantations. It has been mentioned before that anxiety is difficult to measure objectively because the reactions are very different according to age and personal background. Some authors tried to measure anxiety with different instruments such as projective and other tests (Waechter, 1971; Spinetta et al., 1973; Calkin, 1979; Katz et al., 1980). Although a high degree of anxiety has been measured it seems difficult to differentiate which factors cause anxiety. Anxiety in measurements refers mostly to a construct and ignores its relevance for the individual as part of the coping processes. In addition circumstances and the pain involved in some
procedures might be included in the measurements of anxiety as well as individual reactions to issues such as loss of control (Susman et al., 1987). Conclusive research about age related coping processes has yet to be undertaken.

The loss of personal control is also a major issue when the child becomes a member of the institution hospital as a patient. Not only is the private sphere opened up to many strangers, there are also new rules which apply and a certain behaviour is expected in the new role, which has been adopted involuntarily. Judith Lorber (1975) described for example the expectation which nurses have of a patient:

"Ideally, from the nurses' perspective, all the patients should be sick when they enter the hospital, should follow eagerly and exactly the therapeutic programme set up by staff, should be pleasant, uncomplaining, fit into the hospital routine, and should leave the hospital 'cured'. Good patients handle their illness well, are co-operative, as cheerful as possible, comply with treatment, provide the staff with all the relevant information, follow the rules, do not disrupt the ward or demand special privileges and special attention."

Those expectations influence the attitudes of hospital staff toward children as patients.

2.8.3. The Roles of Health Professionals

The literature about health professionals with respect to the care of a child with cancer reveals a large amount of information about what they should do. However, the care of the child has various realities as David Friedman (1977: 10) notes:

"Every day children are seen for health care and dental care; treated for injuries, illness and dental problems; listened to and counseled; protected from abuse and neglect; and helped by family counseling all by a warm, friendly, capable health professional."
On the other hand, every day, children are forcibly detained, force fed, starved, browbeaten, hoodwinked, tortured, suffocated, drugged, torn from families, tied down, forced to strip and expose, subjected to a variety of indignities, detained without explanation and denied a call for help, denied due process and informed consent, and denied means of presenting case and grievances to the public - all in the name of "their best interest."

One of the main difficulties in the treatment of a child with cancer is to determine the best interest of the child and his family and act accordingly. This area seems to be dealt with in anecdotal reports about successful interventions (Karon and Vernick, 1968) or in advice on how the physician or nurse should behave. Solnit and Green (1959: 106) point out the physician's approach with respect to fatal illness:

"By making the child and parents as comfortable as possible the physician establishes himself as one who will help them endure the crisis for which they are preparing. Through his skill in communicating with child and parents in this situation the physician helps the child and family to feel appropriately dependent on the doctor and his staff."

They argue for early information and acknowledge that physicians have their own fears about death. Physicians might feel defeat and helplessness as well. With regard to the personal reactions, Solnit and Green (1959: 111) state:

"However, if he becomes involved to the extent of grieving with the parents, his helpfulness will be much reduced."

This seems to be a concern which others have noted as well that "professional objectivity" might be lost if "physicians become too involved with their patients" (Tietz and Powars, 1975). Similar problems are reported with nurses who are supposed to work toward the same goals as the physician. In books on pediatric nursing these goals are stated as follows (Leifer, 1982: XIII):
"The goal of pediatric nursing is to foster the growth and development of children and promote an optimum state of health - physically, mentally, and socially - so that they may function at their peak capacity."

The promotion of health is limited with a child with cancer. During the treatment, nurse and physician have to do a number of things which seem to have a detrimental effect on the child's health, for example the side effects of the drugs which can cause illness (toxicity) and change in appearance (hair loss). The goals of pediatric nursing to be concerned with "promoting, maintaining, and restoring the health of children and their families" (Sarah B. Pasternack in Smith et al., 1982: 38) seem to be more distant. The realities of the cancer treatment do not seem to match the expectations which cause burnout, going from enthusiasm to stagnation, frustration, and apathy (Edelwich and Brodsky, 1980; Kramer, 1974; Yasko, 1983). Despite their own anxieties and frustrations, health professionals have to live up to the expectations set by their professional goals. Catherine Kneut (1982: 416) reports four factors leading to nurses' burnout:

1. Working in stressful situations for too long,
2. inadequate support systems,
3. loss of professional perspectives,
4. lack of professional challenges.

Other authors believe that the major cause for staff burnout is that they "generally keep their "unacceptable" or difficult emotional reactions to themselves, an isolating process" (Teyber, Littlehales, 1981: 61).

Some authors suggest team approaches in the treatment of children with cancer (Adams, 1979). This, however, seems to be a difficult task in a
hierarchically organized hospital setting, when responsibilities are split amongst different professions. This organizational system can also be structured to act as a defense system against anxieties as Isabel Menzies (1970) notes by attaching the nurses for example to a strict administrative structure where they have to follow the instructions irrespective of personal considerations. A good nurse carries out the instructions accurately (Menzies, 1970: 11ff.)

It has been noticed that health professionals, because they do not always want to be the "bad guys" who are inflicting pain, look for rewards in the relationship with patients, which can lead to competition between staff and parents (Stacey, 1970). This conflict is even addressed in textbooks on pediatric nursing (Marlow, 1977: 82):

"Many nurses believe that they can accomplish their mission in child care by providing "parent love" for each child with whom they come in contact. The nurse may believe that expressions of affection, tenderness, warmth, and concern will be rewarded by the child's love in return."

But of course parental love can never be substituted by health professionals.

In addition nurses might be in a kind of catch 22 situation when they have to apply their "textbook behavior" (Marlow, 1977: 91):

"The nurse should never be critical of a parents' attitude, however unreasonable it may appear."

It is obvious that this attitude affects the openness of the communication and gives nurses no chance to a mutuality in the interactions.

Attitudes influence the openness of communication and therefore it is interesting to note that in a survey conducted by Wiener (1970) a majority of the physicians replied that parents should usually or always be given the
Issues Concerning the Child with Cancer in the Literature / 40
diagnosis of the fatal illness of their child. However, the majority answered
"seldom" or "never" to the question: "Do you believe most children should be
informed, at their level of understanding, of the nature of their illness?" (Wiener,
1970: 702); and this belief increased with the years in practice. While more
recent reports investigate the benefits of giving information (Slavin et al., 1982)
there is no evidence yet of a general openness in communication with children.

2.9. THE VARIOUS PERSPECTIVES
The approaches which have been taken in the published literature vary from
individual opinions to case studies and to the development of measurements and
instruments in an effort to deal with the complex processes involved. In general
terms one can state that many researchers seem to be preoccupied with
individual aspects from different professional viewpoints. Efforts have been made
to quantify the information which results in the development of instruments
measuring constructs such as anxiety. However, a link between the insights of
different perspectives combining the backgrounds of all the persons involved in
the care including the child himself seems to be missing. In addition the question
what to tell children has to be paired with the appropriate mode of
communication, how it should be done. This involves parents as well as staff in
the hospital setting and must reflect many contextual variables (Binger, 1984;
Chesler et al., 1986).

Communication can be seen as an essential area with respect to the
coping processes. A thorough analysis of the human interactions in this context
has to study how meaning is generated and communicated. This must include an
understanding of the perspectives of all persons involved in the interaction. The
interactions are affected by their context and the hospital setting itself may have considerable influence on behaviour and communication. The extent of this influence as well as the processes of communication in the setting have not yet been thoroughly investigated. These considerations led to the conceptualization of this study.
3. CONCEPTUALIZATIONS

It has been mentioned\(^4\) that the theoretical base for this research project is linked to the theory of symbolic interactionism. In the following paragraphs I will give a brief outline of the main ideas of this conceptual framework which seem relevant in the context of this study. However, this does not constitute an attempt to provide an exhaustive review and critique of symbolic interactionism and its various lines of thinking.\(^5\)

The name "symbolic interactionism" was coined by Herbert Blumer (1938) and has links to the thoughts of George Herbert Mead, John Dewey and other authors in social psychology. Some authors (Joas, 1987) also refer to the Chicago School, which points at the historic development of the main ideas with George Herbert Mead's thoughts as the focal point.

Social psychology examines the experience of the individual, but also seeks to determine the links to the social structure in which the individual lives. According to George Herbert Mead (1934) society becomes the general framework for action. Actions consequently become social acts within this context. Society is linked to minds and selves of its individual members, who are - just as society - subject to evolutionary development. Self is not a physiological and fixed unit, but it is rather developing from the interaction of an individual with society and other individuals. This means that the self arises from social experiences. Through the self an individual can be a conscious actor within society. Contrary to the physiological body the self can also become object to himself which enables reflection of oneself and sets the stage for the development of reason.

\(^4\) see The First Chapter.

\(^5\) The book "Symbolic Interaction" edited by Manis and Meltzer (1967) provides a good overview about various trends and their applications.
Becoming object to himself makes the self "essentially a social structure" (Mead, 1934: 140) and transcends the stimulus response mechanisms of animal behaviour.

The self as a social process has two analytically distinguishable parts, the "I" and the "me". George Herbert Mead states (1934: 175):

"The 'I' is the response of the organism to the attitude of others; the 'me' is the organized set of attitudes of others which oneself assumes. The attitudes of others constitute the organized 'me', and then one reacts toward that as an 'I'."

It is essentially the "I" which creates new activity in social process and where important values are attributed. The "I" is also responsible for reflexiveness and the development of innovative behaviour.

Communication is a form of social behaviour in which the individual may become an object to himself (Mead, 1934: 138ff.). In order to achieve understanding, a relationship to common interpretation between individuals in an interaction has to be established. The understanding of gestures, symbols requires that a connection can be made to more abstract processes of evaluation, to conceptualization which goes beyond the immediate response to a situation. However, according to George Herbert Mead meaning is constituted in social acts and is not based in independent ideas as idealist philosophers claim.

"Meaning is thus a development of something objectively there as a relation between certain phases of the social act; it is not a psychical addition to that act and is not an "idea" as traditionally conceived."

(Mead, 1934: 76)

Meaning is expressed in significant symbols which are interpreted by individuals and lead to subsequent behaviour. The reflection of self which is necessary to
interpret symbols and act purposefully constitute the development of mind. Mind enables the interpretation of meaning and makes it possible for an organism to take the role of the other within social acts. Mind is "the reflective intelligence of the human animal" (Mead, 1934: 118) which enables the individual to determine present and future conduct. Mind requires awareness of actions which means that the self becomes object of itself as a process of reflexivity.

"Mind arises in the social process only when that process as a whole enters into, or is present in, the experience of any one of the individuals involved in that process. When this occurs the individual becomes self-conscious and has a mind; he becomes aware of his relations to that process as a whole, and to the other individuals participating in it with him; he becomes aware that of his relations to that process as a whole, and to the other individuals participating in it with him; he becomes aware of that process as modified by the reactions and interactions of the individuals - including himself - who are carrying it on."

(Mead, 1934: 134)

Reflexiveness is the essential condition for the development of mind because it enables the individual to take attitudes of others toward him/herself and consciously adjust to social processes.

Similarly objects of experience do not exist a priori. They do not have any meaning per se. They are linked to processes like food to physical organisms. George Herbert Mead states (1934: 77):

"That is to say, objects are constituted in terms of meanings within the social process of experience and behavior through the mutual adjustment to one another of the responses or actions of the various individual organisms involved in that process, an adjustment made possible by means of communication which takes the form of gestures in the earlier evolutionary stages of that process, and of language in its later stages."

It should also be mentioned that George Herbert Mead distinguishes between
physical objects, social objects (involving social acts) and abstract objects (concepts which refer to ideas). However, it is important to highlight that according to Mead human beings live in a world of objects to which they give meaning in processes of social interaction.

It has been said that Mead’s theory as a good analytical scheme lacks definite links to the empirical world. Blumer regards theory as being closely connected to the empirical world and not isolated from it. He states (1969, 141):

"Theory, inquiry and empirical fact are interwoven in a texture of operation with theory guiding inquiry, inquiry seeking and isolating facts, and facts affecting theory. The fruitfulness of their interplay is the means by which an empirical science develops."

Without this connection theory has little value and in addition theoretical concepts cannot be static because there is an ongoing interplay between theory and empirical facts. Concepts are needed to organize and identify meaning in empirical science. Herbert Blumer elaborates (1969: 143):

Theory is of value only to the extent to which it connects fruitfully with the empirical world. Concepts are means, and the only means of establishing such connection, for it is the concept that points to the empirical instances about which a theoretical proposal is made. If the concept is clear as to what it refers, then sure identification of the empirical instances may be made."

Consequently Blumer and others established this link with the concepts of symbolic interactionism.

Based on Mead’s ideas the theory of symbolic interactionism focuses on communication with symbols within a society. A key concept in symbolic interactionism is that communication happens with the use of meaningful symbols which are interpreted by individuals within a social act. The use of symbols
requires interpretation and the involvement of self with the use of objects. As Herbert Blumer notes (1969: 80):

"The object is a product of the individual's disposition to act instead of being an antecedent stimulus which evokes the act. Instead of the individual being surrounded by an environment of pre-existing objects which play upon him and call forth his behavior, the proper picture is that he constructs his objects on the basis of his on-going activity. In any of his countless acts - whether minor, like dressing himself, or major, like organizing himself for a professional career - the individual is designating different objects to himself, giving them meaning, judging their suitability to his action, and making decisions on the basis of judgement. This is what is meant by interpreting or acting on the basis of symbols."

The individual perceives things, evaluates them and acts on the basis of the meaning which s/he gave to objects. Behaviour cannot is not merely the result of external stimuli or internal factors such as motivation or attitude, but rather it is generated during interactive processes involving individual and his/her social environment.

Meaning evolves from interactions between persons as a product of social acts and is therefore not a static concept. Blumer (1969: 4) states:

"The meaning of a thing for a person grows out of the ways in which other persons act toward the person with regard to the thing. Their actions operate to define the thing for the person. Thus symbolic interactionism sees meaning as social products, as creations that are formed in and through the defining activities of people as they interact."

This highlights again the focus on interactions as social acts, which are the essential processes that form meaning and generate understanding.

The rules of society or a particular group are represented in the conception of a generalized other. This means that reality is shared by different individuals which involves the development of a joint perspective. An individual
can follow rules and adopt perspectives which may have grown historically within society. The generalized other enables an individual to follow a generalized set of expectations or definitions (Charon, 1979). This concept is implicit in group perspectives, such as perspectives of a professional group in a hospital, because it shapes individual behaviour.

In summary symbolic interactionism is a conceptualization of social processes which focuses on the interaction of an individual with society by means of symbols which are actively interpreted. Herbert Blumer (1969: 50) outlines the central conceptions of symbolic interactionism:

"These central conceptions are:
1. people individually and collectively, are prepared to act on the basis of the meanings of the objects that compromise their world;
2. the association of people is necessarily in the form of a process in which they are making indications to one another and interpreting each other's indications;
3. social acts, whether individual or collective, are constructed through a process in which the actors note, interpret, and assess the situations confronting them; and
4. the complex interlinkages of acts that compromise organization, institutions, divisions of labor, and networks of interdependency are moving and not static affairs."

Individuals become actors within social processes which they shape in interactions by using symbols which give meaning to the objects of their world.

The process oriented focus of symbolic interactionism clearly makes it necessary that research strategies must reflect the human interactions within their context. To understand the processes of interaction a researcher must be able to gain insight into the roles of the individuals under study. The method of inquiry must reflect the individual and social level as well as situational aspects. This means that methodology cannot rely on a static and detached theoretical concept with static instruments of investigation. The method of an inquiry has to
be regarded as a process which has to be adapted to specific situations in order to capture the elements of human interaction. In particular the researcher must get insight into the interactions from the point of view of those s/he studies.

The processes of interpretation are subjected to development from the perspective of the society as well as from the individual. A child learns more about the world surrounding him/her in a developmental process with language being the most important element in terms of social interaction. Children also have a developing self which enables them to determine their own actions, take the role of another, establish and follow rules. This all happens in a process of socialization which evolves in interpersonal relationship. Norman Denzin (1977: 2) defines this:

"Socialization from the standpoint of symbolic interactionism, represents a fluid, shifting relationship between persons attempting to fit their lines of action together into some workable, interactive relationship."

Socialization is seen as an ongoing social process which happens in interactions between individuals, when they take each other's roles and produce joint lines of activity. Language development is a crucial parameter in childhood socialization because it establishes the link to society (Mead, 1934; Denzin, 1977). Authors have placed the development of self in an environment distinguishing several stages of the development of self (Charon, 1979):

1. In the preparatory stage the child imitates the acts of significant others without necessarily understanding their perspective.
2. In the play stage the child takes the role of significant others by analyzing, identifying, and directing self without organized perspective.
3. In the game stage the child takes the role of the generalized other within
Community, group, games and can react to the self from the standpoint of rules.

4. In the reference group stage the individual can take the role of several groups and the self can be divided between various social worlds. While these stages depict a developmental concept they must also be seen in the situational context. It can be hypothesized that children joining a new group or being placed into environments such as the hospital may go through these stages while they familiarize themselves with the setting. Identifying individual stages then becomes a very complex multilevel process which is connected with various social situations.

The view of a child underlying this study is in line with symbolic interactionist thinking that a self-conscious organism is able to define his/her own reality and define, shape, and negotiate his/her own relationship to objects of that reality (s.a. Denzin, 1977). This implies that the child him/herself is able to shape the ongoing developmental process of socialization within the given context. Language in combination with expressive behaviour can be seen as important reflections of the socialization processes and the development of self within the hospital setting. They form the focus of this investigation.

The theoretical view influences the methodology which is used to obtain information as well as its interpretation. An example may illustrate this influence on the interpretations: An expression of a child’s pain is not interpreted as a mere stimulus-response action, but the role of a child as an actor in the social situation is also taken into account. During painful medical procedures a child may also react to situational aspects, to the persons who are present, to previous experiences, and many other variables. Symbolic interaction implies that a child is able to shape his/her own reaction to a stimulus and interact with
others in any social situation.

The following chapter will explain how the theoretical frame of reference shaped the methodology which was used for data collection in the setting.
4. CONDUCTING THE INQUIRY

The problems of developing appropriate research methods is not new. Aristotle wrote in "De Anima" (Ethics I: 1):

"...it might be supposed that there was some single method of inquiry applicable to all objects whose essential nature we are endeavoring to ascertain (as there is for derived properties the single method of demonstration); in that case what we should seek for would be this unique method. But if there is no single and general method for solving the questions of essence, our task becomes still more difficult; in the case of each different subject we shall have to determine the appropriate process of investigation."

"If to this there be a clear answer, e.g. that the process is demonstration or division, or some other known method, difficulties and hesitations still beset us - with what facts shall we begin the inquiry? For the facts which form the starting-points in different subjects must be different, as e.g. in the case of numbers and surfaces."

An appropriate method of investigation has to be found in relation to the research and its focus: the communication between a child with cancer and the persons involved in his/her care. The analysis of communication as a dynamic and interactive social process must also take its context into account. The context of communication in this study consists of the influences of the social and physical setting, personal attitudes, family background, and emotional variables. It also has to be taken into account that the investigation takes place in often emotionally intense circumstances.

The theoretical base for this research is linked to the theory of symbolic interactionism. Children and adults alike possess a self which enables them to interpret behaviour and act purposefully on the basis of those interpretations (Blumer, 1969; Denzin, 1973). Meaning is generated in interactions and is used to create new behaviour in a particular context. Interactions do not happen in

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6 See chapter "3. Conceptualizations".
an empty space, they take place within a context and proponents of symbolic interactionism have often described how communication changes with the setting in which it takes place (Goffman, 1959; Manis et al., 1967; Blumer, 1969). The hospital setting as the interactive context for this study generates its own social rules and behaviour patterns. The emotions of the participants in interactions can also influence communication and this is of special concern in this study which analyses interactions at a time when intense feelings occur.

Before the necessary methodological steps can be outlined, context and limitations of the study have to be examined. These limitations are found within the parameters of the illness and the persons involved.

4.1. CONTEXT OF THE STUDY

4.1.1. Phases of the Illness

Four main stages in the course of the illness can be distinguished:

1. Health;
2. first signs of illness;
3. treatment process,
   a. professional assessment,
   b. diagnosis,
   c. medical treatment;
4. remission.

There are important differences between remission and recovery. Remission means that no signs of the illness can be found, but treatment continues for some time. In addition there is also a danger of relapse, at which time the intensive
treatment process is repeated with a shorter stage of professional assessment.

Parents and child make their first contacts with health professionals during the stage of professional assessment. However, the illness has not yet been defined. Thus the study can start with the establishment of the diagnosis and hospitalization. From this point one can distinguish three phases:

1. Diagnosis - treatment - first remission;
2. first relapse - treatment - second remission;
3. multiple relapse - treatment - remission/death.

It would be ideal if the whole course of the illness could be investigated in several longitudinal studies. However, this was not practicable within the limitations of this research project. The initial phase was considered as crucial because it involves the first confrontation with the illness and requires a maximum of cognitive and emotional adjustment. Advances in medical treatment and resulting improvements in prognosis put an additional emphasis on the first phase of treatment. Therefore this first phase has been selected as the focus of the study.

Since children of different phases were present during the observations on the hospital ward where they were treated their reactions and communication patterns could be observed as well. However, they were not part of the core of this investigation as their interactions could not be followed up as closely.

4.1.2. The Persons Involved

The first phase of cancer treatment in the hospital setting involves three groups of persons:

1. Health professionals,
2. parents, and
3. children with cancer.

To generate an understanding of the communications of members of each group a researcher requires background information beyond the literal symbols which are exchanged. This shows the importance of a longitudinal perspective which involves spending more time with the persons under study in order to get to know interpretations from his/her specific viewpoint and learn about changes in the social processes. Therefore all three groups have been the object of intensive observations in this study.

The position within a setting influences the perspective (s.a. Piore, 1983). It therefore seems important to make sure that the researcher has mobility within the setting so that he/she can shift perspective and investigate various roles of others.

An additional parameter is provided by developmental considerations with respect to children, especially young children. Developing quickly in every aspect of their lives they also go through the formative stages of social behaviour. For young children the impact of cancer may be especially severe because their understanding of the events is limited and they have difficulty in conceptualizing illness and treatment. Since a new stage of development begins with puberty, involving new issues in socialization processes, the age of the children studied was limited to a maximum of ten years.

In summary, the focus of this investigation is on children with cancer and their families during the first phase of the treatment while the age of the children does not exceed ten years.
4.2. AN ANTHROPOLOGICAL APPROACH: PARTICIPANT OBSERVATION

A methodology for this investigation must be able to reflect the process oriented character of the social acts between the persons involved in this study. The most applicable methodology seemed to be a qualitative approach using observation procedures in order to gain insight into the roles which are adopted in the hospital setting. This is consistent with the theory of symbolic interactionism, because it can take into account the dynamic processes of interactions while generating understanding for the perspectives of the persons involved.

Qualitative approaches such as participant observation are common in anthropological or ethnographic research of various cultures, but they have also been used to investigate social organization within one's own culture (Douglas, 1970; Messerschmidt, 1981). One may also regard the hospital setting as a separate cultural entity, which generates its own distinctive patterns of communication and human behaviour. Culture can be defined in this context as "the acquired knowledge people use to interpret experience and generate behavior" (Spradley, 1980).

It is the aim of an anthropologist to become a student of the observed persons, who then become the teachers. The anthropologist is usually involved in the activities of his research subjects as a participant observer. The degree of participation can vary in a continuum of complete, active, moderate, passive, non-participation (Spradley, 1980). Every observation in which an observer is physically present must be considered as participation. Non-participant observation can be considered when the observations are taking place through technical devices such as video or one way vision\(^7\) without direct involvement of a person.

\(^7\) Those devices may have their own influence on the data collection.
Complete participation, which is on the other end of the spectrum means that the researcher takes the role of the observed person completely. This has been done for example in a research project for palliative care, in which the researcher with the help of a physician was labelled as dying, and then could experience the care of a dying person from a patient’s point of view (Royal Victoria Hospital, 1976).

Possible roles in field work have been discussed by several authors (Gold, 1958; Denzin, 1970; Spradley, 1980). The dialectic relationship between participation and observation has been highlighted by Raymond L. Gold (1958). He points out that between the two extremes of complete participant and complete observer there are the roles of "participant-as-observer" and "observer-as-participant". Complete observation indicates a high degree of detachment from the situation and is in danger to revolve around the theoretical preconceptions while a complete participant may succumb to his/her role and lose the function of an observer.

In the case of this study the participation was kept to the minimum possible within a "participant-as-observer" role (Gold, 1958). The minimum participation was chosen in order to avoid influencing the delicate emotional processes and recording an "original" state of the interactions as much as possible. The minimum participation also enabled the researcher to keep away from involvement with power within communications in the hospital hierarchy. This can be regarded as one of the preconditions for possibility to change perspectives and roles within the setting which was of paramount importance for the research project.

The issue of observer involvement must not be confounded with the issue
of objectivity within the interpretations. Objectivity in this context does not imply a separate entity which is detached from the process of information gathering. There is no presupposition of objective social meaning as in theories of positivist objectivism who claim that objectivity can be attained within a scientific method. Symbolic interactionists (Blumer, 1969; Manis et al., 1967) have stated that theoretical detachment from the empirical world leads only to a subjective reflection of the researcher's concepts. On the other hand a researcher must be able transcend the individual bias of him/herself and the persons s/he studies to identify concepts and interpret empirical data. Objectivity thus becomes a process which occurs within the interaction between an individual and empirical facts.

As part of this process the researcher must become an object of the investigation, as well as the individual subjects under study. This also helps to monitor the effects of the observer on the setting and make biases explicit (s.a. Myrdal, 1969). This problem has been addressed by providing a self-reflective chapter "Participant Observation: A Personal Account", which highlights processes and problems during the conduct of the study, and individual observation accounts in the context of all groups and subgroups of persons under study.

It has to be taken into account that any observer has an influence which is correlated to the degree of awareness of his/her presence by the observed persons. This influence may be diminished with appropriate behaviour of the observer. This can be addressed by attachment to an existing role in the setting, i.e. acting as a doctor. This happened in the observations of the professionals when the researcher was perceived to be in connection with one particular professional group and therefore rarely challenged by others.

If the least possible degree of participation is the goal then the observer
has to blend in with the setting, so that s/he is barely noticed. Every participant will be noticed and therefore influence the situation. An observer has to respect general behavioral rules of politeness which are expressed with physical and verbal symbols. If a person does not even say "hello" s/he will most likely be looked at as an unwelcome stranger. However, if the observer keeps his participation consistently to the situational minimum possible, s/he will soon disappear into the background and more important issues have priority in communication and attention. This can be considered as a 'wallpaper effect', which means that the observer becomes part of the general physical background in the perception of the persons observed. This has also been noted in this study when individuals "forgot" the presence of an additional person, i.e. an observed person said to the observer after an involved conversation with another person: "I completely forgot about you".

Unobtrusiveness which can be achieved by appropriate behaviour in the setting has also disadvantages for the analysis. The relevance of issues cannot be examined immediately without changing the degree of prominence of the observer (s.a. Denzin, 1970). For example, if the observer suddenly asks questions during and interaction s/he observes the role changes from a passive to an active participant. If the choice is made to remain in the background, an opportunity for clarification may be lost. However, this problem was addressed with the interviews which were conducted throughout the study.

It has to be noted that in a participant observation methodology analysis is carried on sequentially using inductive processes (Becker, 1958). Issues and patterns are noted during observations which have to be examined during further observations. This means that analysis does not take place separate from the
data collection, but is rather a dialectic part of it. Observations without structure do not necessarily make sense and analysis separate from the observations is in danger of leaving out important clues. Therefore observations move from generalized to focused levels, and interviewing proceeds from a general informal to a focused and formal level.

The observations can be classified into three different types: descriptive, focused, and selective observations. As a rule the wider scope of descriptive observations is applied at the beginning of studies and the scope is made narrower with regard to events and patterns which evolve. The focus of the observations was changed when issues needed clarification. However, a general view was maintained in order to be perceptive with respect to other issues which may not yet have been addressed. The scope of the observations therefore became an oscillating process throughout all the stages of the research.

Interviewing was used to clarify issues arising out of the observations. It served to focus and elicit patterns of interaction in the setting. Interviews were conducted in two ways:

1. Informal interviews were any questions of clarification or information, which were asked in a situational context rather than in prearranged situations.

2. Formal interviews were prearranged sessions during which issues arising from the observations, such as obtaining information, specific problems with the treatment, etc., were addressed in a focused situation; these interviews were recorded on tape or by note-taking if prior consent had been given.

Interviewing has to be adapted to the situation in which it takes place and is also influenced by the way in which it is conducted (Becker, 1956; Rieken, 1956; Spradley, 1979). This is also true for the interviews which were conducted in
this study.

The informal interviews were very much influenced by the specific situational context. Frequently they occurred at the nursing station where people would come to gather information. Some consisted out of single issue questions to clarify an observation, i.e. "what does this mean?" and others were casual talks with parents or staff about a current concern, i.e. if the medication had arrived. Also many brief conversations in the hallway or in the cafeteria are within this category. While lunchtime - an occasion for informal feedback was regularly shared with staff members during their observations, meetings with parents in the cafeteria happened only by chance and never involved children. Generally I kept a low key listening role during conversations which I attended and would only occasionally use the opportunity for an informal interview clarifying issues when they came up.

Formal interviews were usually arranged at the request of the observer and were scheduled in advance. The individual staff members who agreed to being followed were interviewed after the observations were completed in addition to some who served as informants. Sixteen formal parent interviews were conducted in addition to the in home interviews of parents participating in the case studies. No formal interviews were arranged with the children because it was assumed that they would react strongly to the situational context and thus not be helpful providing actual answers. During formal interviews I took a more active role by addressing issues which I had observed and by following up with questions.

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8 For more details see the chapter "6. Hospital Staff".

9 For more details see the chapter "7. Parents and Families".
It is quite common in anthropological research to use informants (Spradley, 1979; Agar, 1980). These are persons who have particular insight and are accessible to the researcher. They can help to introduce and reflect issues of the setting under study and also assist in getting access. This study was no exception and some key people, especially within the professional setting, were available to answer questions and discuss issues. This was particularly helpful in obtaining the necessary information about medical and organizational procedures.

A case study approach was chosen as a device to provide a frame of reference for a richer understanding of the proceedings of the treatment. It enabled investigation of the dynamics of interactions as processes and not as static events. Following a small number of individual children provided an opportunity to gain more understanding of their perspective, because a treatment procedure could be observed in the contextual frame of reference of the child. It gave important insights into the meaning of hospital processes for children and interactions could be observed in their historical, personal and emotional context. Most of the scenes concerning the perspective of children, which are presented as examples later, derived from those case studies.

In a way one might argue that the hospital under study was a case in itself, but reference to case study is made here with respect to individual children who were in the appropriate age range during the first phase of cancer treatment in the hospital setting. This involved four different families whose children were within the age range under study. The observations of these

10 Details about the cases are given in subchapter "7.1.1. The Case Studies", in the context of the chapter "Parents and Families", and in subchapter "8.1.1. The Case Studies", in the context of the chapter "Children". The way in which parents and children were approached is stated in the subchapters "4.4.3.1. Parents", and "4.4.3.2. Children".
families also provided a convenient frame of reference for observations of children and families in the hospital setting.

Additional cross-sectional observations of other children on the ward were also made to provide a wider degree of information about the functioning of the setting and to achieved a greater degree of generalizability of the issues within the setting. While being with the individual children under study I became a feature of the setting and was able to watch other children interact and openly show their emotions and attitudes.

A certain amount of overlap between the observations of children and parents was inevitable and to some extent beneficial. It was important, however, to make distinctions and observe the individual approaches towards a communication from the viewpoint of the respective person.

4.3. ACCESS

In order to be able to collect information, which is sometimes of a very personal nature, access to the setting and to the persons involved is very important. In such an emotionally tense situation access can be quite difficult and yet it is crucial for the success of the project.

Some researchers have developed a gradual approach in order to gain access and sharpen the research focus. Spradley (1980) called this "reconnaissance". This can also be part of the data collection because it often reveals interesting details about the setting. A similar approach has been chosen for this research project in order to expand the access to the various levels of the setting and to tune the appropriate observational behaviour. The first part of observations of professionals (hospital teachers) was undertaken as a pilot study.
A very important issue is the degree of acceptance the observer is able to get from the members of the setting he/she studies over time. This influences his/her ability to collect data and to get access to the more intimate functional details of an organization. This dynamic process can also have considerable influence on the degree of observer participation (Light and Byerly, 1981).\footnote{See also the chapter "5. Participant Observation: A Personal Account" which includes more details about the processes of acceptance in this study.}

Having a regular presence within the hospital setting proved to be an important asset for gaining informal access to the individual persons acting within it.

A more formal access procedure involving medical and administrative authorities had to take place before individual persons could be approached to give their consent to take part in the observations. University requirements as well as concerns of the hospital administration had to be addressed. This involved formal proposals and presentations at appropriate committees\footnote{Several experiences are highlighted in the subchapter "5.4. Stage 4: Fieldwork".} before individual consent could be obtained. No individual observations were done without the explicit consent of the persons involved\footnote{See consent statements in the Appendix.} and it was made clear that this consent could be withdrawn any time. The respective procedures of getting consent are included in the introductory statements preceding the accounts of every group of persons involved. It should also be noted that the reflective accounts about the observations indicate additional issues arising from the conduct of observations and observer behaviour.

Access cannot only be seen as getting permission to undertake the research project and conduct observations, it must also involve access to
Conducting the Inquiry / 64

information. This depends very much on the actual conduct of the observer and his/her relationship with the persons under study. It is a process rather than a step which reflects its characteristic of a social act.

4.4. FIELDWORK

The immersion in the field is the central piece of any study using ethnographic methods such as participant observation. Fieldwork took place over a time period of three years, three months and two weeks. A total of twelve months involved direct observations in the hospital setting. The timing of observations had two distinct phases lasting approximately six months each: observation of hospital staff and observations of children and their families. Observations of hospital staff initially excluded social workers, because the department was in a transition involving staff changes at that time. Observations of social workers were appended at the last part of the second phase of the study. The intermediate time between the fieldwork phases was used to obtain a more formal access and consent from various committees.\(^\text{14}\) In addition field notes were analyzed and evaluated.

Many persons in the setting changed during the gap between the phases of fieldwork. This interval provided an opportunity to decrease misperceptions of my role, particularly by parents and children who in the first phase usually saw me associated with staff roles. Because some time had passed, I was able to make a new beginning when I was observing children and their parents.

The daily time of observations was determined by staff shifts or the main timeframe of activities between breakfast and supper on weekdays. However,

\(^{14}\) See also chapter "5. Participant Observation: A Personal Account".
unusual times for major events such as nightshifts and weekends were also taken into account and became occasionally part of the fieldwork in order to examine the situation personally.

It has been stated earlier that an effort was made to minimize interference with hospital routines, events and reactions. Therefore the observer's conduct was as low key, friendly, and as unobtrusive as possible.\textsuperscript{15}

4.4.1. The Setting

The fieldwork took place in a modern pediatric hospital. Treatment for cancer was administered on a specific ward with 22 beds. Most of the observations took place on this ward. The hospital provided a treatment facility for a large area and therefore many families had to travel great distances. All families who took part in the case studies lived within a four hour transportation radius.

4.4.2. First Phase: Hospital Staff

The various health professionals became the first target for the observations. Their consent was important for the general access to the setting. Participant observations of several different health professionals who worked in the hospital with children with cancer were undertaken using direct observations while following a staff member through his/her work. This enabled me to get to know the setting as well as being introduced to the people. Being with staff members also gave me a role definition and enabled me to adapt observational behaviour.

Getting access involved personal contact with the respective staff members.

\textsuperscript{15} Experiences made during observations, such as changes in dress, conduct, reactions of those observed, are attached to the chapters reporting finding of the fieldwork, e.g. 6.2.9. Observing the Teachers, 6.3.8. Observing the Nurses, etc.
as well as consent by the professional hierarchy. This required introducing myself and the research project to the head of the respective department and to the various staff members who I wanted to observe. After verbal agreement was obtained the observational schedule was set up with the respective staff members.

The observations of staff members were made over a period of almost six months. Most professional groups were observed directly for two weeks. The observations began with the teachers (2 weeks) who conducted classes in a separate room outside of the actual ward, but they were also involved in bedside teaching with children who were unable to attend classes. This provided a more general introduction to the hospital because the teachers were involved with children on many different wards. Observations of the Head Nurse (2 weeks) followed who then changed role and became Nurse Clinician (1 week). Several days of general ward observations followed and attention was given to the general activities on the ward, some staff rounds, as well as the number of persons who were passing through. Nurses were observed during various shifts over a period of three weeks. Observations of Child Life Worker (1 week) and Therapists (1 week) followed. The first phase of direct involvement in the field was concluded with observations of residents and senior physicians (2 weeks). The Social Worker was not part of the direct observations at this point because several staff changes were taking place at this time.

The conduct of the observer had to be carefully adapted to the professional groups and the situational context. This made variations in behaviour as well as in clothing necessary, e.g. wearing a lab coat while observing...
The daily timing of the observer's presence was adapted to the working hours of the respective staff member.

Formal follow-up interviews were made with all staff members who were observed. These interviews were held in the framework of feedback sessions in their respective office in which specific attention was given to the influence of the observer on their work but it was also an opportunity to clarify issues arising from the observations. Staff interviews were generally recorded via notebook. This avoided the threat of tape-recording which could raise the fear that they would leak out and could be used against them within the professional hierarchy.

4.4.3. Second Phase: Parents and Children

Observations of parents and children were combined over a time period of almost six months, which included five months of direct observations in the setting. Initially two weeks were spent on the ward without being involved in case studies as an introductory part of general observations. During this time period almost two hundred different children were admitted to the ward. Most of the parents and children had informal contact with the researcher.

Observations of the Social Worker (1 week) were conducted immediately after the conclusion of the studies involving parents and children.

See also the chapter "5. Participant Observation: A personal Account".
4.4.3.1. Parents

The research project was introduced to the parents who were considered for the case studies due to their child's age and stage of the illness by the senior physician who was assigned to the case. This usually happened after the diagnosis had been established. The physicians signed a consent form\(^8\) to signal their agreement. Then I introduced myself personally to the parents and gave them a written statement\(^9\) explaining the aims of the research and asking for their cooperation. It was made clear that the study was not involved in any aspects of the medical treatment.

The parents who participated in the case studies had to give consent for the observations of their children as well as themselves. Parents were told that their consent could be withdrawn temporarily or permanently at any time. I stayed in the background as much as possible to achieve a "wallpaper effect", which means that the researcher became almost part of the physical background due to the uninvolved approach. Arrangements were made with the parents to ensure that they did not feel bothered by the length of the researcher's presence. The observations soon became part of the daily routines. On several occasions I passively resisted efforts to draw me into a helping network which would have influenced coping, communication, or other processes.

When important meetings between parents and staff were set up, I also arranged to take part in them. These sessions involved mainly nurses and/or physicians and parents and dealt with the implications of the treatment. For example, in one case the father had decided to take the child out of hospital

\(^8\) See Appendix

\(^9\) See Appendix
and nurse clinician and head nurse talked with him about the care at home as well as emotional issues.

Parents participated in informal and formal interviews. Formal interviews were held upon request of the observer with the parents who were involved in the case studies after the completion of the first treatment phase in the hospital. If possible, these interviews were conducted at the respective family’s home in order to include their perspective within the context of their familiar environment. Three of the four parents participating in the case studies were interviewed during home visits which were tape-recorded, transcribed, and analyzed. A copy of the transcript was made available to the parents for further comments.

The initial contact between observer and parents who were not part of the case studies usually developed in a casual manner. Parents often learned about the research from other parents and became more interested which triggered questions. Some became curious about this person who was taking notes all the time. This initiated many informal conversations and gave me an opportunity to introduce myself.

After an initial contact had been established and parents had been introduced to the research project they were asked if they would like to share their own experiences with the observer who was interested to record their perspective. This led to several more intensive interviews which lasted between one and two hours each. Those interviews mainly involved the mothers, because they constituted the prime parental caretaker in most cases. If possible the fathers were also included. While a focus on parents with children who were in the initial phase of the treatment was maintained, experiences of parents whose children were in the final stages of the treatment were also included. In fact
three children died shortly after long interviews with their mothers had been conducted.

The sixteen formal interviews involved fifteen different families. Usually they were conducted in a separate room, e.g. residents' office or parents' lounge and involved only mother in nine, father and mother in three, and only father in two instances. One additional interview was made with one mother who wanted to address a matter of her concern in more detail upon her request. Four interviews took place in the child's room. One interview took place at a house where parents, who did not live in the city, were able to stay during their child's illness. Three interviews involved children over ten years of age. The interviews were recorded with the help of a notebook during the conversation. The resulting notes were then reinforced by additional expansions immediately after the session. There were also follow-ups to several interviews when parents told the observer additional experiences.

In addition several general meetings of parents were attended with their permission. There was a weekly meeting for parents, which was offered by the Social Workers on the ward. This afternoon meeting was attended usually by a small group of parents, but it was an opportunity to establish further contacts. During the study parents organized a self-help group which was part of the Candlelighters. The Candlelighters are an organization of parents of children who have cancer, who have parent groups in many North American communities. They also publish a monthly newsletter.
4.4.3.2. Children

The observations of children varied according to their respective ages. I introduced myself to the child in question and requested his/her consent to my presence after I had received consent from the parents, but it was up to the child to give or withdraw final permission. The individual child was given the opportunity to decide about my presence each time I entered the room. In most cases the first introduction was done by the parents or health professionals known to the child.

While undertaking observations focused on individual children other events on the ward were also recorded keeping in mind the perspective of the child. Informal contact with many other children on the ward was also established. During the case study observations interactions involving other children in the same room could also be observed very closely. This involved a total of twentytwo children who shared the same room between one and twentytwo days. Only one child from the case studies, who had a short hospital stay, stayed in the same room while the others changed two to three times between single, two-bed, and four-bed rooms.

Being with the children without communicating with them might have been perceived as disturbing. Therefore I sometimes engaged in minor activities with the child such as playing games, casual conversations, etc. if the situation required this. However, it was always my aim and attitude to stay in the background as much as possible and perceive communications, events, etc. from the perspective of the child. I was present on the ward at regular times during

21 See "Children's Consent" in the Appendix.

22 See chapter "Children" for more details.
the week. A typical observation day began when medication was administered and breakfast was given until supper was served. This seemed to be the timeframe for most important interactions, which was confirmed by occasional observations during evening hours and on weekends.

4.5. RECORDING PROCEDURES

The observations as such were recorded according to the perception of the observer. The observed verbal and nonverbal reactions were recorded in writing, as well as the circumstantial aspects, e.g. noise level, activities, place, etc. This part constitutes the factual observations. However, all activities take place within a dynamic interpretive context. All the observations are also influenced by the observer's perception. Therefore an additional record was kept which included subjective statements from the observer's point of view, i.e. assuming sadness, experiencing stress, tiredness, etc. With respect to these observations inferences could be made on the actual background of the recorded communications. These different observations can also be seen as external and internal observations, where external refers to the description of behaviour and internal addresses the experiences of the situation.

The participant observer has inherently a dual role, to participate and to observe. At the same time s/he serves as the instrument which records and interprets. These functions must sometimes be separated for analytic and evaluative purposes although they are combined in one person. The participant observer assumes a dynamic role which should elicit access to the meaning of complex human interactions.
The Notebook

LEFT SIDE

Contents: Secondary Observations

Examples: supplementary notes written some time after the actual incidents

Explanations

MSI = Medical Student Intern, meaning of terminology, etc.

Comments, questions, hints

shaky voice - anger?
looks helpless,
loud voice as way of coping?

Personal Feelings

feel tired,
difficulty concentrating

Evaluations

seems to be sad,
does not seem to cooperate

Physical Setting

drawings of floorplans with explanations and descriptions

Supplementary Space

additional primary and secondary observations

RIGHT SIDE

Contents: Primary observations

Examples: descriptive records taken immediately or just after an incident containing:
- literal records of communication
- summary records
- detailed reports about activities
- descriptions of behaviours
- information about location

Timing

regular records of time intervals
Different aspects of observation were reflected in the field notes.\(^2\,^3\)

There were quotes and literal records of people in the setting, but sometimes also nonverbal expressions of emotions were important for an understanding of an interaction. Perceptions of the observer were also clues to the meaning of certain communications. Therefore an observation of the observer was also conducted. Self reflective records were taken regularly and recorded on tape. In addition regular meetings with a psychologist took place during the observations in order to keep a record of changes within the observer's perspective. Those records have led to an additional personal account of the observations.\(^2\,^4\)

The participant observer has to make several judgements during the analysis regarding the significance of the things s/he observes. It is the role of the researcher to organize the overwhelming amount of information and be theoretically alert. This means that the structure of issues evolves as a theory from the setting (s.a. Glaser, 1967). Basically two levels of significance are relevant: significance highlighted by persons in the setting and significance attributed by the observer. Both derive from interactional processes and therefore include personal bias of the participants. A staff member may communicate something to the observer because s/he wants to direct the observations in a certain way in order to receive a more favourable description of his/her own role. The observer on the other hand has preconceptions and may reflect only those instances which suit them. Several steps were taken to address the issue of significance: First, decisions on significance in this research project were linked the question of representativeness. For example, issues highlighted by individual

\(^{2\,3}\) See tabulation of "The Notebook".

\(^{2\,4}\) See chapter "Participant Observation: A Personal Account".
members of one group were examined with other members of the same group in interviews or by shifting the focus of observation to the object in question. Second, the observer was object of explicit self-reflection as intrinsic part of the data collection. Personal bias were recorded as feelings, ideas, opinions in field notes, reflective tapes and by becoming observed through the special set of interactions with a psychologist. Third, the processes of data collection were made explicit and extensive samples should enable critical readers to make their own evaluations. This process oriented character is in line with concepts of symbolic interactionism. It has to be taken into account that the explicit immersion in social processes become the basis for new understanding and knowledge in this study rather than the notion of reflecting an independent notion of truth.

4.6. POST FIELDWORK ANALYSIS

It has been mentioned before that an analysis within the ethnographic framework is an ongoing and sequential process involving reflection and examination of issues (s.a. Johnson, 1975; Spradley, 1980; Hammersley and Atkinson, 1983). This was done by marking issues in the notebooks, reflective note-taking and tape-recording as mentioned above. However, some key decision still had to be made, especially how the information could be presented. A separate notebook with research ideas which were put down during the field work contained some additional ideas for this problem.

The field notes were analyzed several times. At first issues were simply noted, identified and grouped in to a separate book with a brief content description. This was basically a more thorough continuation of the analysis which had taken place during the fieldwork. Then an organizational framework
was established which addressed communication between the various group formations, gathering of information, and reflection of the observer's presence. The emerging issues were checked again against the descriptive notes from the fieldwork.

Supplementary issues such as professional goals or rewards were added in the accounts of hospital staff because they seemed to be influential for motivation. It also emerged that treatment procedures such as lumbar punctures or bone marrow aspirations were a major focus for medical staff, parents and children. Therefore they are described in more detail. During the fieldwork an effort was made to follow the handling of information through the various groups of persons in order to look at the differing degrees of importance which it obtained. This was included under the topic information, e.g. the discovery of a tumor (in the chapter "Nurses"). Particular problem situations covering several fieldwork sessions were also included if they seemed to represent important concerns which had been identified in the setting, i.e. a child with nightmares who had not been told that he had Leukemia representing issues of the awareness context (in the chapter "Nurses"). A special note was made whenever the observer was addressed during interactions.

The first idea for the final presentation was to give composite daily accounts for every staff member. However, this was discarded because too many issues would have to be put into one day's account, which would make it less representative of actual daily routines. In addition it would be difficult to cross reference issues concerning parents and children. The structure of intergroup relations evolved as the scheme for data presentation. This makes it possible to compare various categories of interactions and still leaves space for direct field
notes which provide informative details.

The analysis of the data is presented in the same sequence as it was collected. Literal quotes and scenes from the setting are included in order to communicate the atmosphere of the setting as well as the attitudes of the persons who were involved. All names have been changed in order to protect the identity of the persons who provided the data for this study.

The general conceptual framework of this study has been made explicit in the preceding chapter. The details of recording procedures and analysis of the data make the conduct of this study and the analytic processes transparent and should permit a high degree of replicability.

Ethnographers typically become involved in a setting and try to understand the different patterns of behaviour and communication between the people involved in it. Interpretations do not follow preconceived definitions, rather they evolve from the fieldwork. Van Maanen (1983: 255) states:

"It is in my view that we are best thinking of qualitative research in terms of some of the organizing principles surrounding the the activities (and topics) of those who do the work."

Generalizations are built from the ground up from the data of the setting under study. The researcher has a crucial role in gathering the data necessary to understand and interpret the organizing principles of activities. The perception of the observer and researcher is also very important for others who read the interpretations. Therefore multiple reflective and descriptive accounts have been provided in this study which focus on the observations themselves. A whole chapter (Participant Observation: A Personal Account) addresses the process of the observations and the perceptions of the observer. In addition there are
reflective accounts (e.g. Observing the Nurses, Children, etc.) which highlight issues of observational conduct and the experiences which were made during the observations of a particular group. These chapters should enable a reader to understand the information which is presented not only as a result but also as a process.
5. PARTICIPANT OBSERVATION: A PERSONAL ACCOUNT

In this study the observer was a tool for data collection. A subjective account of the observer is included which shows the evolution of the study. It may also make personal bias and experiences more transparent and help others in their assessment of the findings in relation to other similar studies. It is meant to facilitate a more objective evaluation.

I have already referred to the origins of my personal interest in children with cancer which began with the experience of cancer in the family and led to my earlier work in this field in Munich.

Although the study was a dynamic process, several stages can be distinguished, each with its own focus and difficulties. They are addressed in this account in order to provide additional understanding for the context of the study and the interactions relevant for its conclusions.

5.1. STAGE 1: PREPARATIONS

There were challenges by various levels of the settings which were involved. The first hurdle in the direct approach to the actual research was access. Being a doctoral student getting access to a hospital setting involved five steps. I had to get permission from various people:

1. The research committee of the university which supervises the research project all the way and is important for its academic approval. Because my research was interdisciplinary the research committee grew until it consisted of seven members from different faculties. Organizing meetings required considerable effort and was very time consuming.

2. The Human Subjects Committee of the university looks at the ethical
aspects of a research project and is especially interested in consent letters.

3. A **medical authority** in the hospital is probably the most important person in order to get access to the setting, which seemed be closed without the appropriate insider support. Personal contact and interest in my research proved to be very helpful.

4. The **administrative authority** in the hospital was represented by a research committee which screened all research involving patients or hospital facilities. This committee did have some concerns with respect to my methodology and I was invited to a meeting to answer some questions, e.g. what results did I expect and would they be generalizable, etc. Representatives from different departments were present. After the meeting my research proposal was circulated and some changes were suggested to my consent letters emphasizing that the hospital had nothing to do with my research. These changes, which seemed to be precautions against possible legal consequences or detrimental publicity effects, were incorporated into the consent letters.

5. The **observed persons** were hospital staff members, parents, and children. Staff members gave verbal consent. Parents had to give written consent for themselves and for their children. Children were asked individually if my presence was acceptable and told that they could tell me to go away whenever they wished to do so.

Some of these steps incorporated several smaller steps; for example some committee members had to be approached individually as well as during the formal meetings. In the hospital there were also the lines of professional hierarchy which had to be respected. Whenever I wanted to observe a member
from a particular professional group, I was introduced or asked to introduce myself to the head of the department. Getting permission was an ongoing process during the different stages of this research project.

5.2. STAGE 2: THE PRELIMINARY FIELD WORK

The actual study in the hospital setting began with a preliminary study which became the initial part of my data collection. This made only a partial permission necessary and postponed some of the administrative hurdles. Thus the field work can be categorized into a semi formal level (preliminary study) and a formal level which involved all the levels of consent mentioned above.

The primary access to the setting was achieved through a personal contact with a medical authority at the hospital. Major advantages of the preliminary field work were that I established myself in the setting and made personal contacts. I could also train myself in the observation and data processing skills which were necessary for the field work in this particular setting.

Due to my academic background in education it was arranged that the observations in the setting started with the teachers, who represent the educational side. A senior member of the Faculty of Education helped me to get access to the hospital school.

After I had made initial telephone calls and presented myself to the acting head of the hospital school, I was initially allowed to stay with different teachers for certain days of the week. I soon learned that the school was not part of the hospital hierarchy and the legitimacy of my presence had to be taken into account. One or two of the teachers raised the question of the need
to have my work with them approved by the School Board, but after I happened to meet the school principal in the hospital and discussed my work with him this suggestion was not pursued. I was able to overcome the first apprehensions of the teachers. However, when they raised questions about how long I would be staying, I began to wonder how long the outsider would be tolerated. The teachers knew that I had an academic background in education which helped to establish a collegial atmosphere. They involved me occasionally as an assistant in teaching activities. However, I also sensed a fear of supervision when teachers tried to justify their activities in my presence.

The whole setting was new for me and I had much to learn. The teachers sometimes engaged me in their classroom activities. I was asked to supervise a child, help out when a teacher was sick, etc. The things I had disclosed about my professional background were used to involve me. Although I had wanted to be a non-participant observer I did not want to refuse, because I felt that I still had a somewhat fragile position in the setting. Later I was more careful with disclosures about my professional background.

The observations of the nurses which followed were a complete shift of perspective within the setting. They involved the medical authority in the hospital, which at that time primarily meant a senior haematologist/oncologist. When I was introduced to other persons no one really questioned my presence if I was attached to another professional. Interestingly, at the formal level of my fieldwork, which involved basically parents and children, the nursing hierarchy felt somewhat ignored in the process of seeking and getting permission. However, during the preliminary field work I began my observations of nurses with the Head Nurse which linked me with a high nursing position on the ward. With
the help of the Head Nurse I was able to get myself introduced to the ward and to the persons related to it.

Observing nurses also made a change in my appearance necessary, if I wanted to keep up my unobtrusive role.\(^2\)\(^5\) Whereas the teachers wore street clothes the nurses wore uniforms and were subjected to a dress code. Consequently I had to change into some sort of uniform in order to stay unobtrusive. I began to wear a white lab coat which also brought my appearance closer to the physicians.

Blending in with one particular group also was a limitation in some respect. I would only receive communications which were addressed to members of this group. In addition there was no opportunity to ask members of other groups, e.g. parents, more directed questions without changing my role.

Most of the nurses were female, but most of the physicians were male. This added to my physician image in the perception of some parents. Parents sometimes tried to consult me with medical questions and at one point even a nurse came to me and asked me if I would do the bone marrow aspiration. Of course I directed those requests to other persons, but it showed how much symbolism was involved (white coat & male = Doctor). I did not wear a name tag which all hospital employees had to wear and I was usually introduced by my first name followed by an explanation of my research.

The Head Nurse helped me to set up my observations of the other nurses on the ward. The nurses usually consented. However, I began to notice that a certain pattern evolved with respect to my field work.

1. A brief *introduction of my project* to the nurse I would be observing was followed by some questions, e.g. "Are you doing this for the university, for

\(^2\)\(^5\) See discussion about unobtrusiveness in chapter 4.2.
Participant Observation: A Personal Account / 84

a degree?", etc. Later when nurses became used to my presence they sometimes asked or made jokes, e.g. "Who are you following today?", "You like her, eh?"

2. This was followed by a period of getting used to my presence. The nurse would do her work but look at me from time to time or ask "What do you want me to do?" I usually said that she should ignore me but should do it so she could feel comfortable with it.

3. A couple of hours into the day a reorientation took place which was a more detailed version of the initial introduction and was usually initiated by the nurse's question: what are you actually doing? This was frequently paired with questions like "Am I doing things right?" At this point I explained my study again more thoroughly and emphasized that I was not there to evaluate their work but rather wanted to understand it and a nurse's perspective.

4. Then a normalization period followed where relatively little attention was given to my presence. Sometimes jokes were made in the communication with other nurses, i.e. "he is actually from the administration" or as an ironic precaution "he is writing down everything you say".

5. Late during the shift or sometimes in combination with the reorientation my motivation was explored, e.g. "why are you doing this?" I frequently told at this point that my brother had died of cancer which sometimes initiated a conversation about their own motivation.

6. At the end of the day there was usually mutual feedback. I tried to find out if there were any tensions related to my presence and if it had influenced the work. The persons I observed sometimes asked in turn if I had found it useful or in a more ironic way "was it exciting for you?"

The questions during the reorientation puzzled me at first. Why did more detailed questions about my research appear again after I had explained my study and had been with that person for some time. I looked more thoroughly at my introductory statements in order to find out if I could clarify those questions at the beginning. However, after this pattern had taken place several times I realized that it was just part of the information gathering process. In the beginning something new is seen from the outside and then the mind turns it around for a while until more clarification is needed. This process seems
somewhat parallel to the process which has been reported from parents who receive the diagnosis of cancer in their child. Their situation is complicated by the severity and the emotional impact of the information, however their questions also need time and surface later when their mind has been able to deal with the initial situation. Variations of these phases occurred during the observations of other staff members later on as well.

Being with nurses made it necessary for me to learn many new acronyms and expressions. I did not know what "getting a bone marrow", "LP", "BPQID" meant. In addition I had to learn the names of a number of medications and that the degree of their side effects made the distinction between a good drug and "horrible stuff".

Some nurses involved me in their activities, e.g. helping to make the bed. However, I was less involved than I had been with the teachers. When important conversations were going on and there was a great deal of movement, it was difficult to remember things correctly, particularly since I could not record them immediately. There was not enough time to write while my head was loaded with things I wanted to put down on paper.

The nurses usually introduced me to the parents or patients when they went into a room. These introductions varied from saying that I was doing a study to simply "he is with me". Parents never objected to my presence. Teenage patients, especially girls, were sometimes shy when a physical examination took place. Then I stayed further in the background, behind the curtain which was put around the bed, or even remained outside of the room.

In one isolated incident a mother reacted to my lack of participation and

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26 A mixture of English and Latin for: "Bloodpressure four times daily"; see list of acronyms in the appendix
said: "You look like the most useless guy I've ever seen." At first I was concerned when it seemed that my lack of participation could provoke angry reactions. I learned later that this mother was very direct, and in fact she had made an accurate statement from her perspective of need. She showed quite an interest in my study after I had been able to explain it to her. I began to gauge my activities according to the minimum level possible relating to the current situation. This required some sensitivity, and experiences like the one mentioned above helped me to find the appropriate behaviour for the setting.

It was very interesting how important my notebook became for others. Many asked me what I was doing when they saw me writing. One nurse whom I observed became quite upset when she noticed that I was writing while she was looking for clean sheets, something she considered unimportant. Although I explained to her that I sometimes needed to empty my head and that I was not looking at how many sheets she took out or if she took too much time for "unimportant" things, she remained suspicious. I often saw suspicious looks at my notebook and sometimes a nurse would come, look at what I was writing and ask "What do you write". I did not hide my notebook or my activity. I explained my study, whenever someone asked me. However, it seems that keeping a record makes people suspicious because they feel that they may be made accountable for something, and that their position in the hierarchy of the organization may be threatened. Physicians never asked those questions.

It seemed to be important that I had a proper role within the setting. After I had concluded my observations with nurses I sat in a corner on the ward for one day and recorded the activities near the nursing station and the number of people who were passing by. This was the day I received most
attention. I did not seem to have an appropriate role, in fact I was not doing anything in terms of care, and I was taking notes. Many nurses and other staff came to me after they had watched me for a while and asked me what I was doing. It was a good opportunity to explain my study to a number of people and I also wrote a short note in the "Communication Book" for the nurses. It was also an indication about the incomplete communication between staff. My presence, although mentioned frequently, had not been explained to all nurses on the ward. One must of course take into account that my work was not directly related to the immediate care and thus I did not have a functionally important role.

Because I did not have a function within the system, my position was somewhat tenuous. If there had been a problem or a complaint, I could easily have been asked to leave and my study would have been jeopardized. Therefore I was careful not to step on anyone's toes, which sometimes made me tense and very cautious. This was especially true during the first preliminary field work of the project.

After the observations of nurses I followed the Child Life Worker on the ward. This had been prearranged with her. I was introduced to the head of the department who seemed to be very interested in my study. This shift of professions again involved quite a shift in perspective and outlook. I got rid of my white gown and wore normal clothes. I felt relieved that no more painful treatments were applied. Child Life activities take place in a small separated area on the ward. Because the activities involved play and interesting toys children appeared to be more cheerful. Nurses who were passing by frequently

\[\text{see chapter "Nurses"}\]
waved at children or stopped and said "give me a smile". Although nurses often had to help adjust IVs or gave oral medication, they now seemed more as intruders into the private sphere of the children.

During the coffee and lunchbreaks Child Life Workers from different wards sat together and bits of information from their respective situations were exchanged. Most of the conversations dealt with casual personal issues. I felt quite accepted and my presence did not seem to cause any problems.

Being with Child Life gave me a more playful approach to the children. In fact it was the first time that I was able to spend longer periods with them. Although there was a constant coming and going in the play area the children were more stationary. I could observe how children reacted differently to the various persons passing by. I was happy to see some "normal" reactions of children like jealousy of each others toys, or interest in many different things at the same time. The narrow space of the play area sometimes made it difficult to be in there because of the physical limitations.

After my observations of Child Life I spent time with the "Physio" (Physiotherapist) and the "OT" (Occupational Therapist). Their work led me away from the ward and gave me some insight into other parts of the hospital. Suddenly the ward I had concentrated on became just another part of the hospital. Each ward had its own distinct atmosphere although the physical setting was often similar. I also had to adapt to the different problems and dynamics of respective departments and their roles within the whole hospital system.

Some Occupational Therapists and Physiotherapists share the same office space. However, the heads of the departments have separate offices. Differences in personalities seemed to be issues within the respective departments. The
workplaces of the therapist were spread throughout the hospital. Although there were treatment rooms close to the offices, many "inpatients" required treatment on their ward. There were also two gyms near the hospital entrance and between wards. This decentralization seemed to make the members of the department somewhat more loosely connected.

Following the physicians required again a shift in appearance in order to stay unobtrusive. I began to wear a white lab coat again. Physicians did not inquire very much about my research. It seemed that once I was with them I was just there as a part of their activities. Consent did not seem to be a problem. They were used to medical students and they probably regarded me as just another one.

Being with the physicians opened my eyes with respect to the small amount of time that they actually spend with patients and parents. I was somewhat disappointed that their job seemed to be to manage medical knowledge. A close doctor-patient relationship seemed to be of secondary importance. I took part in many meetings which I sometimes found difficult to follow when they involved a great deal of medical terminology.

There was a split in the hierarchy between senior physicians, the haematologists/oncologists and the residents. The residents were considered to be in training and there were regular teaching rounds where they had to present cases to an audience of physicians from different departments. Discussions and disagreements took place in medical rather than personal terms. The senior physicians were the ultimate decision makers and somehow the revolving points in the hierarchy of the ward.

The residents spent more time on the ward and signed most of the
medication orders. Sometimes I had the impression that they were struggling to come to grips with the responsibility of signing orders and on the other hand learning what they actually were dealing with. Protocols and different calculations of various medications combined with a lack of sleep due to long hours in the hospital did not contribute to sound decision making. Some residents vented their frustrations about this. The long hours also led to exhaustion which made them care less about personal concerns of patients. At one point I considered spending the whole shift of up to thirty-six hours with a resident in order to study the effects in more detail. This would have given me some first hand experience, but it would certainly have been difficult to keep up the notetaking in a sensible way. The problem of exhaustion, however, may be worth some more study.

On the other hand I began to understand how they would come to look at their profession as just a job which interferes too frequently with their personal lives. Things had to happen quickly with minimal effort in order to have enough strength to cope with the long hours. The language which refers to patients as cases of specific illnesses became understandable. Personal factors seem to be functional parameters which either contribute or are detrimental to medical progress.

When the senior physician had meetings, which sometimes took place at a different hospital, I was initially concerned about my reception. However, it did not seem to be a problem since I was in company of another staff member. Sometimes the physicians forgot to introduce me and commented later that they had forgotten that I had been there. I took this as a positive sign for my unobtrusiveness and the minimal effect of my presence on the setting.

One interesting observation was that during lunch or coffee breaks the
professions rarely mixed. Nurses usually sat together with other nurses and physicians with physicians. The next level of sharing a break would be the respective ward if there was no one else available. One more step down involved the field one was working in, i.e. inpatient and outpatient cancer clinic would sit together. The physicians were commonly from different areas when they sat together during a break. I never saw Social Workers share a lunchbreak with the nurses. Child Life Workers did this from time to time as well as junior physicians.

After I had observed those professions there was a break in my field work. I had not observed the Social Workers yet, because they were in a transition between old and new staff. Initially I considered to begin the next phase of observations with the social worker which could give me at the same time an introduction to the parents. However, I later decided that this might attach me too closely to one profession in the setting for the eyes of the parents.

5.3. STAGE 3: THE FORMAL PROPOSAL
A break was necessary, because for the observations of parents and children I had to go through the appropriate channels of getting consent. My committee asked me to prepare a more formal proposal.

From the perspective of the university administration my research was based in education due to my academic background. However, the interdisciplinary character became more and more obvious and my committee has to reflect this and expanded accordingly.

This caused organizational and academic headaches. Meetings were very
difficult to arrange. Different committee members represented different faculties
and backgrounds. During the preparation of my proposal and throughout much of
the research I felt frequently torn between the various demands. My proposal
expanded until it was fairly extensive. I received mixed responses and prepared
a shorter version, which was finally accepted by the research committee.

After this I was able to get the official consent from the various other
committees. They had their own routines and various minor changes had to be
made which were nevertheless time consuming as a process. I felt that I had to
defend myself constantly for the unsettling undertaking of my research. This
whole process took several months to complete.

Getting approval from the different committees was quite an interesting
process. Three authorities were formally involved (University Research Committee,
Human Subjects Committee, Hospital Research Committee), and all changes would
have to be approved by all of them. The submissions to the various committees
had to be planned carefully in order to ensure that changes to the proposal
which were made by one committee would not interfere with the approval of
another committee. This could have caused major delays.

The Human Subjects Committee of the university looked at the ethical
issues of my research project. It turned out that the Hospital Research
Committee was also concerned about the methodology in addition to ethical and
legal considerations. During a meeting of the research committee in the hospital I
was asked what kind of generalizability my data would have and what my
results would look like. The general atmosphere was friendly and the committee
appeared to be interested. A while later I was told that some changes to the
consent letters, which had already been passed by the Human Subjects
Committee of the university, had been suggested. The meeting of the research committee took place only once per month and because some members were sometimes not present all communications were sent around for approval. In the end I had to make minor corrections to the unchanged parts, because different persons had suggested changes which had to be adapted to the actual text.

The procedures showed an example of the different lines of authority which are present in a hospital setting. The changes which were made to the consent letters were administrative safeguards against legal implications of my research. I had to emphasize again that this research was no part of regular hospital activities. Finally the formal approval was given and I was able to go into the setting and begin my fieldwork officially, which still required approval from the persons I actually wanted to observe.

Parallel to those struggles another concern developed which became my constant companion. I needed money to live while I was doing the research and therefore multiple applications to various grant agencies were made. However, the lack of success was disappointing because cancer agencies did not seem to be interested in anything but medical research and as a foreign student I was not eligible for many government grants. The financial perspectives were a constant strain and in the end limited the research project.

5.4. STAGE 4: THE FIELDWORK

When I first entered the setting again I was careful to explain my project to the nursing staff. There had been quite a turnover and most of the nurses were relatively new. Even the Head Nurse had changed. I wondered if I was looking at a socially different setting. However, although different persons had created
some change, the ward seemed to be buzzing in its usual routines.

Initially the new Head nurse felt left out in the process of information and getting consent. Although nursing had been represented in the hospital research committee and I had gone to talk to the director of nursing, the information had apparently not been passed on. The Head Nurse wanted to take my research as an example of a lack of communication within the hospital administration. After I had explained my project and told her about the administrative processing which I had gone through I asked her to be somewhat careful because I was eager to start my fieldwork. I explained that I was afraid of more delays or - even worse - that parts of my research would be put in jeopardy, because I felt that my position in the hospital setting was not very strong.

We agreed that the nurses should be informed and I explained my research to several small groups of nurses on the ward. I gave them the consent letters to read and said that I would try to be as unobtrusive as possible. Several nurses were obviously informed about qualitative research and asked interesting questions.

It was important for me to get early access to record the first difficult adjustment phase. However, this coincided with an emotionally very difficult time for the parents, because they had to cope with their own feelings. Although I had made up an introductory statement I did not feel totally comfortable myself in asking the parents to participate in a study. My efforts to find the right approach were probably also reflected in the presentation of myself to the parents.

Initially two parents gave the consent letter back to me a little while
later and decided "not to take part in the study."

(A 28)

"We have talked it over and I think we’ll pass on this," said one father and handed the consent form back to me.

Björn: "That’s ok. If you want to talk sometime later, I will be around."

I was somewhat disappointed because I was eager to start, but any setback is also a challenge to learn something new. Later I discovered that the reasons for these refusals were mainly related to the timing of the request.

Over time I developed a relationship with the parents in which they talked to me about their concerns, which enabled me to understand reasons for their initial rejections. One couple had just received a treatment protocol which they had to sign prior to my introduction. In this protocol their child was given only a 30% chance, something they had not been aware of before. Parents said later that they had been in a state of confusion and wanted to withdraw and did not want to talk to anybody. Other parents referred to their emotional state as "being out to lunch".

Rejections at this point were disappointments for me, because I wanted to get going with my case study observations. I could relate to the feelings of the parents, but so many variables were out of my control. I was afraid that the whole study might collapse if I could not get over this hurdle. It made me even more cautious in my approach.

Another problem with attaining early access was that physicians did not sign their consent form before they were definitely sure about the diagnosis. This could mean that a couple of days passed while the child was being tested. In
addition I would then meet the parents at the most difficult point, just after they had received the bad news. In one case I was able to establish an early contact with the parents of a newly admitted child who were quite interested in my study. This enabled me to record some pre-diagnosis behavior of a hospitalized child on the ward. It turned out - luckily for the child - that there was no cancer. There had just been some abnormalities in the blood counts which could not be explained. This time the researcher in me was disappointed and the human being was happy.

I spent some weeks establishing my presence on the ward. I was able to observe many interactions between children in the play area and elsewhere on the ward, but I felt a bit like an intruder, especially in the patient rooms. It was frustrating that I could not proceed with my case studies right away. Some of the time I was not able to do anything but be there and stay out of the way. However, I felt that it was important to force myself to go to the hospital regularly - against an increasing inertia - in order to establish my presence as nothing unusual.

During that time I also established some contact with the Social Workers on the ward. They organized regular rounds for parents once a week in which I participated. This enabled me to get to know some of the parents although they were mostly parents whose child had been diagnosed some time ago. Some parents introduced me to other parents and I was able to interview some of them.

Finally, after mentioning my interest again to the physicians, and asking them to discuss it with the parents since I couldn't be be present at their first meetings, a family agreed to participate. Since the family was quite distressed
after learning the diagnosis I waited another day before I introduced myself and asked them if they would consider allowing me to be present as an observer. They agreed to participate and when I came the next day I gave them the consent form, which they signed.

On the one hand it was a relief that I could finally begin to study, but on the other I knew I had to be careful not to jeopardize it and put too many demands on the parents through my presence. I also introduced myself to the child and whenever I came I asked child and parents if it was okay for me to be there. To my relief it worked out fine although both parents were there most of the time which meant that the child was usually accompanied by three adults.

At the beginning the child was alone and I sat on a chair at the other end of the room where I hoped to be out of the way and out of sight most of the time. When another child was admitted to this room I sat down under the TV which was mounted high on the wall.

The TV turned out to be quite disturbing for me. It was switched on most of the time and sometimes made it difficult to understand conversations. When the children were alone in their room and a remote control was available then some would play with it and change the channels frequently or turn it really loud. Nurses who came in rarely seemed to be concerned with which channel was on. They were only there for a short time. If I could see the TV then it distracted me occasionally from the actual observations. I had to force myself to redirect my attention. When I left the room and had a break I felt sometimes quite drained by all the TV noises. I wonder what effect it had on the children.
After the family was used to my presence I was included more frequently in conversation. I did not start the talk except in the mornings when I came in, but responded when I was addressed. The more time I spent in the setting the more everyone got used to me and I was more frequently addressed by staff. I sometimes sensed this as a threat to my unobtrusiveness. While walking around with parents or children I usually stayed a couple of steps behind them but prepared to step up to them when they wanted to talk or when they were at a door which they were holding open for me. I tried to be prepared for changes in direction or speed so that I was able to be with them without hindering them.

Another consideration was the timing of my presence. In the beginning I was careful to give parents and children time to get used to me. On the other hand I wanted to catch important incidents which influenced mutual behavior and communication. Therefore I tried to be present during all medical procedures like lumbar punctures, bone marrow aspirations, and when the child received an IV. I was also limited initially by my own attention span which increased during the research.

It turned out to be very difficult to plan anything. Scheduled procedures were delayed for several hours or changed in the last minute without telling parents or children. I felt somewhat in the same boat with them and I learned to understand what it meant to wait long hours for something to happen. During those times of waiting I could sometimes observe the processing of information. In the mornings before I entered a patient’s room I spent some time at the nursing desk and wrote down patients names and room numbers in order to keep up with the changes. Since I had become familiar with the charting and
planning routines I was sometimes able to learn which procedures were planned for the day. Then I could witness the processing of information to the parents and from there to the child. As parents got to know their child's treatment protocol they sometimes were more aware than nurses about the procedures which were going to happen.

Frequently I encountered my own ambiguous feeling with respect to the research. When the consent forms had been signed by parents I encountered the feelings of joy for the researcher and concern for the situation of the child and the family. Waiting for consent had already put me into a strange situation where I was on the one hand waiting for new children to be diagnosed and on the other hand I felt terrible considering the fate of childhood cancer. There was this split between the researcher and the human being, a strange distinction. This was also apparent in some situations during my observations when I wanted to stay within my objective and neutral observer role and felt on the other hand that there was a need for intervention. When does it start to be unethical just to observe and not intervene when things go wrong?

Similar feelings with respect to coping came up when one child who had been one of my case studies suddenly died and I was able to start with a new case-study of a newly diagnosed child the next day. The researcher was happy because it fitted so nicely into my timeframe, but for the being it was difficult.

My presence also had tense moments. I could especially feel the tension during difficult medical procedures. I always felt as if I was walking a tightrope, one careless step and I would be out.

During one lumbar puncture a child "would not cooperate", which meant
that the child was fighting the procedure by every means at his disposal. I witnessed the initial failure to perform the procedure. Finally the physician called a colleague and an "experienced nurse" who was able to force the child into the necessary position (which upset the nurse who was first present). Sensing the tension I checked with the physician and he indicated that he would "rather not" have me in there and added that the procedure was actually very simple if the child was held right. I stayed out of the room and was left wondering what an effort it took to perform such a simple procedure.

If there had been a major incident where my presence would have been considered a nuisance or a threat I probably would have been in trouble with my research. Therefore, whenever I sensed that someone felt uncomfortable with my presence, I tried to talk to this person at an appropriate moment.

When my study was underway and I had spent considerable time on the ward, the children I observed became quite attached to me. Although I was not involved in direct activities with them, my constant and non-threatening presence must have been comforting for them.

The last child of my case studies was mostly alone in the hospital because his parents had to continue their professional work. I became the most consistent human contact for this boy and he became quite attached. He sometimes referred to me as "my buddy" or "my friend". At one point he gave me a Valentine card which said, "How, ....'bout being Valentines!" I felt that it would create a hardship for him if I just left. Therefore I stayed with him until he was discharged, especially since he was alone most of the time.

He became more open with me and talked to me although I did not initiate conversations. He also became interested in my notebook and sometimes
took my pen and scribbled something on a page. When he was discharged I gave him a notebook - just like mine - and a pen as a present.

5.5. STAGE 5: ANALYSIS

When I changed from one stage to the other I was usually looking forward to the different work which was ahead. The data collection had been concluded and I could go ahead with the analysis and put everything together. It was a new development and another step toward the completion of the project. However, after I had begun to analyze my field notes and transcripts, I soon felt overwhelmed by the size of the task. Three thousand pages of notes in bad handwriting plus transcripts and tape recordings had to be managed. Preset personal deadlines of completion of chapters passed and my work did not seem to have a major impact on the amount of paper. A new sense of frustration about my own capabilities arose regarding the task to make sense of the massive amount of data.

The analysis was complicated because findings in different parts of the field notes made reconfigurations of the evaluations necessary. They reflected the exploratory character of the study within a dynamic interrelated setting. In order to maintain comparability between the groups of persons who had been observed the chapters were structured in a similar way. Changes often had a series of implications within the network of this report. This again made the task to present comprehensive insights into the interactions in a hospital setting very complex and challenging.
6. HOSPITAL STAFF

6.1. INTRODUCTION
A multitude of different professions are involved with the care of patients in a hospital setting. They are organized in different interrelated hierarchies. Admission into a hospital also means many new relationships. This begins with the receptionist and continues with nurses, physicians, technicians, etc. A child entering the hospital has to cope with numerous encounters with strangers who nevertheless seem to be very important. The setting itself poses many puzzles for parents and child. Only gradually they become able to unveil its mysteries and learn about the links between the persons they are interacting with.

6.1.1. The Social Setting
When a child is hospitalized s/he usually stays on the ward which deals with particular illnesses, i.e. cancer. However, a few children were diagnosed of having cancer during their treatment for a different illness while they were in the hospital. After diagnosis they were then transferred to the Oncology ward for cancer treatment. Those children had to get acquainted with an additional group of hospital staff and different routines, which increased the number of new persons s/he was confronted with.

The Oncology ward itself involved a considerable number of different professions. Directly concerned with various aspects of care were the following groups:

1. Physicians
   a. Haematologists, Oncologists, and/or other physician in charge of a
patient,

b. Specialists (when consulted), i.e. Radiologists (frequently), Dermatologists, etc.

c. Oncology Fellow,

d. Senior Resident (changes every two months),

e. Junior Resident (changes every two months),

f. Medical Students (MSI = Medical Student Internship);

2. Nursing

a. Head Nurse,

b. Nurse Clinicians,

c. Chemotherapy Nurses,

d. Registered Nurses,

e. Licensed Practical Nurses,

f. Unit Clerk,

g. Aide/Porter,

h. Student Nurses,

i. Public Health Liaison Nurse (when consulted);

3. Technicians

a. Laboratory Technicians (bloodtests),

b. Radiology and other test Technicians (when consulted);

4. Therapists

a. Occupational Therapist,

b. Physiotherapist;

5. Social Workers

6. Child Life Workers
7. Psychologist (when consulted)
8. Teachers (according to children’s age)
9. Dietitian
10. Housekeeping Personnel

In addition the children frequently received radiation treatment, which took place at a separate institution a couple of blocks away. Sometimes parents brought their child there, but if a child was connected to an IV\(^2\text{8}\) an ambulance was called. Thus the child got involved with a number of other professionals:

1. Ambulance Drivers/Attendants
2. Radiology Receptionist
3. Radiology Nurses\(^2\text{9}\)
4. Radiologist (physician)
5. Technicians (making a cast).

Nurses were clearly the largest group and some professional groups or subgroups consisted out of one or two persons only. The number of professionals as well as their daily presence determined timing and conduct of the fieldwork. The observations focused on the persons on the ward which seemed to be most involved with the children and their families, while an effort was made to gain insight into agenda and conduct of the respective professional group.

\(^2\text{8}\) Intravenous infusion, see appendix for acronyms.

\(^2\text{9}\) The organizational hierarchy and qualification of the nurses involved with radiation therapy was not followed up during the short visits.
6.1.2. Observational Approach

The various health professionals were the most organized group in the hospital. Their consent was important for the general access to the setting. Therefore they became the first group within the observations.

Participant observation of several different health professionals who worked in a hospital with children with cancer was undertaken as a pilot study. This enabled me to get to know the setting as well as being introduced to the people and to adapt observational behaviour. Getting access involved personal contact with the respective staff members as well as consent by the professional hierarchy. This required introducing myself and the research project to the head of the respective department and to the various staff members who I wanted to observe. At this stage of the study, only verbal agreement was obtained which also involved a certain degree of tentativeness. Any conflict with the observer could lead to a withdrawal of privileges.

The conduct of the observer had to be carefully adapted to the professional groups and the situational context. This made variations in behaviour as well as in clothing necessary, e.g. wearing a lab coat while observing physicians. Formal follow-up interviews were made with all staff members who were observed. These interviews were held in the framework of feedback sessions in their respective offices in which specific attention was given to the influence of the observer on their work but it was also an opportunity to clarify issues arising from the observations. Staff interviews were generally recorded via notebook. This avoided the threat of tape-recording which could be suspected to leak out and be used against them within the professional hierarchy.

See also the chapter "5. Participant Observation: A Personal Account".
Experiences with the observations of the respective staff groups and description of observational adaptations can be found in the last chapter of every account of a staff group.

6.1.3. The Structure of Analysis

All reports about the various staff members are structured in a similar way. They begin with an introduction to the respective professional group including their setting and professional aims. This is followed by a statement about their acquisition of the information which is necessary for their work. Then their relationships to other staff, parents and children are described and summed up as the perspective of the respective staff group. A summary of the observations at the end of every section gives some insight into the mode of data collection, including its difficulties, adaptations and observer influence.

The accounts in the analysis of staff observations are in the same sequence in which the observations took place.

6.2. HOSPITAL TEACHERS

It is the purpose of this section to describe and understand hospital teachers within the hospital environment and display their perspective within the hospital setting. Since the children are allocated to a teacher according to their ages, differentiation according to age has been omitted in order to ensure anonymity of the teacher in question. All quotes in this chapter are direct accounts from the field notes unless indicated otherwise.
6.2.1. The School Setting

There are five full time teachers in the hospital. Four teachers conduct classes in one classroom on the third floor. Teacher A teaches Kindergarten through grade 2, teacher B teaches grades 3 - 5, teacher C teaches grades 5 - 7, and teacher D teaches secondary students. Teacher E works in a separate classroom in the Psychiatric Inpatient Unit on the second floor. All teachers are female.

All teachers are employed by the local school-board, but they are attached to different schools (elementary school, high school). Teacher C is acting as the head of the school program. During the 1984/85 academic year almost 1600 children participated in the program. Their attendance varied from single days to several months.

During the morning (9:00-11:00 hrs) teaching usually takes place in the classroom where often volunteers assist. In the afternoons the hospital teachers usually do "bedside teaching" (13:00-15:30 hrs). Teachers do not wear uniforms.

A description of the classroom may give a general impression of the physical environment:

The classroom is a large room on the third floor between the wards illuminated with neon lights. The wall facing the double entrance doors consists of glass windows and double glass doors which separate a corridor from windows and glass doors overlooking a patio. The other walls are covered with pictures, maps, big letters, notices, etc. apart from several bookshelves and cupboards. On the wall left from the entrance are several built-in cupboards and a sink. Four areas are separated by mobile room-dividers. In every area are tables and chairs.

The descriptions in this chapter refer to teachers A - C.

This may be important because almost all nurses are female and mostly mothers stay with their children.

See subchapter "6.8.5. Volunteers".
which vary in size and arrangement, and mobile blackboards which are actually white. In two areas are individual desks facing the wall with boards on the sides.¹⁴

Across the corridor facing the main entrance of the classroom is the teachers office, a small room without windows, two tables, chairs, and several filing cabinets.

6.2.2. Teaching Aims

In a document written for the school board the teachers formulated the aims of the hospital school (Teachers A - C):

"The purpose of the hospital school program is to ensure that optimal development of the individual is achieved providing continuous quality academic programs while admitted to hospital, and assistance in arranging smooth transition back to the regular school program when the student leaves, so that the child through acquisition of knowledge, essential skills and positive attitudes can develop into a self actualizing, self respecting individual."

In addition the following program objectives are listed:

1. To normalize a child’s hospital experience by providing a valuable link with normal life, thereby reducing the distress of separation, illness and personal insecurity.

2. To keep the hospitalized child progressing at the same rate as his classmates, and to act as a liaison between the student and his school.

3. To individualize an instructional program, by adapting it to the student’s ability, and by systematically working through the program on a one to

³⁴ At first the classroom seemed confusing, especially when classes were in progress. It gave an impression of coming into a large office, which was in this case more colourful than usual, where many people are talking and working and one feels slightly out of place. However the classroom did not have a cold atmosphere. Since there were no real walls between the different class areas one was always made aware by sounds or voices that there was something else going on in this room.
one ratio and to provide remedial instruction whenever necessary by assessing the needs of that student and producing a suitable program.

4. To keep abreast of new developments and innovations in the educational system as well as working with a variety of professionals within the hospital.

The teachers told me that their major aim was to help children keep up with their education despite illness or injury. They said that they wanted to help with school and also give help with learning. One teacher said that she would focus on individual support which could be done better here than in school, because the classes are smaller. In addition they would "arrange placement if necessary."

The main teaching aims of the Hospital Teachers may be summed up as stated in a description of the hospital school published by the hospital itself ("Speaking of Children" Vol. 9, No. 1 Summer 1984):

"For all of them (the children), the school program works to create a normal, familiar environment within the hospital setting, helping children keep up with their education despite illness or injury."

6.2.3. Rewards

It is important for motivation and engagement that the work provides rewards. Teaching in a hospital setting is quite a challenge due to the constantly changing situation. As one teacher put it: "You've got to be really flexible. I prefer to go without plan." The task to switch from one child to another and from one program to the next challenges the teachers creativity. One teacher said: "If you do not know what to do with a child then you are at the wrong place anyway." Thus a teacher can get a great deal of satisfaction from the mastery

This means special placement within the regular school system if the child needs special support.
of these tasks.

As an extrinsic reward one must add the notion of being helpful as support for a normal life. The result, however, is not seen immediately - if at all.

6.2.4. Teachers' Position in the Hospitals

The teachers are administratively independent from the hospital, because they are employed by the school board. This makes them independent from the organizational hierarchy of the hospital, but it also makes them outsiders. In addition their work is not directly illness related and serves different purposes. Teachers seem to be somewhat peripheral in the medical setting.\(^3\)\(^6\) This also becomes obvious in daily activities. They have to arrange their schedules constantly around medical procedures. Frequently they are not even informed when treatments take place during school time.

Teachers visit the children in their rooms before class starts. They wish them "good morning" and ask them to come to school after they finished breakfast, got dressed, etc. However children are often late for class because school does not have a high priority for the nurses.\(^3\)\(^7\) When children come late they distract other children for a while until the group has resettled again. Classes are also frequently interrupted by medical staff who take the child to treatment or examination.

\(^3\)\(^6\) This has become more apparent during the observations of medical staff. The teachers are probably the staff members who wait politely for the longest time at the nursing station until they get an answer. Most other staff would just interrupt conversations and ask.

\(^3\)\(^7\) A reminder for the nurses to bring children to school in time (written by a nurse) stated: "School is part of their regular social life (whether they realize it or not)." I interpreted this synonymously with "believe it or not."
On the other hand teachers are dependent on the information which medical staff have about children.\textsuperscript{38} They also have to rely on the nurse when a child's intravenous pump starts beeping. Then the teacher has to phone the respective ward and ask a nurse to come and check. The frequency of those interruptions varies. One day there may be three children with a combination of five IV-pumps in one class, another day there may be none.\textsuperscript{39}

Generally speaking teachers constitute a separate entity in the hospital setting. They are a connection to a "normal" world which seems to some extent subordinate to the medical problems which are relevant in the hospital.

6.2.5. Information

The realization of teaching objectives is influenced by the information available to the teacher. They need information about a child’s school program, effects of illness and treatment, therapy schedules, and duration of hospitalization. Data about family background also helps to assess the needs of the child.

Teachers receive listings of school-age children. They approach the children and have to find out what their individual school programs are. Sometimes the regular teacher has prepared a statement about the program. In most cases, however, the teacher has to phone the school and find out the details. Sometimes the child or the parents can help. The school counsellor is phoned when several teachers are concerned to simplify the information gathering process for the Hospital Teacher. This task can be quite time consuming, especially when several long distance calls have to be made in order to reach the regular

\textsuperscript{38} I never observed that teachers looked through a patient’s chart. All other staff (except housekeeping) consult the charts frequently.

\textsuperscript{39} Children with cancer get IVs quite often.
Background information about the child and his/her illness is provided by the "social round" of a ward. Once a week Head Nurse, Teachers, Child Life Workers, Occupational Therapist, Physiotherapist, Dietitian, Social Workers, and Public Health Liaison Nurse meet to exchange information about the children on a ward. Because teachers have students from different wards they may have to go to several such rounds.

During the "social rounds" for the Oncology Ward the Head Nurse usually reads short statements from a Kardex which lists diagnosis, routines, treatment schedules, etc. for every child. Sometimes she makes an additional comment or a question is asked by another person in the round. Usually the information which are passed on are about a child's age, illness, treatment, behaviour observations, and family background. The communication is "problem" oriented. Sometimes the Head Nurse will say "no problems" and then proceed to the next patient.

The Head Nurse looks at the Kardex which is lying in front of her, half on the table half on her lap.

Head Nurse: Karen had abdominal sutures removed today.

Social Worker: Are there any chances of her getting out?

Head Nurse: They said they were stopping steroids and they have. They want to see how she goes. We are going to stop the bleeding. Peter ...

Teacher: Peter said he would leave today.

Head Nurse: Not that I know. Georgia Town is preparing to deal with him. Mom was given the chance of experimental drugs, but didn't take the chance.

The composition of these rounds varies from ward to ward, i.e. a physician might be present. The round in Oncology is taken as an example here.
Social Worker: Mom first suppressed it intellectually but now she is giving a lot of support.

Head Nurse: She doesn’t want to talk about it any more.

Social Worker: She has built up her own support system now.

Head Nurse (continues to read from the Kardex): Judy is settling in now, bone marrow (transplant?) was not successful. ...

Comments can trigger questions and further comments from other staff. It seems that sometimes personal and professional coping are put together. Imitations of a child’s behaviour may serve as relief valve for frustrations deriving from the work with a difficult child. Medical and organizational data are combined with the perspectives of the respective staff members.

"George sixteen, CCABC every day and physio arranging schedule, has short term memory loss, is frightened if nurse does not come right away. He said to nurses (Head Nurse imitates high pressed voice): "I don’t want to be in pain" or "why me", gets frustrated when he cannot tell things. He does not know what is happening with his body.

Social Worker: Mother says it’s not her boy.

Head Nurse: Mother needs a lot of encouragement.

Teacher: How much can he actually see?

Occupational Therapist: He is worried about schoolwork, but he can’t see, his eyesight is twenty-twenty.

Teacher: I am up the creek with him because of behaviour problems and if he cannot see I don’t know what I am supposed to do with him.

Occupational Therapist: I make him dress himself. When he cried I said: "Why are you crying like a baby?" he says (imitates a weepy

\*1 dealing with the illness

\*2 Cancer Control Agency of British Columbia where children receive their radiation treatment.
"I can't help. I know I am not a baby. I am 16 years old." I try to make him independent.

**Public Health Liaison Nurse:** He acts out with his mother. He is whining a lot.

**Occupational Therapist:** He is good when he knows how long it is going to take. He always says that he can't do it first, but when you don't do it he does it.

**Head Nurse:** He has a brain tumor. He will get more radiation and more chemo.

(Head Nurse pauses briefly and then continues to read from the Kardex) Susan will have a scan today and tomorrow. Brian is fine..."

Information is passed on in a mainly anecdotal way and a deeper analysis of individual problems was not observed in this context. Very rarely the opportunity seems to be used to plan an overall program for a child. The round deals with up to twenty-two children within one hour. The time for every child is very limited. Most information in these meeting relate to medical treatment. Although the teacher participates in the interactions quoted above, it has been observed that teachers generally have a more passive role in those rounds as listeners.³

The teacher also tries to obtain information from the child. The usefulness of this information depends on the knowledge and the age of the child. The attitudes of children toward school may also vary due to variables of the personality or the feelings caused by illness and treatment which may make the child reluctant to disclose anything.

³ The information in these rounds seem to be only marginally helpful for the actual work of the teachers despite this being their main source of background information about the children they teach.
6.2.6. Teacher and Children

The children's reactions toward the teachers seem to have two extremes. Some children are quite eager to do school work as if they want to escape from the medical world of illness. Many children, however, see schoolwork as an additional hassle and have a "leave me alone" attitude. They try to avoid schoolwork as if they want to say "I have enough trouble so I deserve a break".

From the various comments one could distinguish three different categories of reasons for rejection of school:

1. The child does not like school due to prior experiences.
2. The stay in hospital is regarded as a break from all normal activities.
3. The child rejects school work because he/she is afraid or confused by the unfamiliar environment or because he/she feels physically not fit enough.

A negative attitude toward school can make a teachers task very difficult because the rejection denies relationship and access to basic information. A first encounter between teacher and future student may look like this:

*The teacher looks at her list and then proceeds to the oncology ward. She enters a patient's room with two beds through the open door. Then she looks around and proceeds to the bed of Bruce who has two IVs standing near his bed connected to a catheter in his chest.*

Teacher: Are you Bruce Wilson?

Bruce: (nods)

Teacher: I am Miss Travis the school teacher in the hospital. I

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*4 4 Because this issue was not in the focus of the observations it is difficult to quantify the numbers of children in each group and indicate in how far this behaviour relates to their prior school experience. However, I had the impression that school rejection was stronger with teenagers and generally during the initial period of hospitalization.

4 5 Teachers are usually addressed by their last names whereas children address other hospital staff (except physicians) by their first names.*
would like you to come to school.

Bruce: umh.

Teacher: Can you tell me a little bit about your program?

Bruce: no *(looks down most of the time)*

Nurse comes in, checks IVs and adjusts them.

Teacher: Did your teacher give you anything?

Bruce: no.

Teacher: Do you have any books with you?

Bruce: no.

Teacher: I will try what I can find out about your program. Can you come to school tomorrow?

Bruce: no.

Teacher: You know there is a new English word: yes!

Nurse: Come on Bruce do what you have been told.

Teacher: I will see you in school tomorrow morning.

Teacher pats his leg, turns around and proceeds to another patient room which is empty. ...
given. Teachers on the other hand respect the privacy of children. I observed a teacher sliding a note under door into a child’s room when the curtains of the windows facing the corridor were closed.

Teachers also have to cope with illness or injury related handicaps of children which influence a child’s behaviour. Most hospitalized children have special needs. Sometimes teachers try to defuse the child’s negative attitude by addressing it in their own way:

*Teacher enters a patient's room. Maud is lying in bed and watches TV. Her right arm is tied to a cast with bandages. Another bed is empty. The teacher greets Maud, switches the TV off, and sits down on the side of her bed.*

**Teacher:** "Please be nice to me today."

**Maud*** looks at her quietly.

**Teacher takes a book and a notebook from Maud's bedside table and instructs Maud to do every second calculation. Maud complains sometimes with a whining voice and writes awkwardly with her left hand.**

**Maud**(looks at her writing): "This doesn't look right. I am not used to write with my left hand."

**Teacher:** "Do you know when you'll be home?"

**Maud:** "If it's not soon I'll beat the brain out of them."

**Nurse** (enters room with a little plastic cup with pills in her hand): "What do you wanna take this with?"

**Maud:** "Water."

**Teacher:** "Please."

**Maud:** "Pleeease."

**Nurse** (leaves room briefly and returns with a cup of water): "Here you go Maud."

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[47] The majority of the teachers did not have training in Special Education and they have to rely on their experience.
Maud hesitates.

Nurse: "I am a little bit short today. It's not you, it's because I got stuff to do, you know that."

The nurse leaves the room. Maud swallows pills and then continues her schoolwork while the teacher watches and helps.

The teacher tried to gain control from the beginning when she came into the room and interrupted the TV session without comment. The girl displayed some anger against the hospital staff. However, the staff - including teacher - were task oriented and left little space for a child to vent emotions.

Teachers tried to absorb many different reactions of children with the explanation of the specific situation. One teacher said to a girl which was obviously reluctant to do schoolwork and made several rude remarks: "Because you are in hospital I am trying to absorb it, because you are not feeling that well. But in a classroom the teacher would send you out." This statement also depicts the special attitudes teachers strive to adopt within the hospital setting.

Most interactions between teacher and child are school related. However, other topics are mentioned during the interactions as well, i.e. illness related issues, visits of relatives, etc. This happens especially during bedside teaching. Illness related issues are mostly addressed from a lay-perspective which involves non-medical levels as well. A Teacher may ask a child "When will you be home?" or "Why are you here?" which is rarely done by other staff members because most of them already "know".

The teacher visits Ellen in her room, introduces herself "I am the school teacher in the hospital", explains that she wants to take her to

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8 In this case the nurse eased the tension by explaining the background of her behaviour. This made it possible for Maud to take the pills without a fight. The explanation served as an apology.
the classroom, and pushes her in a wheelchair into the classroom.

**Teacher:** "Why are you here?"

**Ellen:** "Because of my leg."

**Teacher:** "What’s wrong with it, does it hurt?"

**Ellen:** "Yes it hurts." *(Ellen looks down at her books)*

**Teacher:** "Who is your doctor?"

**Ellen:** *(Pause)* "I can’t remember."

**Teacher:** *(Pause)* "We’ll start with reading."

*The teacher puts the open book in front of her and Ellen begins to read.*

The information for the teacher is scarce, but there are opportunities for more talk about illness related issues. Teacher and child may talk about feelings of pain and other issues of being sick when they arise, however task orientation toward schoolwork limits those possibilities.

Sometimes issues are addressed indirectly by teachers in conversation with others while the child is listening. Once a child overheard a conversation between her teacher and her mother about the various cells found in her blood. After a while the girl said: "Don’t mention cells in the blood. Girls with five don’t understand this." A self-protective attitude became apparent when she did not want to listen to the communication about her illness.

During the interactions teachers react slightly different compared to the other persons within the setting. They ask more questions and guide the child to find his/her own answers to problems rather than telling the solution right away. On the way back to the ward a teacher will say "Which way do you think we should go?" instead of "Go this way." On the other hand teachers do not use much of a "hospital language" with many special words and acronyms.
6.2.7. Children's Attitudes

Children do not seem to give school much importance while they are in hospital. The younger they are the more normalization seems to be connected with home and parents rather than with school. It takes a while until they can grasp that schoolwork can distract them a little bit from the hospital routine or support them with their lives. Most children seem to reject the hypothesis that schoolwork in the hospital will actually help them when they return to regular school.

Children rarely talk about school amongst themselves. School may come up when a child has made something visible at school (i.e. a painting): "Did you make that at school?", or in the form of a negative comment during a conversation:

Boy 1: "Do you like school?"

Boy 2 shakes his head.

Boy 1: "I hate school!"

Very rarely children talk about something that happened at school. Adults seem to find school a much more interesting topic for conversations than children do. Visitors or staff frequently ask "How was school?" The usual responses are something like a neutral "um" or "fine."

6.2.8. The Teachers' Perspective

Several things make it difficult for Hospital Teachers to pursue their objectives. Teachers are in between many different relationships within the hospital setting. As a head of a hospital school program notes (Lee, 1975: 23):
"Teachers in hospitals frequently walk a tightrope in their relations with the medical, nursing, domestic and paramedical groups, as well as with patients and parents.

The school is a separate entity within the hospital setting. The teachers are not part of the therapeutic decision-making processes concerning hospitalized children. They have to organize their programs around all other events which makes planning very difficult if not impossible.

The classes are frequently disturbed. Children are often taken away during schooltime or arrive late. There are also other interruptions like IVs are beeping, nurses have to be called, etc. In between the teachers have to organize the program and do occasional phone calls. Although classes in the hospital are smaller than in the regular school (between 4 to 8 children), there are many interferences with the continuity of instruction.

It is difficult and time consuming for a teacher to obtain enough information in order to be able to plan an individualized school program. There are also many different subjects to teach according to a variety of programs, which creates complicated variables for successful teaching.

All this opens a gap between the teaching aims and actual schooling achievements. This gap can be increased by the attitudes and moods of children due to the effects of illness/injury and hospitalization. In addition one has to take into account that there is a rapid turnover of children which requires that teachers adapt their programs to the special needs of children they sometimes hardly get to know.

Normalization which is in the focus of Hospital Teachers' activities seems to have a number of different interpretations within the hospital setting. The teachers highlight the social, school related activities of a child. The child should
continue with normal daily life despite extraordinary circumstances. It is a widespread view that a school program in a hospital represents a link to the normal world (Kirten/Liverman, 1977: 170):

"A part of the real world becomes a part of the daily hospital-life program. This gives the child hope for recovery and eventual return to the outside world."

However this has to be matched with the perspective of the child who initially tends to see school more as an additional burden. Immediate feelings due to illness or treatment as well as the duration of hospitalization influence a child's attitude. The briefer the stay in the hospital, the less distant is the outside world, however the shock of hospitalization is likely to be more acute. The longer the child is hospitalized the more adapted he/she becomes to the new environment and the more the outside world fades into a distance. On the other hand children need time to adapt themselves to the new environment and it is very understandable that they are at first reluctant to go to school while they are in hospital.

The benefit of a hospital school program for children is subtle. Everything is imposed by adults who are doing what they think is in the child's best interest. Younger school-age children do not see the contribution of a hospital school program to their normal life. It does not help them to get out of hospital any sooner. It must be the role of the adults to offer a bridge.

Hospital Teachers can indeed offer a chance in terms of distraction from hospital activities, compensatory learning (keeping up with school), and social remedies (smooth transition back into regular life). However they have to succeed in enabling the child to grab these opportunities.
At the moment children in hospital rather seem to be put into a solitary togetherness which Lee (1975: 27) describes:

"He sits alone on a bed with spaces on both sides in a middle of a company he did not choose and cannot change."

The teaching objectives seem to be put beyond reach. Teachers' ambitions and sincere efforts to help the sick child are hampered by implicit organizational problems and sometimes by the children themselves, when they do not seem to fit into the challenges of their new environment.

6.2.9. Observing the Teachers

The teachers in the hospital were the first group in the observation cycle. They were to some extent my introduction to the setting as well as they were trainers for my conduct as participant observer. The teachers were directly observed for two weeks. Additional notes were taken during some observations of children.

At first teachers expressed on the one hand interest in my study, and on the other hand concern about interference with their work and how my presence would work out. One teacher said that she was concerned that I would be following her constantly because she already had enough to do. She considered addressing the school board to legitimize my presence.

One teacher retrospectively expressed anger that I had shared a lunchbreak with her. She said that she had to go to the washroom in order to escape and have some privacy. In this instance my presence was considered to be a threat.

It is interesting to note that I could not perceive any clues for an
apparent buildup of emotions. On the surface there had always been friendliness and interest for my research. But my presence must have been perceived as a threat. Retrospectively I can interpret several remarks in a different way. When I came back into the classroom during the last phase of observations of children some time later, teachers responded "Oh I didn't know we would see you again" (to do observations) and asked after some days "How long will you be here?" (in the classroom). Now I was alerted and interpreted this as a possible warning that my presence became a burden. I addressed the issue of my presence in conversations with the teachers. After several interactions one teacher said that she had actually found my presence difficult "because it was the first week and I wasn't organized yet." This had not been communicated to me before. This seems to be supported by comments of teachers which indicated that they tried not to show their emotions, problems with organization, etc. to the children, because it may influence them negatively. They rather wanted to present themselves with a friendly attitude in order to facilitate progress in school.

After a while teachers included me as an assistant in their work. When I was asked to do something I usually mentioned that I was really only an observer, but I did not refuse to participate. Although participation was clearly not my objective I wanted to find a natural approach to the setting and make my presence as unthreatening as possible.

Taking part in activities seemed to give me a proper role. Maybe my background in education was also a contributing factor which seemed to make an

Another possible interpretation might be to look at the school as a system, which has its own rules and behaviour patterns. Problems are kept under the surface up to a certain level. When they exceed this level of tolerance they may be solved in referring to a higher level in the hierarchy, i.e. the principal or school board which then would have to find a solution.
involvement appropriate. However, a resulting difficulty for me was that my notetaking had to be postponed until the activity was over.

Generally I was able to develop a relationship with the teachers which made it possible to share jokes and chat if there was an opportunity, as well as to do my observations.
6.3. NURSES

This section focuses on the registered or general duty nurses because they have most interactions with the children. The different outlooks of other nursing staff are mentioned in individual subchapters after their respective duties have been laid out.

The nurses represent the group of health professionals who implement the greatest part of the treatment and care to the children. They are considered to be, as one nurse put it, "the heart of the hospital."

6.3.1. The Nurses' Setting

The nurses in the hospital as a group consist of a number of subgroups. Directly involved on the ward are:

1. *Head Nurse*, who organizes nursing activities on the ward. The definition of this position in the job description states:

   "A Head Nurse is a registered nurse with required academic preparation and related experience engaged primarily in the management of patient care in a nursing unit. The Head Nurse works in close co-operation with the Nurse Clinicians and cooperates with other members of the patient care team in coordinating patients' total needs."

   The Head Nurse is responsible for the nursing care and the nursing delivery system on her unit and usually works from 7:00 a.m. to 3:00 p.m.

2. *Nurse Clinicians* serve in two different areas. Two Nurse Clinicians were mainly involved in teaching parents, children and staff about special procedures, i.e. catheters, and about the respective treatment protocols. Two other Nurse Clinicians who shared one full time position were responsible...
for chemotherapy and generally called "Chemo Nurse."

The definition of this position in the job description states:

"A Nurse Clinician is a Registered Nurse skilled in paediatric nursing with a strong interest in, and an expertise in, the care of paediatric patients in a subspecialty. Her/his overall commitments are to clinical practice, advancing nursing knowledge and assisting others in developing high level performance. The Nurse Clinician works in close co-operation with the Head Nurses."

Nurse Clinicians usually work from 8:30 a.m. to 4:30 p.m. Nurse Clinicians were gradually replaced by Clinical Nurse Specialists, who had a higher academic degree but otherwise the same mandate.

3. **Registered Nurses** constitute the largest group of nurses on the ward (25 full-time, 4 part-time). They are graduates of a school of nursing and are registered with the nurses association. They implement most of the medical care which is prescribed by the physicians.

In the job description they are referred to as "General Duty Nurse" who:

- assesses needs of individual patients or small groups of patients,
- implements plan of care for individual patients or small groups of patients,
- utilizes appropriate techniques in the care of selected patients and small groups of patients,
- documents nursing care on patient record,
- evaluates the care of individual patients and/or small groups of patients,
- initiates appropriate referrals.

Registered nurses have to take part in teaching, i.e. model good health and hygiene, and in evaluating patient care. In addition they have to assume "responsibility for development and maintenance of her/his professional
competency." One of the senior Registered Nurses acts as a Charge Nurse during a shift. She checks and organizes assignments for the day (i.e. who is responsible for a patient’s care, who gives medications for the children cared for by Licensed Practical Nurses), assigns first and second breaks, organizes daily routines and paperwork, and checks staffing for the next day. She stays mainly at the nursing station. Registered Nurses work in 12 hour shifts from 7:00 a.m. to 7:00 p.m. and vice versa during the night.

4. Licensed Practical Nurses are mainly assigned to housekeeping tasks. They do not give any injections but they assist when injections are given, i.e. by holding the child. The purpose and scope of their work is defined in the job description:

"The employee works under the supervision of a registered nurse. He/she shares in assessing the physical and psychosocial needs of, and in planning, implementing, evaluating and documenting the nursing care for, an individual patient or group of patients."

Initially three Licensed Practical Nurses worked eight hours from 7:00 a.m. to 3:00 p.m. and from 3:00 p.m. to 12:00 a.m. until their shifts were adapted to the twelve hour shifts of the Registered Nurses.

5. A Unit Clerk receives most of the telephone calls at the nursing station and does a considerable amount of paper work, i.e. preparing charts, filing bloodcounts, checking orders, etc. The purpose and scope of this work is

50 Quote from job description.

51 A nursing shift is divided into two coffee, lunch, dinner breaks to assure that there is always someone on the ward. This forms subgroups who will sit together and chat for the day. The breaks are important for social contact among nurses and one may check with another: "Are you on first?"
defined in the job description:

"The employee works under the supervision of the nurse in charge and acts as a clerical assistant to duty nurses. The employee is responsible for reception duties, maintenance of supplies, charts and files."

There are three Unit Clerks. One person usually works from 7:00 a.m. to 3:00 p.m. and another one continues until 7:00 p.m. and there is also a weekend shift.

6. One Porter/Aide transfers patients, specimens, and necessary papers between the different departments of the hospital. Nursing Aides work eight hours from 8:00 a.m. until 4:00 p.m.

7. The Community Health Liaison Nurse is consulted when home care is necessary for a child. Children with Cancer frequently have special care needs due to their low blood counts (danger of infections), if they are not able to walk or move around easily, or if they have a catheter.²

8. Additionally there are sometimes 3-5 Student Nurses from three different schools of nursing on the ward.

This listing is done according to the hospital hierarchy. For children the hierarchy is presented in a totally different manner. They will hardly have contact with the head nurse and the registered and practical nurses are much more important for him/her because they spend more time with him/her. Most children will not make a distinction between practical and registered nurses because they perform similar tasks, however they are very aware of the

² Many children get a "Hickman Line." This is a catheter which enters the body at the chest and a blood vessel at the neck. Blood can be drawn and injections given without a poke. However, catheters require special care in order to avoid infections.
difference between Nurse Clinicians and "Chemo Nurse" although their nametags indicate the same profession. Smaller children sometimes started to cry when the "Chemo Nurse" looked at them because she was automatically connected with painful injections.

Many organizational and personal changes occurred during the observations of this study. The nursing administration put an increasingly stronger emphasis on academic training of nursing staff. Nurse Clinicians were partially replaced by "Clinical Nurse Specialists" who held a Masters degree. After the conclusions of the observations the positions of Licensed Practical Nurses were deleted and partially replaced by Registered Nurses. In addition there was a considerable turnover in the nursing staff on the ward.

All nursing staff on the ward were female, with the exception of one Porter/Aide, who worked there for a limited time.

6.3.2. Nursing Aims

The hospital's department of nursing formulated in a statement of philosophy several aims:

1. To provide skilled nursing care to children and their families.

2. To foster an environment for children and families in hospital which assures their rights as individuals and provides the daily living activities necessary for growth and development.

3. To identify, plan, implement and evaluate with the cooperation of other disciplines, educational programs which meet the health needs of children and families.

4. To identify, plan, implement and evaluate nursing research projects and to cooperate with the research of other disciplines involved in the care of children.

5. To provide an environment for nurses which encourages individual
and professional growth.

The provisions for growth of the individual child, parent, and nurse is emphasized in a cooperative framework with other professions. This is paired with "skilled nursing care" which has been defined by the hospital administration as follows:

Skilled Nursing Care: (continuous process)
- Assessment of patient/parent needs.
- Planning of action.
- Implementation of nursing intervention to effect a change in the needs.
- Evaluation of results of care.

It becomes obvious that nursing care is action oriented. For example listening skills, which are of paramount importance for assessment in a social setting, are not mentioned. The provisions for growth are also emphasized in textbooks on pediatric nursing (Leifer, 1982: XIII):

"The goal of pediatric nursing is to foster the growth and development of children and promote an optimum state of health - physically, mentally, and socially - so that they may function at their peak capacity."

The "optimum state of health" is closely linked with the physical condition of the patient in a hospital setting. In fact it seems that there is a hierarchy between physical and other needs. If physical needs are met then there is space for social and mental needs. Examples will show that communications may become increasingly task oriented and thus reflect the needs of the medical perspective.
rather than the needs of the child. It is interesting to note that emotional needs are somehow buried in those definitions. Daily routines of giving medications and providing care may challenge nursing aims. Although nurses rarely talked about their aims, it was evident from their comments that there were some areas of conflict (5-19):

**Nurse:** "Sometimes when it comes to the end and they are using these test drugs, then I ask myself, what are you doing?"

The dissatisfaction with the effects of their work centered sometimes on the medication (4-65):

**Nurse:** "...a horrible medicine, I don't know why they give it."

When medication did not seem to work and had severe side effects, it was considered bad because there were no good results. From these and other interactions it became evident that the accepted nursing goals did not always match the reality on the ward where sometimes medication did not work or had severe side effects. The huge nursing staff turnover is also an indication for conflicts. The literature on Burnout (Kramer, 1974; Yasko, 1983) describes the widening gap between goals and actual achievements which leads to frustration with the job.

As a counterpoint nurse seem to develop their own attitudinal goals. In their attitude they must make things work:

**Nurse:** "You have to look at the good things, that it will help. If you are always looking at the negative things, then you are in the wrong job."

However this positive attitude is frequently in danger of being overturned by
adverse realities. In some cases all efforts fail and the hopes for success dwindle.

(6-20)

Nurse: "It makes me feel sad when you have been through so much and then you have to look at an end."

It seems that when the activities lose their meaning in terms of medical success, some more space for empathy is available.

There are many conflicts in the day to day nursing activities, especially when those involve painful procedures. Nurses may be confronted with their own attachment to children. This may make it increasingly painful for them to see children suffer.

(P-13)

Nurse (complains to me just before an LP is begun): "Why do I have to go? He is my favorite boy and I wanna be with him except when he goes in there. Do you wanna hold him and I take notes?"

This reflects nurses’ emotional involvement and shows that they are quite aware of their pain inflicting role.

The relationships seem to play an important role with respect to the rewards nurses get from their work.

6.3.2.1. Nurses’ Rewards

There seem to be two main areas of rewards for nurses’ work. One is achieving nursing goals the other is the relationship between nurses and patients or parents. One nurse said when asked for the rewards of her work:
"You have a supergood relationship with the parents and the kids. When the kid comes here bleeding all over and they get their IV, bloodtransfusion, etc. and it stops, they feel like life is given back to them. Or look at Martin, he had Aplastic Anemia a really nasty disease and now he is running around again. You don't know for how long, but anyway, this is really neat. And the staff is really neat. You probably noticed that we do a lot of bitching but they are really neat, every single one of them."

It can be assumed that "supergood relationship" refers to the emotional involvement and to the depth of issues. However, relationships are somewhat ambiguous in this setting as we shall see later.

Success of the treatment is also an important reward. To see a positive outcome is a reinforcement of the work, although there is always uncertainty and unsuccessful cases challenge achievements and pose a threat to treatment strategies. Nurses are usually delighted when a child, who was in remission came to visit. It did not really matter if the child had been difficult during his/her hospitalization. It was important to see that a child was doing well as a sign that the treatment really worked.

6.3.3. Information

Nurses have to cope with a considerable amount of information. General information about treatments and hospital routines has to be updated constantly. The personal and medical background of every patient has to be taken into account. The actual condition of a patient is a dynamic process which is made more complex by changes in the treatment plan. Information about those things is vital for the work of nurses and it requires continuous updating.
Information was passed on through several levels of communication channels which were maintained on the ward:

1. **Formal level** (the official channel of information):
   
a. **Patient charts**
   
   contain information about diagnosis, treatment, doctor's orders, consent forms, family background, etc. They are the primary source of information for all hospital staff.
   
b. **Kardex**
   
a cardfolder which contains individual information about diagnosis, daily treatments, medications, etc.
   
c. **Morning or evening rounds**
   
take place at the end of a shift when the incoming nurses listen to a taperecording about nursing routines with every child, which the outgoing shift has prepared. Charge Nurse and Chemo Nurse take part in the morning rounds with physicians where medical treatment plans for all patients on the ward are discussed.
   
d. **Oncology rounds**
   
take place once a week lasting one to one and a half hours where physicians (Hematologists, Radiologist, Oncology Fellow, Residents), Social Workers, Dietitian, Nurse Clinicians, and the Charge and/or Head Nurse discuss medical treatment plans.
   
e. **Social rounds**
   
take place once a week and Charge or Head Nurse, one nurse clinician, Physio and Occupational Therapists, Hospital teachers, Dietitian, and Child Life Worker discuss children's individual psychosocial behaviour and treatment; a short record from these meetings is kept in a book at the nursing desk.

2. **Semiformal level** (channel for internal information exchange between the nurses):
   
a. **Communication Book**
   
nurses write down notes for other nurses about events on the ward (i.e. when a child died), when something has gone wrong, complaints, etc. Sometimes Social Workers also write notes into this book (i.e. about a home visit to parents). The book is kept at the nursing desk.
b. "Peter's" rounds

"Peter's" rounds take place once or twice per week when a member of the psychology department conducts a meeting for nurses on the ward who talk about their coping with difficult situations or just chat about recent events.

c. Newsletter

During the last phase of the observations a newsletter for nurses was produced by nurses on the ward, which contained humorous comments about activities on the ward, gossip, and some personal information about nurses (i.e. birthdays).

3. Informal level (information channels which were not formally organized):

a. Conversations at the nursing desk

A lot of information was passed on casually at the nursing desk, which is the central point for nurses in the ward. Usually the chats are often short comments about incidents or observations (i.e. "Dorothy is shaking when she gets her medication"), or questions (i.e. "Does anyone know where the scales are?"). Many things are said in passing, but everyone seems to listen.

b. Conversations in medication room or office

If something is not meant for everyone (all nurses) it will be talked about in the nursing office (i.e. comments about physicians or patients). The Medication Room is a very small room adjacent to the nursing station. Medications and syringes are prepared by the nurse here. Only two nurses are able to work there simultaneously due to the size of the room. The physical closeness seems to trigger an exchange of information about incidents.

c. Conversations at coffee, lunch, or dinner breaks

Breaks are important events during the day of a nurse. Conversations, which usually take place in a cafeteria, deal mainly with personal things. However recent events on the ward and background information about some parents and children are usually dealt with

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5.3 This round is named after the psychologist who usually conducts them. (The name has been changed)

5.4 I observed that sometimes a nurse would comment on a conversation from the nursing office although she did not take part in the interaction at the desk.
during the first part of the break. These levels of information are mainly addressing communication among nurses. Other staff becomes involved via the patient’s chart and in the Oncology or Social Rounds on a formal level. Informal exchanges between nurses and other staff occur mainly at the nursing station, however, they mainly deal with organizational questions, e.g. when a child gets treatment, where is he/she?, etc. Answers to a question like "how is she doing?" are answered according to the status of the other person. The openness increases with the proximity of the professional group and decreases the more a person seems to be removed from the medical staff. Information about patients is passed on according to its medical importance through the various levels of information and to other staff.

It would exceed the scope of this chapter to give examples for all levels of information. However, if one follows the information gathering process on an informal level, attitudes and evaluative processes become more transparent.

(5-17ff.)

Paul, a ten year old boy is lying on a table with his head in a big machine, the CT-Scan. His eyes are closed. Generally he seems disoriented and spaced out.

In an adjacent room a physician and nurse 1 look at a monitor. The physicians explains some features of the brain which are visible on the different images.

Physician: "There is an abscess here (points at the monitor). It could be some fresh bleeding."

Nurse 1: "Is it large?"

Physician: "No" (measures size on the monitor).

It seems that nurses first have to clear their minds from work before they can interact on a more personal level.
After the procedure is finished Paul is transferred to a stretcher and brought back to his room. On the way they meet the two residents from the ward. Nurse 1 tells them with a low voice in passing:

"They found an abscess in his brain."

On the ward they meet the Oncology Fellow and nurse 1 tells her the same message. After Paul has been transferred into his bed another nurse looks briefly into the room.

Nurse 1 (whispers to her): "He's got an abscess in his brain."

Nurse 2 frowns and leaves the room.

After the lunchbreak nurse 1 meets Paul's mother in his room.

Mother: "What did they do the scan for?"

Nurse 1 (thinks for a moment): "I don't know" (pauses) "Maybe you ask Dr. Lee."

At first hospital insiders, medical staff, are informed. Although the information is considered important which is demonstrated by the fact that every opportunity is used to pass it on to the medical staff, parents and patient are excluded. This shows that not only children, but also parents may be protected from some information. However, if the child is alert he/she may can pick up the information on several occasions.

The rationale for this approach is to provide a somewhat controlled environment where parents and children get their information from one source and that ideally they would not have to cope with fragments of frightening news. However, the environment is contaminated with all sorts of information and physicians, who are hierarchically responsible in this case, may not be available at the appropriate moment, which may leave parents and children in an emotionally tense state confronted with a high degree of uncertainty.
Frequently information about patients arrives in bits and pieces. This can be illustrated with a new admission of a patient during the night shift. The following quotes show how fragments of information are put together and how the situation is evaluated. The example focuses on the interactions about the new admission, a girl who has previously spent considerable time on the ward, and leaves out some of the unrelated activities in between.

(6-42ff)

22:15

*Nurse 1* finishes a telephone conversation at the nursing desk and goes to *nurse 2* who is preparing syringes in the medication room.

*Nurse 1*: "Theresa Dalton is coming tonight. Her platelets are down and she has been bleeding a bit."

22:25

*The Medical Student Intern (MSI) arrives at the nursing station.*

MSI: "Did you hear that Theresa is coming?"

*Nurse 2*: "Yes, she might."

MSI: "I guess she is coming for sure."

*Nurse 2* (walks around and tells the other nurses): "She is coming for sure."

Another telephone call is received at a desk that another baby patient is coming. *Nurse 2* is busy at the nursing desk.

*Nurse 1* (talks while preparing something in the medication room): "So she is bleeding."

*Nurse 1*: "I think it has been almost a month." (pause, turns to *nurse 3* who only recently came to work on the ward) "It's an improvement because normally she got blood transfusions twice a

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56 The night shift permits a more controlled environment, which means that there are less things happening with fewer persons involved than during the day. One has the feeling that one is on top of the events on the ward.
23:35

Nurse 1 (after she finished a telephone conversation): "She sounds like she is fairly sick. She is bleeding and has a temperature of 40.5." 5 7

Two MSIs come to the desk, look at a list which nurse 1 has prepared and get some things from the medication room. Nurse 1 is telephoning again.

Nurse 1: "It sounds like she is bleeding quite badly."

Nurse 2 prepares a room, gets alcohol, gauze, etc. She comments: "I wanna get halfway organized before she comes." She phones for Theresa's old chart.

1:55

Nurse 1 answers a telephone call at the nursing desk.

Nurse 1 (after she finished the telephone conversation): "Theresa is still in River City. Her BP is 64 over zip and they are just ambulance guys. They don't know how to start an IV."

Nurse 2: "But she has a Hickman Line and we could tell them how to do it."

They continue with their activities. Nurse 2 checks a beeping IVAC. Then she returns to the nursing station.

Nurse 2: "It's irresponsible of the parents to leave it to the last minute."

Nurse 1: "Maybe it's the hospital in River City because she has been there this morning."

3:20

Telephone call at the nursing desk.

Nurse 1: "The ambulance will be here in 15 minutes. She is in quite a bit of pain."

The two nurses collect some medication and walk downstairs to emergency.

5 7 This announcement came without reference as to whom she was talking to, but everyone seemed to know.
Only fragments of information are passed on. However everyone seems to be aware of the situation and knows how to fit in the pieces although no proper references are made to the actual case. In addition the information trigger a series of activities (i.e. preparing a room, getting materials, etc.). Quick judgements are made on the information available. This is a necessity for the work within this setting, however it may also lead to false assumptions.

The information which nurses get has a direct impact on their work and their perspective. Their point of view is also influenced by their position within the setting.

6.3.4. Nurses' Position in the Hospital

Nurses on a ward regard themselves as one group. They make a distinction between nurses and other staff, and between the staff on a ward and staff outside of the ward. Medical staff on one ward, i.e. nurses and physicians, become one group with respect to outsiders. This becomes apparent in the verbal communications. When nurses talk of "we", they mostly refer to all nurses on the ward. Accordingly "they" is used as a reference to other groups, i.e. physicians, nurses on other wards, parents. However, when nurses talk to parents or visitors "we" may include other staff on the ward as well, e.g. physicians. The ward becomes the smallest group unit in this case. This may also signal a united front which is presented to parents. A "we" may enable staff members to hide behind the agenda of the staff as a whole and defer individual responsibility.

The distinctions have two aspect. On the one hand they are inclusive as they define the membership in one group. On the other hand they also have an
Paul is lying on a table in a sterile looking room in the Nuclear Medicine department to get some x-ray photographs done. The nurse is waiting in an adjacent room.

Technician (comes to nurse): "Paul just pooped on the table."

The nurse goes to Paul and cleans everything.

Technician (while watching): "It's lovely to be a nurse."

The nurse nods.
exclusive aspect when others are denied access to certain information because they are regarded as outsiders. This happens to other staff when they are excluded from informal levels of communication at the nursing station and to parents when they do not get direct answers to their questions.5-8

The distinctions between the different group levels may also lead to confusion in interactions between nurses and parents. Parents may not be aware of the reference of a "we" or "they" and may interpret this as inclusive whereas they are really excluded. For example a nurse may talk about treatment plans and procedures in a "we" format (meaning nurses and physicians) while parents interpret this as an if they would be directly included (parents and nurses together). When the actual procedure happens parents may find themselves waiting outside.

The nurses on the Oncology ward seemed to have a special position among their peers in the hospital. This was probably closely related to their work, which is quite demanding. There was mostly a fairly high level of activities. Nurses disliked low activity levels, e.g. a nurse commented (6-14) "When it is so slow, I think I got the wrong job. I should not be paid for this." With a high level of activity short chats and teasing increased, which sometimes spilled over into the communications with patients. However, this atmosphere was different from other wards and probably increased the group feeling among Oncology nurses.

Although the nurses are the professional group responsible for the actual delivery of the treatment they are hierarchically dependent on the physicians who give the orders. Nurses may know more about the practical effects of the drugs

5-8 See also the example in Image 7: "Telling Mother".
because they give them to the children and observe them afterwards, however the planning is left to the physicians. They have to implement the orders given by the physicians.

On the other hand the nursing administration seemed to have some clout within the hospital. Many changes were initiated and some also raised concern among the nurses on the wards, e.g. the move to more academic requirements for nurses. They are the largest professional group in the setting. Nurses may use the administrative power to challenge physicians' medical authority. Some nurses stressed that being in the middle of the hierarchy makes good relations important, e.g. (5-35) "You know what it feels like to be treated badly by the ones above you."

The hierarchy may be used as a pretense in order to defer responsibility. This happens with respect to the prescription of drugs and also in the interactions with parents. A nurse may not tell everything she knows, even though she is asked, because informing parents or children is considered to be the physician's responsibility.\textsuperscript{59} In one instance a mother came to visit unaware that her daughter had just died. She found the room empty and inquired anxiously at the nursing station. The nurses searched frantically to find the physician in charge of the patient. When the mother finally broke down crying a nurse told her and went with her to the quiet room. This example shows how the hierarchy is used to refrain from personal engagement in difficult situations. The hierarchy may inhibit communication between nurses and parents or children in two ways. Nurses may not dare to pass on information, because it is beyond their responsibility. On the other hand this may also be used as a protection

\textsuperscript{59} See also the example above in which information about the abscess in the brain is being passed on to medical staff and to parents.
against personal involvement and anxiety.\(^6\)\(^0\)

6.3.5. Nurses and Parents

The main aspect of nurse parent interaction is information. Nurses, especially nurse clinicians, provide parents with probably most information about illness and treatment. Nurse clinicians spent some time with parents and explain treatment protocols and procedures. They are in a way the liaison persons between the parents and the medical world.\(^6\)\(^1\) However, all nurses add to the medical information level of the parents who frequently ask questions. These questions help the parents to digest little pieces of information rather than being overwhelmed with everything at once. Nurses may clarify wrong concepts of the illness in such interactions, e.g. (5-32) one mother thought that Leukemia was contagious and she was concerned about what she would bring home to other people.

Nurses regard parents sometimes as inhibitors of their work. One aspect comes from the physical environment when nurses feel limited in their movements, e.g. (6-26) a nurse said about visiting parents "I hope they will not be here the whole day. The room is just so small." On the other hand nurses may also feel inhibited in their personal relationship with the child when they feel that they are being observed by parents. It also seemed that they spent less time with those children. When parents are present communication was more between adults and about the children rather than with the children.

\(^{60}\) Isabel Menzies (1970) describes how the organization of a hospital is used as a defense against anxiety.

\(^{61}\) See also the chapter "6.7. Social Workers" in which the partially overlapping aims of social workers and nurse clinicians are compared which nevertheless show different approaches.
Parent behaviour is frequently analyzed and judged. This happens during rounds or other conversations, e.g. (7-15) "mother takes diagnosis very well". In some cases the educational agenda of nurses becomes apparent, e.g. (4-44) during a morning round nurses expressed concern that a mother let her child watch TV until 10 p.m. and another nurse reported that she would do that at home as well because otherwise the child would be crying. Nurses also exchange information about parents in their chats or during their breaks. This mostly involves information about particular incidences or behaviour.

It seems that nurses look at parents more in an evaluative mode and examine how they fit into behavioural expectations. This means that the understanding of parents' actions is also limited by those expectations. This also seems to have an effect on nurses' attitudes towards children.

6.3.6. Nurses and Children

Two main modes of interactions between nurses and children could be observed. The main mode is the goal oriented interaction which culminates during a treatment (i.e. injections, lumbar punctures, bone marrow aspirations, etc.). In addition nurses try to establish a more casual and private mode of interaction. Some examples can display those different interactional modes.

6.3.6.1. Treatments

No universal procedure for the preparation of a child for a treatment is being used. Sometimes preparation does not take place at all or it happens at the last moment. In addition little might actually be communicated to the child about the procedure. An early morning interaction can look like this (5-10):
The nurse looks into the Kardex and into a chart at the nursing station. Then she enters Paul's (8 years old) single bedroom. He is lying in his bed eating crackers.

**Nurse:** "Good Morning Paul!" *(proceeds to his bed)* "Are you feeling sleepy?"

**Paul** *(looks at her)*: "No."

**Nurse:** "Do you know that you have a bone marrow today?"

**Paul:** "No."

**Nurse:** "That's what we gave you the medicine for, to make you sleepy."

*She waits a moment and then proceeds to the medication room.*

The information about the treatment is passed on in a very casual manner. The child is confronted with the imminent treatment which has in fact actually begun with the injection. No further attempt is made to facilitate personal coping processes. The child seems to be a part of a process which takes part regardless of personal needs. However, in some cases information about impending treatments is disregarded completely and the child perceives that something is about to happen from his/her interpretation of the circumstances.

Nurses have several strategies to convince children that something has to be done. The initial step is usually a "let's do this" attitude. This may also be done as an instruction, e.g. (6-37) "No nightmares today, ok?"

A second step is bargaining. A nurse promises something if the treatment can take place first, e.g. (5-25) "First I'll put the IV on, then you phone your mom." Those deals may put something off, that a child wanted, or they may promise something when the procedure is finished, e.g. a toy from the treasure box.
Direct orders are given if these strategies fail or if nurses are under pressure to complete something. The child may then also be physically restrained. For example during treatments the immediate goal to finish the actual procedure may suppress other considerations of the personal needs of the child.\textsuperscript{62} As a consequence interactions become verbal or physical power struggles.

(5-17)
Several nurses are talking about the difficulties they had with one teenage boy during treatments.

Nurse 1: "You can't force him. He is too big."

Nurse 2: "You can force little children though. You can't argue with them anyway."

Psychologist: "But the thing is you can cause phobia. You can make a big thing out of it."

This example stresses again that technical aspects tend to dominate individual needs. Within the machinery of the hospital there is little open space for individual coping processes.

6.3.6.2. Casual Interactions

Many interactions were kept somewhat humorous. The humor consisted of a mixture of jokes about the situation and teasing. Teasing and humor can be interpreted as an effort to establish communicative links despite of the conflicts in the mutual relationship. It also reflects some coping strategies.

If a child is difficult there may be an adult collusion in which the adults make jokes about the child in order to cope with the situation. This may include remarks about the child, which show how difficult he/she is. For example a

\textsuperscript{62} Examples of treatment interactions involving children can be found in the subchapter "8.6. Procedures", e.g. getting an IV or Lumbar Puncture.
nurse guided one boy to the classroom remarking laughingly: "I have to bring this terrible kid to school."

The longer children stay in the hospital the more they adapt to this manner of communication which also alters their behaviour toward nurses. One nurse observed those changes in a child and commented (6-59): "You should have seen her when she came in. She was a cute girl and didn’t answer back. We taught her into that."

Nurses try to get positive feedback or attention from a child, e.g. "give me a smile", or "give me a hug", and they are disappointed when the child does not react accordingly.

(4-65)

The nurse walks through the hall and stops at the window of a single room. Monika (a little girl) is sitting in her crib looking towards her.

Nurse (smiles through the window): "Hello Monika!"

Monika turns her head away.

Nurse: "Not a good start for a day." (walks away)

The efforts of nurses to get positive attention from the child have been observed frequently. It is probably meant to soften the role as the "bad guy" who gives painful injections etc. as well.

Nurses want to have a good relationship with the children, however they also see that the procedures interfere with this relationship. For example a nurse reacted surprised when a boy gave her a valentine and said (P-50): "I thought you didn’t like me after all that we’ve done."

This rejection is very obvious with regard to the Chemo-Nurse. Her
function is well known by parents and children. She administers the chemotherapy which represents most of the treatment and which also has several side-effects. The most obvious connections children draw when they see her are pokes, injections and IVs. Some drugs also cause nausea and pains which make the children afraid.

Quite often younger children turn their head away or even start crying when they see that the Chemo-Nurse is looking at them or coming closer. It is especially difficult for the Chemo-Nurse to alter the child's rejection of her and to develop a more trusting relationship with the child. In addition children see the Chemo-Nurse walking around with syringes and IV equipment and they do not know who it is meant for, which creates anxiety.

If one follows a specific problem with one child one can take a look at the problem solving process and process oriented communications between medical staff and children. One teenage boy had nightmares and had been coming out of his room during the night looking disoriented. Sometimes he had come out despite the fact that he was connected to an IV.

(6-44ff)

22:42

Steve comes running out of his room and says "I wanna go home." Nurse 1 goes to him. Steve kneels down on the floor. He is bleeding from his hand. Nurse 2 also approaches the scene.

Nurse 1: "Steve, do you know where you are?"

Steve shakes his head.

Nurse 1 asks nurse 2 to get some gauze and gets some swabs form the medication room which she presses on Steve's hand. She helps Steve back to his room. He collapses at the door. Nurse 2 helps him to stand up and walk to his bed. Nurse 3 arrives. Nurse 1 wipes the blood spots from the floor.
Hospital Staff / 151

22:52

**MSI 1 enters Steve's room and looks at his hand.**

**MSI 1 (in the direction of the nurses):** "His IV is for Antibiotics because he has an infection. But it cannot be restarted at the same place."

**Nurse 1 (to Steve):** "Do you know what you are doing when you are leaving the bed?"

*Steve shakes his head.*

**Nurse 4 (comes into the room):** "Samuel's IV has to be restarted."

**Nurse 1:** "It's an exact replay of last night."

**MSI 1 checks Steve's veins. The nurses leave the room one after the other.**

**Nurse 1 (to Nurse 3 in the hall):** "He has trouble adjusting or something."

23:10

**MSI 1 meets nurse 1 in the hall.**

**Nurse 1:** "Did you get it started?"

**MSI:** "No, well I got the needle in, but I blew the vein."

*Both continue with their activities.*

23:40

**MSI 2 and nurse 1 enter Steve's room.**

**MSI 2 (to nurse 1):** "Did he get valium?"

**Nurse 1:** "No."

**MSI 2:** "I wanna give him two milligrams."

**MSI 2 tries two times to get a needle into Steve's vein who holds on to the nurse's hand, but he is not successful.**

**MSI 2 (retrieves the needle):** "Ok, I'll call Karen. I gave it my best."

*Nurse and MSI leave the room.*
The resident arrives and together with nurse 1 and the MSI they go to Steve's room. There is little talk. The resident ties a strap around Steve's arm, looks at his veins, and finally inserts the needle while Steve is holding the nurse's hand.

Steve (anxiously): "Is it in?"

Resident: "Yes." She pulls on the syringe so that some blood becomes visible. Steve moans "uuh" and turns his head around. The resident connects the IV and all leave Steve's room.

24:38

Nurse 1 gives Steve a bottle for his urine and asks him to put his arm into a comfortable position. Nurse 2 enters the room with a white jacket with straps on its sides. They pull it over Steve's shoulders and tie it to his bed.

Nurse 1 (explains): "...so that if you want to move around the room you can't." (she finishes) "Now you try and sit up." Steve sits up and is just able to sit before the straps impede further movement.

Nurse 1: "See what happens?"

Steve (nods): "Mmh."

He lies down again and nurse 1 writes something on a chart. Nurse 2 leaves and nurse 1 cleans up.

Nurse 1 (switches of the light): "Good night sweetie." She leaves the room.

2:50

At the nursing station.

Nurse 3 (approaches the desk): "Steve's IV is on the floor."

Nurse 1 (goes to Steve and looks at the blood and the IV-fluid which have been dripping on bed and floor): "How did it come out?"

Steve: "I don't know."

Nurse 1 goes to the nursing station and calls a physician to tell that the IV is out again. Then she returns to Steve's room and starts to clean up.

Steve (with a tense voice): "I am all scared, do they have to restart
it again?"

**Nurse 1:** "Unfortunately yes."

*Nurse 1* continues to clean. **MSI 3 enters the room and nurse 1 goes to the nursing desk.***

.....

*Two days later during a morning round:*

**MSI:** "Did Steve sleepwalk again last night?"

**Head Nurse:** "No he slept well. He was told that he had Leukemia."

**Chemo Nurse:** "Dr. Lee sat down with him yesterday."

This example stresses once again the importance of open communication which has been discussed in the literature.\(^3\) A lack of openness creates a closed awareness context which burdens the child not only with solitary coping with the illness and related emotions but it also inhibits communication about misconceptions and resulting fears. If someone had talked openly to this boy all nightmares and the incidents with the IV may not have taken place. It is interesting, however, how the problems are handled in the situation. Several conversations are made in the presence of the child but no real effort is made to communicate directly with the child about the underlying problems. Technical solutions are found within a medical framework. The IV is restarted and the boy is strapped to his bed.

In addition a number of different persons are involved and the activities involve increasing levels of the hospital hierarchy. Nurses are the first who have to deal with the situation. Then two medical students, who are on duty, get involved try in vain to restart the IV before a senior physician is called. A\(^3\) See literature review for a review of awareness context and 'protective' or 'open' approach (subchapters 2.5. and 2.6.).
third medical student becomes involved later and reassesses the situation. Meanwhile the child’s anxiety increases and the whole process consumes considerable time while the child should be sleeping. In the end the IV comes out again. Maybe this was the only way for this boy to get some of the attention he needed.⁶⁴

6.3.6.3. Understanding Children

Nurses want to get information from the children about how they feel, if anything hurts, etc. However, children do not present their information the same way adults do. Misconceptions or wrong information can be picked up by nurses, if they do not understand how children present information according to their age and their personality. Nurses rarely spend long time periods with children. Therefore their impressions, which may be just momentary glimpses, form their judgement. This may lead to false conclusions and determine the rationale of a nurse’s behaviour toward a child.

Children sometimes become very sensitive to smells during their stay in the hospital. They spend a lot of time in bed and due to their lack in mobility they become more aware of their senses. When nurses react to children they may not be aware of the causes of a certain behaviour, which can be seen in the following example dealing with food.

(X-33)

Anthony is lying on his bed. He takes a box with cookies from his night table and eats one.
Nurse 1 enters the room and says: "Ah, ah, I told you not to eat before lunch." She takes the box away from him, puts it on his night

⁶⁴ Although it does not seem to happen very frequently that an IV is pulled out by the child, it happened with other teenage children during the observations.
Hospital Staff / 155

table and takes his temperature.

Twenty minutes later:

Anthony (stretches his foot toward Björn): "Is it almost lunchtime?"

Björn: nods.

Anthony: "Good" (continues to watch TV).

Almost fifteen minutes later two nurses enter the room and distribute lunch-trays.

Nurse 2 (puts a tray on a table in front of Anthony and lifts the cover): "Chicken."

Anthony: "Yukk."

Nurse 2 (astonished): "You don't say 'yukk' to food," (leaves the room).

John (imitating Anthony): "Yukk!"

Nurse 1 (walks to Anthony): "This is the chicken we ordered yesterday." (She opens the tray, pushes it closer to Anthony, and leaves.)

Anthony sits up and eats a little bit, but then he concentrates on the orange.

After ten minutes nurse 1 comes back and looks at Anthony's tray.

Nurse 1: "The chicken is not moving."

Anthony (blows at the chicken): "Now it is."

Nurse 1: "You know what I will do? I'll hide the cookie box before you eat", (leaves).

Anthony: "You won't see me nurse."

Anthony appeared to be hungry and he was told to wait. But the reason why he did not like the food was probably the smell of it. Several children showed aversive reactions to the smell of the hospital food after some time. The nurse, however, attributed his reaction to the cookies and indicated that she would take the cookie box away. In addition Anthony was made responsible for the choice of
food because "It is your chicken which we ordered yesterday". If the nurse would have known the child and his reactions a little bit better, then she also would have known the cause for Anthony's rejection of the food as well. The interaction also shows fragments of the nurse's educational agenda, "you don't say 'Yukk' to food" and "I'll hide the cookie box ....".  

Children were also sometimes ignored when the nurse was convinced that everything was in order.

(K-18)

A three and a half year old boy whines and stretches his arm to which an IV is attached in the direction of the nurse. The Nurse answered: "No more cries, I checked that."

In this case an assumption seemed to have been made that the child's statements had little credibility. On several occasions nurses seemed to impose their own interpretations and rule out other options. This led to disbelief when children offered their own differing views. The teachers also experienced this:

(P-22)

Teacher 1: "Did you tell Rick that he cannot come to school?"

Teacher 2: "Yes, I don't have any more place here."

Teacher 1: "It's just that the nurses didn't believe him."

Children were not always taken seriously, if they did not fit into the categories

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6 5 There was a little epilog. The chicken was put into the fridge and Anthony asked another nurse almost two hours later to give it to him because he was still hungry. He then just nibbled a little bit and left it again until this nurse took it away for good. However, Anthony was still left hungry because he was not that vocal and was misunderstood in his reactions.

6 6 Please also compare the interpretations of children's statements during medical procedures (8.6. Procedures).
of hospital routines. This means that children's feelings may be ignored or rejected if they do not have an apparent reason, which makes sense to the adults.

Children's private sphere was generally neglected by nurses. Although this is part of the job that a nurse enters a room at any time at her own will, one may ask if this has to happen all the time. Children were interrupted in their activities when a nurse wanted to do something with the child such as taking the temperature. It did not matter if the child was just concentrating on something else.

A child as a patient in a hospital loses much of his/her privilege of being treated as an individual person. The routine interactions between children and nurse could be used as opportunities to re-establish some aspects of the acknowledgement of an individual sphere by introducing greeting, the polite questions which are being used in general conversations, e.g. "may I ....", and in this way expressing empathy and enlisting the child's cooperation. However, during interactions nurses were often not very attentive to a child. If the door of the room was open - which was mostly the case nurses often listened to the conversations of other nurses outside of the room, especially when the room happened to be near the nursing station. Some nurses also contributed something to the conversations they overheard with a loud voice from within a room while they were doing something else with a patient. Nurses also responded to a loud call from the nursing station.

On the other hand nurses were very perceptive and observed the differences in the behaviour of children during treatment and when no procedures were done with the child.
Nurse: "He is so different when nothing is done to him. He says 'yes please', 'thank you' and so on. When he had treatment he was like a little tiger, 'I hate you', 'I'll tell your boss', etc. In a way it is good when they let something out."

Björn: "But it must be difficult for you."

Nurse: "You have to think what's done to them."

There was a great deal of empathy among some nurses for the situation for the children, however, it also seemed to be difficult to express this when they were doing their job. This kind of perceptiveness and empathy could be used to enhance understanding.

Parents also noted that there was a difference in attitudes between the nurses who already have children of their own and the ones who did not have children. The nurse quoted in the interaction above had her own children.

6.3.7. The Perspective of Nurses

Nurses are often torn between the their professional concepts of care and their daily job requirements, as well as between their importance in the delivery of the medical care and their position within the hospital hierarchy. Frequently there is simply not the time available which would be necessary to care for a child's physical and emotional needs.

Nurses can be very busy with the technical aspects of medical care. They have to prepare a number of medications and check the prescriptions carefully since they are dealing with powerful agents. This leads to situations where a patient becomes more or less an object of procedures and his/her needs are ignored. This may also happen due to the timing of procedures when a nurse
Not a Good Morning

8:00

I arrive at the nursing station, "Good Morning". The nurse looks at me and says: "It's not a good morning. Tina quit twice on us." She points with her head in the direction of a room with closed curtains. "They are doing CPR." It is quiet in the hallway as I walk away from the desk. A mother looks at me and asks: "How do you put all this into words. It makes you feel ...", she pauses and frowns. I mumble "I don't know". She shakes her head standing in front of her daughter's room.

A baby cries in the background. Some nurses of the night shift are still there. They are going for a coffee. The head nurse will let them know what is happening with Tina. "Like it's all going to happen within the next ten minutes." Tina has spent several months on the ward.

8:28

A doctor emerges from Tina's room. The head nurse asks: "Is something wrong?" The doctor replies "We've stopped." Tears appear in the head nurse's eyes and she withdraws into her office. More people with white coats leave Tina's room. Their faces look serious, slightly distressed.

One doctor writes something into the chart. One can hear the turning of the pages. It is very quiet. The baby in the background is still crying.
wants to finish preparations before the physician arrives.

Neglecting the child as an individual person is not done on purpose. It comes with daily routines. For example children are crying frequently on the ward. This does not trigger any immediate reaction from the staff since they got used to the sound. However, this of course leads to situations where immediate personal needs are neglected.

Ignoring the needs of a patient can also happen during procedures when staff talk to each other about private things like holidays while preparing an injection or during a lumbar puncture. This seems to be a common occurrence among medical staff which has already been described in a number of popular novels and movies.\textsuperscript{6,7} I witnessed conversations about vacations during the treatment of a child in emergency. Nurses do a job where the routines sometimes obscure the point that one is dealing with individual human beings.

Communication with patient becomes oriented toward achieving the daily goals of the routines. Interactions must have a purpose within the medical treatment plan. Spending time with a child without a definite agenda is not regarded as work and is therefore beyond the requirements of the job. Nurses feel awkward in such situations and may express that by making remarks to other nurses with a smile while they are reading a story to a child, i.e. "This is not in my job description".

All this means that nurses develop a working view of "their" children as patients. They see them in short and sometimes emotionally intense moments within a framework of treatment. However, they may fail to understand the person beyond those short images of behaviour. It seems as if they are looking

at a series of photographs, but they miss the motion of the persons they see.

It seems contradictory, when many efforts are directed toward the individual care of the child, yet they are only dealing with personal background from the treatment perspective. Individual behaviour is judged by its positive or negative effects on the treatment. Coping processes are regarded as successful if the families are able to integrate treatment requirements into their daily lives and show cooperative behaviour toward the staff. There is a danger that maladaptive processes, such as withdrawal, are viewed positively, since they represent less difficulty in handling the child (Calkin, 1979).

The hospital organization can be used to defer responsibility from the nurses and it serves at the same time as a preventative screen against too much involvement with the child (s. a. Menzies, 1970). This, however, as well as the lack of stress free time that nurse and child are able to spend together inhibit meaningful communication and are detrimental to mutual relationship and care. As a consequence these protective mechanisms also diminish the direct rewards nurses are able to get from the immediacy of a relationship. Thus they move even further away from the concepts of care which have been mentioned earlier. This leaves them in a state of ambiguity with respect to the meaning of their work.

6.3.8. Observing the Nurses

My observations of the nurses began with the head nurse who was made familiar with my project. It turned out that she was just in the process of changing her status into a nurse clinician. I remained her observer during that period because it enabled me to meet many different people during the meetings
she attended. I received considerable background information and a thorough introduction to the setting. Head Nurses wear nursing uniforms and because it was my aim to remain as unobtrusive as possible I wore a white lab-coat during my observations. Nurse Clinicians wear street clothes and therefore I did not wear my lab-coat while observing her as nurse clinician. After I had spent considerable time with her I began to observe the general duty nurses who wore nursing uniforms. I adapted my appearance accordingly by wearing a white lab-coat.

During the observation of the nurses I wanted to be able to look beyond the personal attitudes and individual reactions to specific patients. The former head nurse helped me to choose nurses with varying nursing styles. In addition I tried to spend several shifts with the same patient or with the same nurse in order to get a somewhat better perspective on nursing beyond individual variables. A wide range of nursing styles and activities could thus be included.

The activities of the nurses made immediate recording sometimes difficult for me, because much was done while standing and they were almost constantly on the move walking around from one place to another. During some of the interactions I also hesitated to write, when I felt that the writing activity could inhibit the conversation. If I was not able to take notes in the situation itself I tried to write immediately afterwards in order to record as accurately as possible.

One nurse became somewhat tense when I began to write while she was picking up some sheets, which she considered to be an unimportant activity. She asked me if I was doing a time and motion study. I explained to her that I had to empty my memory because I had not written anything during the
### Observational Distribution of Nurses

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Each letter in the top section refers to a specific nurse. The bottom section shows nurse-patient assignments (day=dayshift; nig=nightshift) which also included the care of other patients to varying degrees. There were three types of assignments: individual patients, rooms with up to four beds, or various patients according to demand.

preceding interaction with parents. When we looked back at the situation later she told me that she had found this particular incident stressful. It was a reflection of the fear that I had been sent by the administration and wanted to check nurses' work performance. This was sometimes addressed in jokes, but it also had a serious background and some nurses rechecked asking me again what I was doing.
6.4. CHILD LIFE

The study of the child life worker followed the observations of nurses and the direct observations took place over a period of one week. There was only one Child Life Worker on the Oncology ward. When she was sick a replacement was called in from a list of other people who had experience in working with children.

6.4.1. Child Life Workers in the Hospital

The Child Life department had four staff members and one supervisor. They had only been a separate department for several months. Before they had been called Recreationists and had been organizationally attached to the Occupational Therapy department.

The Child Life Workers in the hospital were assigned to specific wards. Those wards had considerably different populations of patients, e.g. there were a Teen Ward, an Oncology Ward, a Surgical Ward, etc. and therefore their styles had to vary. This also seemed to suit their individual personalities. Apart from larger events, e.g. Christmas party, they worked individually.

Once a week a film was shown in the library, which was a larger area used for Child Life activities outside of a ward. Children of the appropriate ages were brought there from different wards.

The play area in the Oncology Ward was a semi-open space adjacent to the nursing station, which was the center of all activities. A wall with windows, which was about four feet high, separated the play area from the hallway. Many people passed by during the day and leaned over the wall to see what was going on.
Professional distinctions were made according to the academic background. The Child Life Worker on the Oncology ward did not have the required courses in child development and was therefore classified as a Child Life Assistant. She basically was doing the same work as all the other Child Life Specialists, but she received less pay. Incidentally she had been a nurse and had become Child Life Worker after she had taken courses in play therapy.

6.4.2. Aims

The job summary of the Child Life Assistant states the general aim of the department:

Responsible to the Child Life Coordinator, the Assistant works under the general supervision of the Child Life Specialist in conducting planned daily activities designed to further the social, emotional, intellectual and physical development of children and adolescents in hospital.

This is outlined and broken down into several steps in the "Examples of Responsibilities and Duties" which are stated in the job description of the Child Life Assistant.

1. Works in an assigned area in the hospital.
2. Ascertains daily, information concerning the medical condition, developmental level, interests, capabilities and special problems of each patient on the unit.
3. Provides and supervises activities for patients based on the above information.
4. Directs activities in the play area and works with bed rest patients as indicated.
5. Furthers socialization of patients through play activities.
6. According to established policies and procedures, adapts where
necessary, play activities and materials to suit those patients with special needs.

7. Fosters normal growth and development by providing age and developmentally appropriate toys, games and activities.

8. Helps parents recognize the needs of their children in hospital.

9. Assists in promoting increased understanding of medical events and procedures through provision of appropriate toys, books, equipment and activities.

10. Works in cooperation with other hospital personnel, e.g. physio, O.T., etc., in providing reinforcement, through play activities, of treatment being carried out by these or other departments.

11. Assists in planning activities and providing materials which give the patient acceptable outlets for fears, concerns and anxieties resulting from the unfamiliarity of the hospital environment and which facilitate assimilation to the hospital experience.

12. Observes and shares with the Child Life Specialist, relevant information on patients' behaviour, developmental levels, individual needs and adjustment to the hospital environment.

13. Works in conjunction with volunteers and candy stripers.

14. Keeps abreast of new developments and literature pertaining to children and adolescents in health care settings and in the Child Life field in particular.

15. Performs related duties as assigned.

The Child Life Worker on the ward said that she was trying to do different interesting things to get children interested and to make them eat for example, e.g. (7-17) "Like we had a Mexican day and they just couldn't believe it. The children ate a lot." In addition to this kind of support for the therapy she wanted to make contact with all children and would try to involve them.

Interaction with children is the central focus of the work. During a meeting of Child Life Workers the department head said after they had discussed the use of videos (7-73), "I would like to mention that movies shouldn't be used
too much. I don't want movies and video games overused. I know it's a nice way of doing something without putting too much work in it. You should interact with children as much as possible."

6.4.3. Rewards
The rewards lie in the help that the Child Life Worker can give to children in their social development. The Child Life Worker on the Oncology ward had been working as a nurse before and in comparison she found her present job much more satisfying. She said that if she noticed that a child had been left alone by his parents then she would make contact and talk with him. She said (7-43): "It's a long process, but it is good for the children, like you can do something about this anxiety."

6.4.4. Information
A meeting of the Child Life department was held every week. During this meeting the Child Life Workers reported from their respective wards. One member of the department also gave a lecture about issue relating to a specific illness which was treated on the respective ward. In addition to some general organizational issues also general guidelines and problems of their work were discussed. Occasionally issues were also discussed during the lunchbreaks, when Child Life Workers met in the cafeteria.

The Child Life Worker got the information about children in the ward from her participation in the weekly Social Rounds, but she also consulted the charts. There was a special column for her in the Kardex at the nursing station.
During social rounds the Child Life Worker sometimes initiated discussions about the perspective of the children. She would mention statements the children had made, e.g. James had told her (7-12), "I'd be fine if you just would let me go home" and about the nurses, "I hate them all". She also made sometimes an effort to coordinate their various approaches in matters such as food intake e.g. she said (7-14), "we all must pull the same strings."

In addition she received considerable background information from the children while she was playing with them. Parents also frequently talked with her and told her things about their family life, when she visited children in their rooms.

6.4.5. Relating to Other Hospital Staff
The Child Life Worker was a separate entity on the ward. An official contact with the nurses took place during the Social Rounds. There was some other interaction with nurses, but it was more in casual terms. Occasionally the Child Life Worker also sat together with nurses who worked on the ward during their breaks.

The Child Life Worker communicated with other staff without much tension. This was probably due to the organizational independence of Child Life as an individual department and the field of work which was regarded as relief. Nurses often brought children to the Child Life Worker when they wanted to put the child to a safe place, because they had other things to do. On the other hand children's activities were frequently interrupted in the play area when medical staff wanted to do something with a particular child.

The communication between Child Life Worker and other staff reveals
their differences in perspectives. The Child Life Worker seemed to be more concerned with the social and emotional wellbeing of children and their families. She also showed some sensitivity for the quality of communications.

(7-13)

During Social Rounds the Head Nurse reported with a sigh about one mother who had complained recently about the side effects of the chemotherapy. The Nurse Clinician commented that she would still have to go through a lot, "she bursts into tears every thirty seconds". The Child Life Worker asked, "Does she know everything?"

The Nurse Clinician responded, "Yes, she is picking up."

The Child Life Worker expressed her concern about the communication whereas the nurses seemed to focus more on the behavioural aspects. The interaction revealed that in fact this mother may not have received all the information she needed, which could have been an additional source of stress for her.

A difference in the perspectives became also obvious with the comments about the perception of other staff, like nurses. She said that nurses would now begin to diagnose behaviour problems of one boy when he was just beginning to stand up for his rights (7-51).

Nurses frequently looked into the play area to make some contact with children when they seemed to be in a friendly mood. This could be quite disruptive on the other hand and added to the lack of privacy which already existed due to the open construction of the play area. Nurses frequently took children out for injections or other treatments which sometimes created a very transient atmosphere.

There was hardly any interaction between Child Life Worker and physicians. Only when a physician wanted to do something with a child who happened to be playing with the Child Life Worker a few short communications
were exchanged.

Child Life Workers and Occupational Therapists cooperated with respect to individual children and they also exchanged ideas about their activities. The Occupational Therapist organized for example a tricycle or a wheelchair which the Child Life Worker would help to use. The Physio and the Occupational therapists did not just come in and take children out, but they were more considerate and waited until children had come to a conclusion with their activity.

There was not much interaction between the teachers and the Child Life worker apart from little conversations when they happened to meet. However, the Child Life Worker checked regularly if children had gone to school. When nurses had forgotten about it she brought children to the classroom. She also talked with children about their schoolwork after they had returned.

The Child Life Worker made occasional use of other staff, e.g. she consulted a Dietitian for some snack ideas. She had planned a little party which was supposed to encourage children to eat. The Dietitian made some suggestions which were then processed by the hospital kitchen.

Volunteers were frequently present during the mornings and play with children in the play area. Some came very regularly, for example one lady apparently came every Wednesday which she had done for the last twenty years. There are also volunteers who use some of the equipment and play with children on weekend when the Child Life Worker is not present. If volunteers do not come regularly, it is difficult for them to orient themselves in the ever changing situations on the ward. The Child Life Worker noted that they may have problems to remember where things belong. She also said that this could
influence their attitude toward children (7-74), "they may be apprehensive to set rules for the children."

6.4.6. Child Life Worker and Parents

There is usually quite a relaxed atmosphere between Child Life Worker and parents. There are frequently chats about various daily activities and concerns. Those conversations take place when the Child Life Worker visits children at their bed or while children are active in the play area and parents come to participate or they lean over the wall. Parents learn that they can get some relief from their attendance duties with their children when they bring them to the play area.

Sometimes parents asked the Child Life Worker about her training. After they had talked for a while one mother said (7-69), "it’s a nice thing to do." Parents’ attitude is usually quite positive and they use the different toys and games to distract their children.

When parents communicate with the Child Life Worker they also talk about their feelings and intentions. One grandmother told the Child Life Worker for example (7-59), that she would treat the sick child like her own children and he would not get many specialties, that his mother would take the illness very seriously and cry a lot. A considerable amount about the family background can be communicated in this way. The conversations may also refer to very personal topics, e.g. one mother talked about her relationships to men.

Parents and Child Life Worker seem to be able to establish a friendly communication because they experience no tension in their relationships. Child Life Workers do not perform any dramatic treatments, they are rather relief for
Do you really think they are alright?

The Unit Clerk comes to the play area and tells the Child Life Worker, "Can you move all the children to their rooms now?" The Child Life Worker responds that the children are playing and that they are okay. The unit clerk does not seem convinced, "But they'll be moving right along here; do you really think they are alright? The Child Life Worker confirms.

Two men arrive. The Head Nurse approaches the play area, "did Sue tell you?" The Child Life Worker nods, "yes I think they are alright here."

The two men push a stretcher with a body which is covered with blankets along the hallway. A security guard is with them. They stop at every corner and look if the hallway is empty. They disappear.
child and parents. It is interesting, however, that the Child Life Worker receives information about families to which other staff members will most likely have little access.

6.4.7. Child Life Worker and Children

In the morning the Child Life Worker usually walked around and looked into the different rooms to greet the children. The reactions varied from a friendly hello to no response at all. However, the Child Life Worker did not reinforce her presence and she said to unresponsive children for example (7-1): "You will say 'hi' to me later", and continued her round. She encouraged children to come and play with other children. Children were never forced to do something with the Child Life Worker, but she sometimes made jokes when children were lazy in getting up (O-20), "If you still would have been in bed I would have come with a hose."

During visits in a room or when they met in the hallway parents sometimes involved her in a little chat and talked about the their child's and their own feelings. Most interactions with parents and children took place in the play area which was the central workplace of the Child Life Worker.

Children behave differently with the Child Life Worker compared to their interaction with nurses. Some things are just done as a byproduct of the activities which makes it easier for them than if they were doing them as part of a therapy. (J-20/J-42) One boy had problems with walking, possibly because of pains in his legs. It became a nursing task to make this boy walk. One nurse said somewhat proudly to the Child Life Worker: "He doesn't like to stand. I have made him stand a little bit today." The boy had been standing...
quite frequently already. At the end of the playtime he walked several steps with the Child Life Worker who did not make a big deal out of the walking. The next day the boy walked from the play area to his room and then around another corner with the Child Life Worker trying to find a chair. A Child Life Worker is a non-threatening adult who is involved in fun activities. Therefore it is easy for children to cooperate because they do not have to be afraid of painful procedures.

Physical contact is also a way of relating to children. The Child Life Worker frequently carried children on her arm when they were crying. In comparison nurses had the closest physical contact with children during mostly painful medical procedures. Therefore children often rejected their closeness, e.g. when a nurse tried to hug or cuddle a child. The Child Life Worker was able to offer a different and less threatening relationship. The Children's wishes were more accepted, which does not imply that they were always granted. But clear arrangements were made, e.g. (7-26) "James you go to school first and then you can come to the play area. That's the deal." When children are together with the Child Life Worker, they are there at their own will and they do not have to stay. This created quite a different atmosphere compared to the pressures of medical treatments.

In the relationship to children there was also an educational perspective. Children are reminded to be polite and cooperate. For example, (7-19) one boy dropped a pipe cleaner he was playing with. He told the Child Life Worker "Come here!", and pointed toward the floor. She replied, "You have to say the magic word", and picked up the pipe cleaner after a moment of hesitation. She gave it to him and said, "Is it so hard to say please?" This attitude is also
used in order to help the therapeutic process, e.g. (7-8) "next time you come, you come without wheelchair; you can walk." Children seemed to accept this from the Child Life Worker.

The play activities sometimes revolved around medical issues. Children's doctor kits were available as well as dolls which received injections and band aids.

(7-54)

Nancy, a nine year old girl, plays doctor with a teddybear. She looks into his eyes with a flashlight and puts a bloodpressure cuff around his arm.

The Child Life Worker says to Ben, a two year old boy who is sitting on her lap, "See, he doesn't cry; he knows that it doesn't hurt."

Nicole looks into the teddybear's mouth.

The Child Life Worker: "Does he have to have his blood taken?"

Nancy: "Yes."

The Child Life Worker gets a syringe and points at a big smurf, "He knows all about it," (she points at the bear) "but he doesn't know it, so you'll have to do a lot of explanations."

Children are enabled to act out their experiences in this game and at the same time it is a preparation for future treatments. The little boy learns that bloodpressure does not hurt. During those situations children may also talk about their concerns and reveal the information they have understood. While playing games, especially in one to one or one to two situations, children begin to talk about their experiences. The Child Life Worker learns about their perception, e.g. (7-57) their interest in band-aids, in the funny towel with a hole which is used

\(^{68}\) The smurf is frequently used by children for their doctor games.
during procedures, etc. She learned that one six year old boy did not want to know all the information, like when they put the needle in, or another eight year old boy did not want to see the instruments before the actual procedure. Afterwards he did not mind.

In some interactions the Child Life Worker addresses issues with direct questions, e.g. "Do you know why you are here?" If the child does not know the answer the Child can be redirected to the appropriate persons, e.g. (7-37) "Maybe you can ask your daddy, he will tell you."

Children generally seem to react positively to the Child Life Worker once they have learned what she is doing. In some cases children asked her to be present while they received an injection. However, she also encounters many different reactions depending on the emotional state of the child.

(7-60)

A mother meets Andrea, the child life worker, in the hallway while she is carrying Norman, her one and a half year old son in her arms. Norman reaches out for Andrea.

Mother: "Everybody likes Andrea."

Another Child, a six year old girl, passes by. The Child Life Worker greets her, but she does not respond.

Child Life Worker: "I don't know if everybody likes me." She laughs.

The Child Life Worker was able to take the aversive reaction of the child lightly. The understanding and acceptance of children in their individual reactions contributes to a friendly relationship. Children as well as adults addressed the child life worker by her first name.
6.4.8. The Perspective of a Child Life Worker

The perspective of the Child Life Worker seems to be a more comprehensive view of the child's needs. It is somewhat related to the teachers' perspective without the goal oriented framework of school education. All other staff in the hospital seem to have a very concrete task which they are striving to fulfil. Child Life activities seem to create more of an open space for children.

The perspective of the Child Life Worker seems to be the closest staff-children relationship. Her observations and judgements reflect the concern about the children in their relationships. For example, during a conversation between Child Life Workers during a break they shared their concern that it was bad from the parents to tell a child that a needle would not hurt, because children would not trust them any more.

Another example of the Child Life Worker's perspective was shown when she commented that the activities of photographers were not fair to the children. They had just taken pictures of children and had tried to arrange pictures with smiles. They had also made some children upset when they neglected their current activities and intruded without asking with cameras and flashes.

A reaction of Child Life Worker and nurse toward a crying child may reflect the difference in orientation between those staff members.

(7-44)

A little boy is crying in the play area. The Child Life Worker lifts him up and holds him in her arms. A nurse who is passing by says: "I'll get you some juice." The Child Life Worker talks to the little boy. The nurse returns with a bottle with juice. The Child Life Worker continues to hold the boy in her arms and shows him some wooden blocks. She puts the bottle on a shelf. The boys ceases to cry.

The nurse tries to solve the problem by trying to give the child a soother
(juice). However, the Child Life Worker provides human warmth and empathy, which requires more time and contact with the child. The latter perspective seems to be less functional and is also more successful in this case.

Nurses also wondered in the case of a boy, whom they regarded as being very difficult, how the Child Life Worker was able to get along with him. She attributed this to their mutual respect and that she told the boy with her where he was at with her. Her perspective is sometimes shared during Social Rounds, however it seems to have little impact on the overall strategy of care. This is probably due to the position of Child Life Workers within the hospital hierarchy, where they seem to have little clout.

The Child Life Workers also contribute to the positive aspects of coping. It has been mentioned in the literature that coping has two aspects. As Zevon and Armstrong (1981: 1) point out in their report about the impact of childhood cancer:

"The authors view stress management and pleasure management as distinct and independent dimensions of the coping process."

With respect to the roles of staff in the hospital it seems that the Child Life Worker is the only one who enhances pleasure management as a contribution to the coping processes of the child.

A good example of the perspective of the child life worker is revealed in the following statement, which expresses her sense of frustration with the overall organization.

(14-27)

Child Life Worker: "I feel like a watchdog. I have to look that children go to school, or Ralph (a ten year old boy) waits 'til things
are done for him. It makes me angry because then psychologists and others are involved to solve problems instead of taking care of it in the beginning."

She refers to problems which could be resolved easily if addressed at the right time. However, it frequently happens that things get worse and then a solution is found within the hospital system involving other professions like psychologists. This reflects more the working of the hospital system than the individual needs of the child. The child life worker makes frequent attempts to structure children's daily activities, but in the end she feels powerless to change the situation.

6.4.9. Observing the Child Life Worker

The atmosphere with children was fairly relaxed and there were no threatening treatments. I did not wear any uniform or special outfit. There were also many opportunities to observe children in interactions with each other.

The limitation of the physical space of the Child Life area made it sometimes difficult to just sit there and observe. Because it was a semi-open area it was possible to observe from the hallway as well. However, if possible I stayed inside the play area in order to catch all conversations and the atmosphere. There was a difference between the observations from outside and from inside. In the latter case I felt more in tune with what the children were doing and I could perceive the faces of other persons who looked into the play area as intruders.

When I began my observations of the Child Life Worker I explained my research again, which I had already done before to some extent during casual conversations. Then I was introduced to the Child Life Coordinator who supervises the activities and acts as the head of the department. The Child Life
Hospital Staff / 180
department was very positive toward my research and offered help with respect to literature and questions.

The Child Life Worker frequently made comments about her work and her intentions for me. Generally the conversation between us was very casual and sometimes she made little jokes, e.g. (7-31) "Do you wanna play with the children and I take holidays?" During meetings with other individual staff members remarks were sometimes made with respect to my presence which had then become more obvious, e.g. (7-34) the dietitian said to me during one of those meetings, "You can suggest something too, don't just write."

When the Child Life Worker talked to parents she usually introduced me as someone who was doing a study. Some parents became interested and asked me more about what I was doing and with others I was able to establish a relationship of casual conversations. In some cases she also made joking comments about my presence, like introducing me as her bodyguard (7-16). Some parents addressed my presence in the same casual way with which they related to the Child Life Worker. For example, one mother commented once to her, "How come that he let's you do all the work?"

My writing became the focus of the attention. This was the activity which showed that I was doing something different. The Child Life Worker also said to a nurse who inquired if I was writing a book, (7-40) "He writes everything down, if I put a pencil down and when I pick it up." She then told me that she would not be able to write that much.

Observing the Child Life Worker happened in a more relaxed atmosphere because there were no painful procedures and no schedules of medications. It was an open atmosphere which was almost like an island in the routines of the
hospital setting. The playful environment also enabled me to gain a different perspective of the children and their interactions with hospital staff because they seemed to be more tolerant and relaxed. It also showed me that children have their own awareness of the different roles of people in the setting and that they adjust their own behaviour accordingly.
6.5. PHYSICIANS

There were several levels of physicians on the ward:

1. Haematologists, Oncologists, and/or other physician in charge of a patient,
2. Specialists (when consulted), i.e. Radiologists (frequently), Dermatologists, etc.
3. Oncology Fellow,
4. Senior Resident (changes every two months),
5. Junior Resident (changes every two months),
6. Medical Students (MSI=Medical Student Internship);

The observations concentrated on the physicians who were the most involved with the ward. Senior and Junior resident are usually "running the ward" as one physician put it. Most time was spent with the residents, however the Oncologists and Haematologists were also included. Medical Students were not included in the direct observations at this stage.6 9

6.5.1. Aims

Physicians are primarily responsible for the choice and implementation of a medical therapy. Their decisions determine which course of actions will be taken in a particular case. They are also responsible to communicate their decision to the parents of a child and obtain their consent for the therapy. They inform parents about the diagnosis, the chances they can see for the child and recommend a medical treatment. Their decisions are based on the information which the have about the illness. In the case of cancer one must consider a whole group of variations which are treated according to many different treatment protocols which prescribe the kind the amount and timing of certain

6 9 Some observations were made during their interactions with children (see chapter Children).
very powerful medications. Therefore it is no surprise that a great deal of a physicians activity is related to the processing of information.

6.5.2. Information

Information seems to be a central theme in a physician’s job. This was also reflected by the multiple rounds in which various medical topics were discussed. The participation in those rounds varied between the hierarchical positions.

• **Morning rounds** took place every morning on the ward. They were an exchange of information about various patients. Usually the cart with the charts was taken around the ward and the group discussed issues in the hallway. Sometimes the physicians went into a room and looked at the child. (senior, core, junior residents, and head, charge, chemo nurses, and a haematologist usually joined a bit later).

• **Case rounds** took place once a week and served for discussion of mainly the medical background of all patients on the ward. (All physicians including the outpatient oncology department took part as well as head nurse, chemo nurse, Social Workers and therapists.)

• **Teaching rounds** were held once a week and during which residents were given a lecture about particular medical topics.

• **Grand rounds** were an occasion for interested staff to be informed about a medical topic. This was usually a presentation by a physician from one of the local hospitals or from somewhere else.

• **Radiology rounds** were held once a week for the physicians of the Oncology department in conjunction with a Radiologist who reviewed the X-ray pictures of Oncology patients.
In addition there were several presentations by visiting physicians or by representatives of companies trying to sell medical equipment. Some other rounds were also held for organizational purposes, e.g. to inform the physicians who had night shift or on weekend duty about various cases on different wards.

Senior residents, haematologists and oncologists also participated in events at another hospital, e.g. physicians had set up a regular meeting concerning bone marrow transplantations where the feasibility of a transplantation in a particular case was discussed. The physician who implemented radiotherapy worked in a different institution where radiation treatment was given for all cancer patients of the area.

A central source of information for the daily activities was a patient's chart. However, the many different styles of handwriting made it sometimes difficult to read. This also seemed to be a source for mistakes, which were discussed occasionally. The information provided by the charts had to be matched with the individual treatment plan and the treatment protocols. These protocols contained information about medication and timing for specific illnesses. They were also changed fairly often due to the ongoing research. Some protocols, which were used as a last resort or in specific cases, were experimental. When physicians wrote their orders they would often consult those protocols in order to calculate the right dose of medications.

Physicians frequently consulted specialists in particular medical fields. The physicians of the Oncology department had regular meetings with radiology specialists with whom they discussed x-ray pictures of patients on the ward. Other specialist were consulted when it seemed necessary. It also seemed to be a method to defer responsibility. Many physicians could be involved with an
individual child. This was especially true before bone marrow transplantations when many different medical aspects had to be assessed.

Much information was picked up in conversation between physicians or between physicians and nurses. Most of these interactions were quite casual, but they contained nevertheless important information about the condition of a particular child. Individual fates, however, became cases in a theoretical framework in which they were considered to be more or less interesting, depending on the severity of the illness and the degree of complications. This was reflected in the way they talked about individual children, e.g. (9-52) a resident reported about the progress of a child and the senior radiologist, who was supervising this round concluded, "so the decision is not to treat him any more", which the resident confirmed. In another example the covert attitude towards death as a mishap in the system is revealed.

(9-51)

Dr. B.: "What's the overall prognosis?"

Dr. R.: "In the literature which we have, mainly on thirty outpatients, only one survived. We don't expect him to get that far."

The conversation proceeded with other patients. One individual fate is just a case within the informational framework.

Physicians have to be able to handle a large amount of information. In addition they receive different pieces of information at different points in time. For example they may receive information about a patient from the chart, then more during a conversation with a colleague, and a nurse may tell them something in passing. In between they may deal with many other issues which are not related to this case. Maybe this is one reason why physicians limit the
amount of information about one patient to the medical necessities. The social impact of illness and treatment, although perceived, adds another complex reference system which exceeds the functionality of the medical perspective.

This is also reflected in the language which is being used. For example (9-68) one physician asked another, "How are the chicken pox doing?" He was referring to a child with cancer who had been admitted to hospital with chicken pox.

6.5.3. Physicians Relating to Other Physicians

Conversations between physician mostly have an informative character. They center around illnesses and specific case examples. Sometimes this information may be passed on in a humourous way. During the interactions of physicians the hierarchy also becomes clear. The more knowledgeable senior physicians always determine the way. Junior physicians and residents are often questioned by senior physicians. This also happens during rounds where other staff members are present.

(10-27ff)

During the case round one of the haematologists looked into the chart and mentioned to the resident, who was reporting about the case, that he had written down hypertension. The resident said that a higher bloodpressure had been noted.

Haematologist: "Is this your or nurses' measure?"

Resident: "Nurses' measure."

The nurse clinician said at this point that the bloodpressure was going up and down.

Haematologist: "So what are you doing about it?"

Resident: "Watch and see."
Haematologist: "Don't you think you should take the bloodpressure yourself?"

Resident (apologetically): "I was in emerge last night and I had about fifteen minutes to write this down."

The actions of the resident were checked as if he were be in an exam. This seemed to be a frequently used procedure. Residents were kept under pressure to learn by responding to senior physicians questions whenever they were asked. They had to justify their activities almost constantly. However, they also went to senior physicians and asked questions themselves about treatment procedures or the use of a certain medication.

6.5.4. Physicians and Nurses

The main topics of conversations between physicians and nurses deal with information about patients and medication. Physicians have to write the orders for medication, which is sometimes delayed when they are busy with other things. When a physician came to the ward, nurses often approached with an open chart in their hands to get the medication orders signed so that they can continue with their work.

Physicians often use nurses as sources of information about patients and to help them when they deal with patients. Mostly nurses are addressed by them in a general form. For example a hematologist looked into the chart at the nursing station, discovered that something was missing, and asked (10-51), "Can someone explain to me ..?" Or a physician shouted from a room (9-47), "Can I borrow a nurse please?"
6.5.5. Physicians and Parents

It seems that parents are the main partners for communication in the physician patient relationship. Parents have to consent to all forms of treatment and only they seem to be able to understand some of the medical information which the treatment requires.

Most conversations deal with information about illness or treatment. In order to obtain consent parents must have a minimal knowledge about the illness and the impact of the treatment. They have to master a huge amount of new information at a most difficult time, when they have to deal with their own emotions concerning their sick child. The sheer amount of this information, however, is staggering. For example one physician told a mother that the diagnosis of Leukemia had been confirmed for her child (10-8ff), and he proceeded with information about the timing of various treatment phases, about different types of blood cells, their functions and origin, the effects of the therapy on those blood cells, the chances of getting into remission after the first phase of treatment and in the long run (quoting research examples), about side effects of medication like kidney failure, the possibility of burns, loss of hair and differences in the physical appearance, about the chances of cancer cells in the brain, etc. The whole conversation lasted about twenty minutes in which the mother occasionally struggled with her tears. It is not clear if she was able to remember much of the information afterwards.

After they have been in hospital for a while parents seem to use the opportunity of a meeting with the physician more to ask detailed questions about the illness and the chances for recovery. However, it can be frustrating for both

\[76\] A more detailed analysis can be found in the chapter "7. Parents and Family", especially subchapter "7.3. Reactions to the Diagnosis".
physician and parents if clear answers are not available.

(9-66)

One physician talked to the parents of a hospitalized boy and mentioned that one part of his blood "called platelets" was low. The child's father rolled his eyes, mumbled "oh no" and then asked the physician, "Can you cure it?"

After the physician had asked the parents about the child's medical history the father repeated the question again (in the meantime he had forgotten the name of the blood component "platelets"). The physician responded "Don't worry" and explained the diagnostic process, "We have to know what it is exactly first I will come to you with Dr. Rand, who is a blood specialist. I am working with him".

The father asked if other children had similar symptoms and the physician responded that it was possible to give platelets and that the symptoms could also be caused by an infection.

In the end the father asked for the physician's name, who pointed at his nametag. After the father said that he would not be able to remember the name the physician wrote it down on a piece of paper.

Again it is not clear how much of the information the father was able to digest. In a matter of minutes he already had forgotten the name of the blood cells he was concerned about (English was obviously not his native language). The concern for his child had become his focus and he only wanted the assurance that the doctor was able to cure the illness. Later the physician commented about this conversation that he felt that he had not done a good job with them, because he was not able to get across that they should not worry and on the other hand he could not tell them that he would fully recover (9-69). This example shows the difficulty to reach an understanding on the basis of very different perspectives and expectations.

Physicians sometimes have difficulty in answering parents' questions in a very concrete way, because answers may seem speculating in view of the
complexities of issues. They may also hesitate to be definite with their prognosis because they feel so much depends on it and what happens if they are wrong? For example (9-57) after he had finished the examination of the child the physician asked the mother if she had any questions. The mother asked how long it would take, how long her child would have to stay in hospital, which medication he would get. The physician responded cautiously and said, that he could not say anything concrete and that her child would have to be observed for a week to determine if there was an infection in which case he would get antiviral medication. The mother wanted to have very concrete information which the physician was not able to give from his viewpoint.

The knowledge which physicians are assumed to have can lead to suspicion and speculation about things they do not tell and questions they do not answer. However, physicians seem to be reluctant to share the ambiguity with respect to various treatments and the meaning of therapy in advanced cases (s. a. Comaroff and Maguire, 1981). The suspected knowledge may create a barrier in the communication when the importance of the untold things increases.

From a physician’s perspective parents are partners because they are the key to access to the pediatric patient. However, they have difficulties providing parents with the appropriate information. In addition parents may be seen as potential foes who threaten with litigation in cases of errors. Therefore there is considerable ambiguity in the parent-physician relationship as it is presently apparent in cases of severe pediatric illness. Thus the ambiguity is twofold, first with respect to the sharing of knowledge and perspective and second with regard to the respective roles of physicians and parents.
6.5.6. Physicians and Children

The interactions between physicians and children were characteristically of a short and technical nature. Physicians examined children and looked at parts of their body without much of a conversation. Verbal communication seemed to take place in mainly two forms, one was of a question and answer type when either child or physician tried to get some information from the other, and a prescriptive interaction when the physician told the child what s/he should do.

Verbal interaction seemed to be proportional to the age of the child. Younger children received less information and less verbal attention from their physicians. For example (9-37) one resident examined a baby who was crying. He smiled at the baby but did not say a word. Another resident saw this and helped him to restrain the movements of the baby. When they finally left the baby was still crying but neither one of them had made the effort to communicate with the child. It was one rare occasion when I observed a resident who lifted a crying child up and carried him on his arm for a moment.

Physicians usually came into a child’s room and performed examinations without much consideration for the present activity of the child. When the child was found sleeping an occasional exception was made. Younger residents and medical students were somewhat more hesitant and at the same time more considerate of the child’s situation. They mostly asked if it was alright to examine the child and also explained sometimes what they were doing.

With some teenage children there was a somewhat ironic mode of conversation. Although this can be understood as mutual coping with the situation there were interactions which were bordering on misunderstanding. This was enhanced by their short time span. An interaction rarely lasted longer than one
or two minutes and usually only a few sentences were exchanged.

(10-62)

Simon (a teenage boy to the physician who looked into his room): "Will I get out?"

Physician: "No, you will stay here forever, now you know."
(After he had left the room he commented, "he is not that bad").

Although the communication was meant in a humorous and non-realistic way by the physician there was some potential truth in it, which may in turn have been interpreted as a threat from the perspective of the boy. He did not know when he would be able to leave the hospital and the physician's remark, even if he understood its humorous intention, could have added to his insecurity about his fate. A couple of hours later the physician and the boy met again.

(10-71)

Simon (to the physician): "Oh you again!"

Physician: "Now you have to stay, your mom doesn't want you any more."

Again this was said while passing by and the fine line between humour and a real personal threat is also apparent.

6.5.7. The Perspective of a Physician

The physicians seem to have become managers of knowledge. The more knowledge they have to deal with the more issues of personal relationship with patients become secondary. There is little time left between the many short and concentrated activities a physician goes through during a working day. The concentration changes from a paper, to a patient, to a phone call, to a
conversation in another part of the hospital, to a meeting, etc. The shift in concentration is sometimes quite sudden and the periods of concentration are usually short. The longest periods of concentration happen during meetings and seminars. During those occasions I could observe expressions of tiredness and exhaustion.

The treatment measures which are sometimes quite hard and cause considerable suffering are justified with the rationale of a higher good. For example during a meeting about lumbar punctures nurses and physicians talked about the suffering and the best way to organize the procedure. One physician summed up the perspective:

(M-37)

"We have to remember that we are doing it in the best interest of the child and we have to be clear: we're going to do it."

The child becomes an object within the procedures which are made necessary by requirements of treatment procedures.

Some residents talked about their experience and expressed that they found their job quite draining. They found themselves in the middle and questioned the necessities of medical treatment and were more confronted with parents' concerns who they met while they were doing their work on the ward. One senior resident said in one conversation:

(9-8)

"I find the work very draining. This is my personal point of view. But as a core resident I found it very difficult, because you see the parents and the children. I wasn't very good at that."

He continued to say that the treatment measures were sometimes quite hard and that he found them difficult to cope with, but that there had
also been successes during the last years in the treatment of Leukemia.

"Sometimes we're treating because of a statistical success, and there are times when you have to back up. We have to do very heroic measures which are sometimes difficult to justify."

"Sometimes measures are taken because you don't want to accept defeat. That's my personal point of view."

As a resident he had to follow the guidelines and treatment schedules which were set by others. At the same time he was confronted with the impact of his prescriptions. He had to fill out the orders. The position of residents was somewhat similar to the nurse, who also had to follow up predetermined schemes.

Senior physicians rarely talked about their own coping with their job situation. Possibly because they had been in their job for such a long time their own coping style had become part of their routine. However, occasionally a discontent with the technical atmosphere of their working environment surfaced, e.g. one physician said (H-22), "Sometimes I think old times were better when you made house calls".

Coping was reflected in the black humour which physicians seemed to share and in the way they talk about interesting cases which seemed to be removed from human fates. During a birthday party for one of the physicians one physician suggested to spray some Vincristine (a chemotherapy drug), which shows the link between fun and seriousness of the situation.
6.5.8. Observing the Physicians

When I observed the physicians, I changed into a white lab coat again during my daily hospital routines. This made me unobtrusive in the company of physicians and in fact I was mistaken for a physician on several occasions. There was never any challenge with respect to my presence. I was accepted and in most cases I was not even introduced to parents or children.

The attitude toward physicians is distinguished from other staff in the hospital and I was treated the same way. During a morning round on the ward the dietitian introduced someone to the group which consisted of nurses and physicians. She shook the hands of all physicians and myself but just said hello to the nurses. I am not sure, if this lady had been introduced to the nurses before or if it reflected the difference in treatment. However, in the communications with other staff it was always clear that the physicians had the most important position in the hospital hierarchy.

Some physicians made an effort to explain medical things to me and asked if I had any further questions. In some cases they showed concern for my work and tried to put me into situations which they deemed relevant. For example one physician said to me that he would see me later on the ward when he wanted to do some other things, like reading charts. After I had asked him if I could follow him just wherever he went he conceded, "It's actually easier like that" (9-9). When one physician told me to proceed to the ward because he was just going to the washroom before he went up, I had to wait for a considerable time for him. When he finally came he apologized, "Sorry, I got sidetracked a bit" (9-14). At that point and similar others I could empathize parents' feeling who waited in vain for the promised visit of a physician. In
addition I learned that if I wanted to be able to do continuous observations, I had to do just that and be with the physician constantly.

Physicians rarely introduced me to parents and other staff. Occasionally they introduced me with short statements to parents, "He is with me" (10-15) or "He is with us" (10-18). This was usually accepted. Only in one case, when the physician left the room for a moment, parents began a conversation with me.

My presence did not seem to interfere with their work and I seemed to be taken as just another person with them. This was facilitated by the many rounds in which several physicians got together to talk about patients and specific medical problems. In one instance two physicians apologized that they did not let me look through the microscopes, (9-73) "Sometimes we forget that you are there". The physicians seemed to forget my presence, especially when they were involved in an activity, and they became aware again in more relaxed moments. For example, when we were back in the office one physician apologized for not having me introduced to other physicians he had talked to (10-58), "You are doing quite well for your size, you are quite unobtrusive". My presence did not seem to have very much influence on their work.

During breaks at lunch I became sometimes more involved in conversations when physicians asked me about the study or reflected on their work. The conversations addressed various topics from general talk about different countries, medical issues, to their rationale for doing something.

When I was introduced to other physicians it usually was done in a casual way. Sometimes short explanations were given, like (10-47) "he looks at what I do" or (10-26) "he is following different professionals". Occasionally my
presence was addressed somewhat ironically.

(10-49)

**Physician 1** *(pointing with her hand at me):* "Meet my shadow, he'll be yours on Friday."

**Physician 2** *(smiles):* "I know."

Both physicians knew me and had been introduced to my work. The humour helped to overcome the slight awkwardness of the situation in which a stranger was present during a personal talk.

In one situation the physician I followed asked me to stay outside during a conversation with another physician in which they were dealing with financial matters and salaries. At that point she also made a remark which indicated that I should not be around during the afternoon. This left me waiting in limbo and showed me again the lack of self determination I had as an observer. However, when she returned to her office she told me that a physician was visiting and that "I was welcome to be there" (10-57). This example also points to the fact that some physicians wanted to be helpful for my work and asked me if they should show me special cases and, on the other hand, they told me not to come to business meetings because they felt they were boring.
6.6. THERAPISTS

There are two different therapists involved with the children who have cancer. They are Occupational Therapists and Physiotherapists. Although the whole setting is aimed at providing therapy for sick children, they are the only staff members who actually have "Therapist" on their nametags. Most of the members of these two departments shared the same office space.

When the observations took place, the head of the department of physiotherapy was chairing both departments while the head of the occupational therapy department was on vacation. All members of both departments were female. Despite several commonalities their respective outlook was somewhat different and the observations are reported in two separate accounts.

6.6.1. Occupational Therapist

The occupational therapist worked basically in the special care nursery and on the ward with children who had cancer. Occasionally she went to other wards in order to do an assessment of a child.

6.6.1.1. Aims

The occupational therapists stimulate movements and social and feeding skills. In the special care nursery she tried to stimulate the sucking reflexes of the premature babies. She organized and experimented with special nipples which she would then give to the nurses so that they could use them to feed the baby.

If the baby showed difficulty with movements or had joint problems she would also construct a splint. In many cases the occupational therapist will do a developmental follow up. She may phone different professionals where the child in
6.6.1.2. Information

The occupational therapist retrieved most of her information from children's hospital charts. She also participated in several rounds of the wards where she worked. With respect to children with cancer she participated in the social rounds\(^7\) of their ward.

Some chats with parents or with other staff, particularly the child life or the Social Worker, provided also some background information. However these interactions depend on the personal relationships of those staff members. On one ward she would have intense communication with a Social Worker, on the ward where children with cancer were located there were hardly any interaction between Social Worker and occupational therapist.

Before she went to see children she usually tried to read the hospital chart. In some cases she was asked to make a developmental assessment which was usually done by referral from a physician in the hospital.

6.6.1.3. Occupational Therapist and Children

The occupational therapist sees several children on different wards. She usually spent the mornings in the special care nursery where she tried to stimulate babies who are mostly lying in incubators. Some babies pulled back their legs when she touched them. One could see that the tiny feet were sometimes blue from the many bloodtests they received. The occupational therapist was aware of that and commented (8-45), "She is thinking I take another blood test".

\(^7\) Examples of communication in social rounds are given in subchapter "6.2.5. Information".
In the Special Care Nursery

We enter a room with bright neon light. Tiny babies are lying in incubators, a few in an open plastic bowl. Some have legs which are about the same size of my fingers. Monitors, which are attached to some babies, are frequently beeping. From time to time there is a louder sounding alarm beep. The nurses hardly seem to notice it. Only if it beeps a little longer they proceed to the baby to see what is happening. In the background one can hear music from a radio.

One nurse talks about some children in past, "she crushed", and present, "she will not make it". There are smile stickers on some incubators. The Occupational therapist comments that children like black and white at this age. She says, "This is nothing against ICU. It's crowded and alarms are constantly going off and then when they have to switch off the oxygen..." She proceeds quietly.

====================================================================
On several occasions she took the baby out of the incubator after she checked with the nurses. She tried to interact with the baby (8-26), "Do you want to see the real world?" When she had the baby on her arm she commented, "Mother doesn’t come in, now I am his pseudo mother". Although she provides some human contact for the baby her general attitude remained professional. She said while she was holding one baby on her lap (8-11), "This is a nice position because when you talk to them they start working on their head". This interaction reveals her goal of stimulation.

When children were asleep she usually respected that and did not disturb them. However, she seemed pleased when babies in the special care nursery were awake when she came in (8-47), "I can’t believe he is awake for me the second day". In this statement she used a language which was quite common in the hospital which implies that the child is actually doing something for the professional, e.g. "..awake for me..".

For older children she also seemed to be a source of information. In one instance she explained the differences between registered and practical nurse to a teenage boy. Children generally seemed to perceive her presence as being unthreatening. They greeted her for example while she was passing by the play area.

The orientation of the occupational therapist on the interactions of children also influences her attitude. She said that she liked children who smile and others "are a real challenge" (8-5). She also made an effort to visit at children’s feeding times in order to be able to do something with the children.
6.6.1.4. Occupational Therapist and Parents

The occupational therapist usually introduced herself to the parents before she began to do anything with the child. Usually she also explained what she intended to do with the child and asked the parents if it was alright to do it. In general parents seemed to be supportive of her work, e.g. (8-28) when the occupational therapist introduced herself to one mother for the first time she said that she intended to play with her son and wanted to get him to move around a bit in the gym. The mother found this good and turned to her child whom she encouraged to do something with the occupational therapist. Parents may perceive the activities of the occupational therapist as some relief for themselves, somewhat like the child life worker, but in addition there maybe the notion of therapeutic benefits.

Sometimes the occupational therapist establishes a communicative relationship with parents. This seems to be depending on the personalities involved. Parents may chat with the occupational therapist and share background information about their family lives, e.g. (8-21) one mother told about her struggle for mutual independence with her teenage son, who had arguments with her but called home frequently when he went to school or some other place, "You know you are sick of me and I am sick of you so don't call, I won't be home".

The occupational therapist also talked to parents when their child had difficulties with movements and suggested supportive activities. She also produced splints and explained their function to the child's parents.
6.6.1.5. Relationship with other Staff

There were frequent interactions between occupational and physio therapists, because they shared the same office space. There were conversations when they met and information about children were also passed on. In their work there were also some overlapping areas especially in the support of children's movements.

The occupational therapist also exchanged information and hints with the child life worker. They were both concerned about the social development of a child and their professional goals are very close. Child life workers had once been part of the occupational therapy department.

The relationship with nurses differed between the various wards. In the special care nursery the occupational therapist asked the nurses if she could do certain things with a baby, e.g. take her out of the incubator. The nurses in the special care nursery seemed to have developed a somewhat sarcastic attitude as part of a coping mechanism. Most of the premature babies are supervised by machines which frequently beep. However, the sound of the alarms does not trigger any dramatic reactions, for example (8-9) one nurse walked over to a baby's incubator where an alarm was sounding and commented calmly, "That's the one when they stop breathing". Death was a frequent fact on this ward and the nurses commented openly about their patients, e.g. (8-7) "she crushed", "she will not make it". The occupational therapist acknowledged the difficulties of the nurses' work on this ward and commented herself, "they had a difficult week".

Since there are so many different employees in the hospital it is almost impossible to know everyone. It also seems that the knowledge of other persons is even further restricted with respect to professions other than one's own. One
nurse in the special care nursery asked the Occupational Therapist who she was. She responded (8-44), "I am the OT, remember?" She then commented, "She has only known me for two years". It seems that sometimes there is too much information which can be perceived and only if there are quieter moments a person is able to look at some areas which have so far been neglected, e.g. getting to know who this person is who comes in every day and plays with the children.

There were also things the occupational therapist taught the nurses. When she had found out which nipple was best for a specific baby she gave it to the nurse and showed her how to position the baby. She also encouraged nurses to interact with the babies (8-46), "you should play with him, he is really social". She always inquired before she did something with a child which could be perceived as interference with a nurse’s work, e.g. (8-8) in the special care nursery the occupational therapist pointed with her head at a crying baby and said to a nurse, "Do you mind if I settle her?" and the nurse responded "Do we ever mind?"

On the ward where children with cancer were located there was less interaction between nurses and occupational therapist. The different professionals seemed to go their own ways. The occupational therapist seemed to come as a visitor who did her things with individual children in their rooms or at gyms which were in a different location.

She wore a gown while she was working with babies in the special care nursery which covered her nametag.
6.6.1.6. The Perspective of the Occupational Therapist

The occupational therapist seems to be concerned not only with the immediate situation but also has a more longterm perspective with respect to possible developmental problems. During the observations she mentioned concern about the risk of developmental problems on several occasions. Her perspective is very much related to the child life worker's although she does not see children as much on a continuous basis.

In her work in the special care nursery she showed that she wanted to be helpful, e.g. (8-8) "I can't listen to a crying baby, I feel so guilty that I am not doing anything". In another situation a baby had a seizure while she was examining him while the father was present. She said (8-54), "it makes me feel so guilty, as if I have caused her seizure". The father comforted her, "no, no". They had just talked about the frequent seizures of the baby before.

The occupational therapist shares to some extent the outlook of the child life worker, which is to be concerned about children as social individuals. When parents did not visit very often she regarded herself as a mother substitute, e.g. (8-27) "I am his pseudo mother". However, despite her empathy for feelings of the children, e.g. (8-8) "I can't listen to a crying baby", she concentrated on her professional goals of stimulation.

The language occasionally reflected a sense of belonging to a professional group. The occupational therapist commented on a baby's hat (8-48), "With this one you don't know if it's ours or if its from them". Ours refers to the hospital environment and them to the parents. This attitude is not specific for the occupational therapists, but it seems to be a general attitude of hospital staff.

\[7\] See also the use of "we" and "they" in interactions of nurses in subchapter "6.3.4. Nurses’ Position in the Hospital".
The difference in attitudes between professionals can be shown in comparison of occupational therapist and nurses. The occupational therapist hesitated to disturb children when they were asleep. In the special care nursery one nurse told her to play with children anytime despite the fact that they were asleep.

The occupational therapist also emphasized problems of parents. She commented about a family who she said had problems, because nobody communicated properly with them.

6.6.1.7. Observing the Occupational Therapist

When I had been on the ward I had seen the Occupational Therapist occasionally and talked with her about my work. I told her that I would be interested in following her and while I was observing the Child Life Worker I asked her if I could do it in the following week. She seemed interested in my study and did not have any objections.

On the first day of the observations she introduced me to the head of the Physiotherapy department who was filling in for the head of the Occupational therapy department. She also showed her interest in my study and had no objections.

When I followed her into the different wards she introduced me briefly, "He is with me". When physicians and nurses got together for a round in the special care nursery she said (8-6), "He is not a parent, he is with me". This seemed to clear the way. She then explained to me, "They usually kick out parents when they make rounds".

While she was working she explained what she was doing. On the one
hand I found this helpful, but on the other I did not want to be a burden and make her feel that she had to give reasons for everything she was doing. When we were walking down a hallway I told her, "I appreciate your explanations, but you don't have to say anything to me". My intention was to open the way for her usual day to day activities and that she did not have to bother much what I was doing. Later on during the same day she picked this up during a meeting and she she told her colleagues, "don't explain to him, just go ahead".

She sometimes explained what she was doing, especially when she was doing work on her desk. She told me that she was preparing herself for the next child or she commented (8-1), "It will be rather boring for the next half hour". During her actual activities I had little involvement. I once helped to hold the lid of a baby's incubator while she took the baby out.

My notebook and my writing raised some attention. Sometimes explanatory comments were made for me. For example when two occupational therapists were discussing the issue of new uniforms the one I was observing said, "This is an emotional issue" (8-14). The other Occupational Therapist then asked, "I wonder what you are writing". The first one replied, "I don't want to know what he is writing". In another situation she said to me while she was talking to a colleague about her work, "You can write that down in your little book". My writing activity was obvious and raised some attention, but it did not seem to be perceived as very threatening.

Sometimes she also tried to take advantage of my notetaking and asked how much time she had spent with one patient. She also asked me occasionally questions of information like (8-22), "Is that the nurse?"

She was aware of my presence and maybe due to the interactive
characteristics of her job she also talked and made comments to me. Initially she was also concerned about my wellbeing in the hospital. When we entered the special care nursery for the first time she told me where I could find cold water in case I felt sick (8-5). She said that many people were irritated because there were so many machines, but "this is nothing against ICU", which she showed me. This indicated that she had become used to the presence of the machinery, but that she was nevertheless aware of it. The interaction on her part seemed to come normally and I did not have the impression that she went out of her way to do something especially for me.

6.6.2. Physiotherapist

The Physiotherapist also worked in different areas of the hospital. The therapist who worked with children who had cancer also treated children with Cystic Fibrosis in addition to some others on various wards.

6.6.2.1. Aims

The Physiotherapist looked after the movements of children and also implemented a special massage for children with cystic fibrosis. She also applied suction to clear the breathing paths. Her aims are very task oriented and she implemented her therapy according to her timetable rather than to the timetable of children's activities. When children were asleep she frequently woke them up in order to perform her therapy.
6.6.2.2. Information

The Physiotherapist received her main information from the hospital charts of children. They were referred to her by physicians. She also took parts in some rounds of different wards, e.g. the social rounds on the Oncology ward. She kept her own notebook in which she organized her appointments and where she put down notes after she had completed her treatment with a child.

During the weekly staff meetings discussions focussed on organizational matters concerning the department. At the time of the observations there was a long discussion about the dress code and which uniforms should be adopted.

6.6.2.3. Physiotherapist and Children

The Physiotherapist works with children in their rooms or in a gym. She uses playful activities to teach children who have had an amputation to use different muscles for their movements. For example she used a mixture of play and exercises with two babies who had lost one leg due to cancer. She told them how to move around with their artificial legs (8-60), "you didn’t know you had all these muscles before".

Some children do not like doing exercises, especially if they do not feel well. They showed their reluctance and sometimes even resisted the exercises of the Physiotherapist. For example one eight year old girl showed considerable reluctance to movements the Physiotherapist imposed.

(8-66)

Physiotherapist (after she finished exercises): "Tomorrow you’ll get up!"

Nancy: "I don’t want to!"

Physiotherapist: "Sometimes you have to do things you don’t want
(She leaves.)

This probably reflects somewhat the attitude of the Physiotherapist toward children. Children have to do certain things if they like it or not.

In some cases the Physiotherapist commented that she did not like the activities she had to do. When she prepared tubes to suck mucus from a baby's throat she said (8-58), "He hates this. (pause) I don't like doing it because everytime he gets more inflammation of the throat". She was aware of he child's feelings toward her activity and had some apprehensions herself. However, she did not give in to those considerations and proceeded with her therapy.

Older children occasionally asked her questions and received some information for their concerns.

(7-71)

Nancy (pointing at a tube which comes out of her nose): "What's this green stuff?"

Physiotherapist: "That's what's in your stomach when you are not eating. There is something we call acid in your stomach."

The interactions focus on immediate things. The physical closeness of child and Physiotherapist also leads to questions of the personal appearance. For example one child showed interest into a button the Physiotherapist was wearing.

The Physiotherapist also used toys to get a child to move. However, especially younger children resist those efforts. One two year old boy cried when he saw the Physiotherapist and refused to touch any toys she offered. He did not want to use his legs to walk and she made several efforts to get him to take a few steps. After being involved in playful activities with the child life worker for some time the same boy walked from the play area to his room on
the hand of the child life worker without complaining very much.

6.6.2.4. Physiotherapist and Parents

The Physiotherapist passed on many pieces of practical information for the parents. Especially during her consultations with respect to cystic fibrosis children she showed how to manage the massages and how to position the child. She encouraged mothers to do it hard in order to get rid of the excessive mucus and commented later (8-73), "Some mothers don't do it hard enough, they are afraid to hurt their child". When one mother told her that the grandparents were also interested in doing the massages and that she wanted to teach them next week, the Physiotherapist said (8-74), "That's good. We had grandparents who couldn't stand it. They left the room. They thought that their grandchild was beaten up".

Occasionally a conversation developed between parents and the Physiotherapist while she was applying massages to the child. They seemed to have a fairly casual format. In some cases they were also referring to therapy and parents consulted the therapist if they should buy certain things for their child, i.e. a trampoline or a vibrator for the massages. Those conversations did not seem to be very involved from either side. When one mother met the Physiotherapist in the hallway and asked how her son was looking today, she replied "great" which seemed to have the same expression as if one responds with "fine" to the phrase "how are you" in daily conversations.

Parents usually tried to make things convenient for the Physiotherapist and offered for example to postpone feeding in order to facilitate her timing.
6.6.2.5. Relationship to other Staff

The Physiotherapist did not seem to have any particularly close ties with any other professional group in the hospital. Physicians came and interrupted her activities with a child without making an effort to ask. They refer patients to her as support services, but the terms of the hierarchy are made clear with such situations.

There was some cooperation with nurses. For example one nurse helped the Physiotherapist to suck mucus from a child (8-58). In another situation a nurse, who had a crying baby on her lap, welcomed the Physiotherapist as a help to calm the child.

There are occasional conversations with other staff members which mostly seem to happen when the Physiotherapist is looking at a chart at the nursing station of a ward. Those conversation involved the residents, nurses, the unit clerk and the dietitian. Usually those conversations are of a casual nature, but sometimes there are also references to patients and their wellbeing.

6.6.2.6. The Perspective of the Physiotherapist

The Physiotherapists work mostly on an individual basis in different parts of the hospital. They do not seem to have any particularly close link with any other staff of the hospital apart from working relationship with some physicians nurses. They have some links with the occupational therapy department because they share some office and treatment space.

Physiotherapists apply treatments to many patients. They know about children's prognosis, but this is put aside so it does not interfere with their work. One Physiotherapist commented about a baby (8-73), "she is so cute, I
don't wanna think what's going to happen with her".

The interactions with children depend on the respective personalities. I observed that one Physiotherapist continued mechanically with her treatment while the child was crying and another talked to the same boy and actually calmed him down.

Sarcasm is occasionally used as a way of coping with the workload. One Physiotherapist for example came into the office after they had a discussion about their workload and proclaimed (9-6), "Good news, another patient with CF".

6.6.2.7. Observing the Physiotherapist
Initially she commented on her work and suggested that some parts may be boring or that she did not do enough in Oncology. I explained my study and stressed that I did not want to interfere with her work and that she should do whatever she had to do without considering me. In the morning of the second day of my observations of her work, she told me that she would be doing the same as yesterday (8-69), "You must be bored".

When I wrote in situations between the different treatments, when I had the time to empty my memory, she asked at one point (8-66), "You are not making a motion study, don't you". This seemed to reflect the concern which I had encountered with other staff members as well, that I was doing something else than I had told them or that I was involved in some sort of control and evaluation scheme.

She introduced me to parents very briefly, e.g. (8-65) "He is just

\*\* Cystic Fibrosis
following me, so don't worry about him" or she just said (8-72), "He is with me". Most parents accepted this initially, but if I spent more time with them they became more curious and asked what I was doing. I told them about my research project and they usually showed some interest. One mother said (8-64), "You should do a study on cystic fibrosis". Her baby son suffered from the symptoms of this disease.

Generally the pattern of introduction was similar to many other situations in the hospital. At first I was relatively ignored. Then my presence became more obvious over some time and finally questions were asked about what I was doing. Then there was a moment of conversation and interest which again faded into the background the more time I stayed in this situation. This pattern could also be observed with respect to one resident physician who worked on the ward where some children with cystic fibrosis were treated. At first the Physiotherapist explained briefly my study which seemed to satisfy him at first. After he had seen me a couple of times he inquired how my study was going and asked for some more details. He said to me while I stood at the nurses station and wrote into my notebook (9-5), "Uh, our spy is back; what are you actually looking for?" This initiated a conversation about my study.

The Physiotherapist talked less to me than the occupational therapist had done. Only occasionally she mentioned what she was about to do, e.g. (9-1) "We are going to see Jim first, you know the LP guy". Her identification of a particular child related to the medical treatment in a similar way that nurses used to identify individual patients.

As a conclusion we talked about the impact of my observations on her work and she noted that her work had been the same as usual. With respect to
my presence she said that I could talk more since I was in the situation anyway (9-6).

6.6.3. The Perspectives of Therapists

Physio and occupational therapist work to some extent together, especially since they share the same workspace, but their outlooks are different and reflect partially the differences of professionals in the hospital setting between a more therapy oriented perspective versus a more person oriented framework. This becomes more evident in their daily work when the occupational therapist waits when a child is asleep, but the Physiotherapist interrupts the sleep and proceeds with her treatment.
6.7. SOCIAL WORKERS

The observations of the Social Workers took place at the end of the field work, after the observations of children. During the observations of the other staff members the Social Workers had been in transition and a new one was just beginning her job. Therefore the observations were postponed until a later date. However, during the actual observations it turned out again that there was some sort of transition because one of the two Social Workers had just left and one had to do additional tasks which included some rearranging and interviewing of new candidates for the job.

6.7.1. Aims

During the observations it turned out that there had been some overlap between the work of the nurse clinician and that of the Social Worker. Meetings were held to clarify the range of each other's work and in this process in which the heads of the respective departments as well as the head of oncology participated, the aims of those two professions in the hospital were clarified. Those aims were presented in a draft format and served as a thought provoking and clarifying process. The timing of involvement was also mentioned.

(12-14)

The Social Worker sees parents initially within the first two days of their child's hospitalization and makes a short assessment if there are major problems. These first visits last between five and ten minutes and they take place before or shortly after the diagnosis. In particular the Social Worker makes a gross level assessment if there are
• any outstanding issues,
• a family crisis,
• financial needs,
• accommodation needs.

The Social Worker also looks at the emotional response and at the resources which are available for the family.
The initial visit is used to explain the Social Worker's role to the family and to provide a listening ear. Generally the Social Worker aims at practical intervention and uses a systems approach.

The final assessment period which happens during the next two weeks consists of daily visits to quickly check the situation and a formal interview which is arranged. The Social Worker looks at the
- employment status and available resources,
- functioning of the family system,
- stress patterns,
- learning styles and support.

The Social Worker looks also at the feelings which come up and makes a plan and intervenes based on the assessment. Appropriate reading materials are handed out to parents and resources and support groups are explained. A written report is compiled.

It is interesting to compare at this point some of the steps which nurse clinicians are undertaking with the parents. They also are statements which were drafted at the same meeting.

(12-14)

The nurse clinician sees every family. Prior to diagnosis only an introduction will take place. Generally the nurse clinician
- offers support,
- explains tests and procedures and answers questions,
- provides an orientation to the system.

The support of nurse clinicians includes total nursing care needs. This addresses the
- knowledge level,
- physical care needs,
- parental needs, including educational needs,
- siblings educational needs.

The evolved assessment is based on family needs. The nurse clinician is also supportive with respect to the expression of feelings.

Social Worker and nurse clinician look at the family from different perspectives. The Social Worker looks more at the family system whereas the nurse clinician is also concerned with the medical aspects of care and the information about the proceedings in particular. However, there is considerable room for an overlap of
activities with respect to the support given regarding feelings and coping. This was one reason why those meetings between nurse clinicians and Social Workers were held. Both have the whole family in their focus and the nurse clinicians pointed out that (12-15) "with educational needs come support needs right along". The physician who was present at the meeting found it difficult (12-15) "to mess around with the family when the child is in need". As one difference it was pointed out that nurse clinicians got many questions from the parents concerning the medical treatment which the social workers did not get.

6.7.2. Information

The Social Worker retrieved most of her initial information from the hospital charts which she usually consulted before visiting parents or child. The charts were also used as an ongoing source of information about the treatment and progress of a child. The list of patients at the nursing station and listening to the nurses' talk informed her about new patients on the ward.

The Social Worker took part in the weekly case rounds, in which the physicians reviewed all patients on the ward, and in the weekly social rounds, during which the head or charge nurse talked with the child life worker, therapists, teachers about the individual children. In addition she went to the presentation rounds in which residents presented specific cases which were then discussed by various physicians who made recommendations for treatment. However, these rounds dealt only with the medical aspects of the illness.

Social Workers frequently exchanged information about cases and their experiences. This happened either in their offices or when they sat together during coffee or lunch breaks. Some information was obtained during
conversations with other staff, mainly nurses and physicians. Occasionally the Social Worker wrote something into the nurses’ communication book which she seemed to check regularly, e.g. about the organization of a summer camp for children with cancer.

The telephone was also an important tool to retrieve information from parents or institutions in addition to being a tool to implement their work, e.g. organizing support for parents from the Cancer Society. Phone calls from and to individual parents served as means to continue the relationship.

6.7.3. Social Worker and Parents

Parents are in the focus of the Social Workers activities. Conversations occur in the respective patient rooms or in the hallway or in the Social Workers office. Mostly those conversations are chats about daily things which eventually turn toward the situation of the child and/or the parents. In bits and pieces the Social Worker can assemble some background information about a particular family from the different interactions.

The relationship between Social Worker and parents is very different from case to case. Some parents speak frequently to the Social Worker and others avoid the contact because they are afraid that they are being checked out. Before the Social Worker talks to the parents and introduces herself she usually looks at the chart and gathers some information about the family background. This information may also be provided through rounds or through talks with other staff members. However, the hospital chart seems to be the most frequently used source of information at this point. One example may illustrate some of the problems which surface through various sources of information.
initially.

(13-25ff)

The Social Worker enters a patient's room in which nurses are in the process of transferring a teenage boy from the bed to a wheelchair. One nurse points out to the mother that she could go with him to X-ray if she wanted. However, the mother just observes the activities. After the boy has been wheeled out of the room the Social Worker introduces herself to the mother, who shrugs her shoulders and indicates that she does not understand English.

The Social Worker goes to the nursing station where she meets the resident who gives her some information about the family.

Physician (about the father): "That thing caved in on him. He doesn't want to tell his wife nor his family or his son. He wants to know the prognosis, but I can't tell him."

Social Worker (referring to his job): "He might leave his wife here who speaks no English. Mother seems down."

Physician: "They're not stupid. They got transferred from St. Juno to Georgia Town then to Villa City, it's gotta sink in. But dad wants to handle everything himself, what can I tell you."

They continue to talk about some other new patients who arrived on the ward.

The Social Worker walks around and finds the father sitting on a chair in front of the elevators.

Social Worker: "I am Linda Gambit the Social Worker. I talked to Mary the other Social Worker and she told me that you might need a place to stay. There is a possibility in Heather House."

Father: "Is there a more private place?"

The Social Worker shows him the way to her office where they sit down.

The father says that he cannot decide today and that he will stay with a friend tonight. He wants to make a decision tomorrow. The Social Worker tells him that the accommodation at Heather House would cost $25 and the father says that he doesn't know how long he would stay and that he would rent a basement if they would have to stay longer.

Social Worker: "There are possibilities, there are organizations who
can pay for that. I understand it is not easy to ask for money, but most people have not saved for that. ... The cancer society can pay a part."

Father: "Can we talk about that tomorrow?"

Social Worker: "I understand that it is difficult for you at the moment, but it will get better."

The father mentions that he has heard that there was also a possibility to pay for his flights and the Social Worker says that the Cancer Society may pay part of that. Father talks with a pressed voice and it looks sometimes as if he would begin to cry.

Father (after a moment of silence): "Is there anything else?"

Social Worker: "What did the doctor say?"

Father: "I talked to him. There will be more tests and they will know for sure tomorrow, but don’t talk to my wife about it yet." (He pauses and then talks about his son) "He always looked up to his father, whatever I did. He wanted to be with me not his mother, not that he doesn’t like his mother ..." He tells that he started weightlifting for his figure and that his son joined him, that everything was going well and now this disease ..."

"He has always been a good boy. There were no problems. He took care of the other children and the house when I had to go away." The father then talks about his job in a lumber mill and that he wants to talk to his union if a transfer is to Vancouver is possible. He asks the Social Worker if she could do anything. The Social Worker offers to write a letter ... but employers have been good when children are sick". She mentions the Ronald McDonald house as a possible accommodation "... for parents with children with life threatening illnesses".

Father pauses and asks again "Is there anything else?"

Social Worker: "I’ll be here tomorrow in my office. Then we can talk about it."

Father leaves the office.

A little while later the resident returns with the father, "Could you explain him, he thinks that he has to pay the Cancer Society? I told him that the Cancer Society pays Heather House, how much is it?"

The Social Worker explains that the Cancer Society pays most of the accommodation and he would have to pay $5. She suggested to talk about it the next day.
This example shows several levels of support which the Social Worker can offer. There is the availability of concrete and practical help as well as some emotional support - a listening ear. However handicaps for communication become also evident. The distressed father tries to come to terms with the illness of his son and at the same time keeps everything to himself. He makes an effort to protect his family from the information he has. In addition there is a language barrier since the mother does not seem to talk English. At the moment the father is not able to handle much information. Even the information about payments for accommodation has not been fully understood.\(^7\)\(^5\) The next day may already show more of a direction in which things will go. Therefore further conversation is postponed initiated by the wish of the father who himself seems to perceive the difficulty of his emotional situation. The Social Worker was aware of the problem of information and she commented at one point (14-3)

"Sometimes you give them information about financial assistance and you find out a couple of weeks later that they missed the whole thing, even if you gave them the forms."

Many initial contacts between Social Worker and parents just involve an introduction of the Social Worker and some clarification of immediate problems, e.g. accommodation. The Social Worker seemed to be very cautious in the initial approaches toward parents.

Most of the following interactions were fairly casual conversations about daily matters which at some point involve some details about the daily life in the hospital and how things are going. The Social Worker answered some

\(^7\)\(^5\) This example also shows the potential for misunderstanding when a person is trying to cope with emotions while at the same time a great deal of information about the illness has to be digested.
questions about how things work on the ward and which facilities are available. She also listened to problems which parents mentioned, e.g. (12-33) that a child spit out the medication and "wasn't very impressed", or (13-8) that a father only found out when he arrived that his daughter had been scheduled for a treatment, etc. She frequently made offers to talk and that parents should see her in the office whenever they wished to do so.

Once the Social Worker knew more about the parents she addressed them more directly.

(12-32)

The Social Worker enters a room and greets a mother who plays cards with her teenage son, "you seem to be in good spirits". There is a short conversation about the game.

Social Worker: "So is it still discouraging for you?"

Mother: "He had an IV on Saturday to get hydrated. I think they want to redo the bone marrow test. I don't like the idea of a bone marrow, but it's the only way they can see what's going on. At least it's no malignant thing but they have to look further."

Social Worker: "Yeah..."

Many parents, like this mother, told their concerns once they had gotten to know the Social Worker. In most cases the Social Worker made statements of a general nature or related to experiences of other parents and children, e.g. to a mother who was quite anxious about the care of her daughters Hickman line which she had to implement (14-21), "It sounds like a lot, but all parents seem to manage".

In some problematic cases the Social Worker kept regular contact with parents, but was basically listening during the interactions. For example one couple, whose son had a relapse and was not doing very well, were very angry
and disappointed with their physician. They had wanted to do everything possible and they claimed that the physician had given up too early and not even kept some of the promises he had made, e.g. looking intensely for a suitable donor of bone marrow.

(13-37ff)

Social Worker (looking at the child): "He looks better."

Father: "Do you think so?"

Social Worker: "He seems to be more active."

Father: "He complains more too."

Social Worker: "How are you?"

Father: "We are waiting for a miracle."

Social Worker: "Waiting for a miracle can be hard."

The father tells that they had discovered an enlarged liver on Saturday and that nothing had been done until he grabbed a doctor on Monday. He continues to say that they are using the last drug they have and "my doctor said that from his twelve years experience the only chance is transplant, but they haven't found a donor yet". He states that the doctor had promised to look for an oriental donor - other bone marrow would not be compatible - but he had not written the letter he had promised to write two months ago because he was too busy. "Now we're running out of time."

The Social Worker listens, makes some emphatic comments, "it's so hard ..." or tries to clarify, "you would still try, even if the doctor would not recommend it" (the father replies "yes").

The father continues to talk about the rareness of the disease and that he would sacrifice all his savings if necessary, but that in the situation he was not even able to do that. He mentions several other places who had done successful bone marrow transplants in similar cases and then focuses again on his doctor, "for him it's just a case". (Social Worker: "but for you it's your boy", father: "yeah")

The father also says that he wanted to change doctors but that other doctors were busy and they did not want to do that because everyone could do that, "it's politics", but there was no point quarreling.
The Social Worker continue to listen and make some general emphatic statements, e.g. "you feel angry". In the end she inquires:

"Does it make you feel better to talk about it?"

Father (hesitates): "Yes."

Social Worker: "I'll be around."

The whole conversation lasted about forty minutes. The father gave an account of his anger and his concerns and vented some of his frustrations. The Social Worker did nothing to relieve his tension and indicated understanding in general terms. Emotional issues were addressed quite vaguely and other problems with the proceeding were not reflected at all. It seemed as if the Social Worker did not want to get involved too much.

The Social Worker assumed a somewhat low key role and offered some logistic and emotional support for parents. However, the emotional support seemed to consist mainly of an opportunity to dump frustrations and emotions rather than a counselling approach which would make an effort to enhance parents' own abilities to cope.

6.7.4. Social Worker and Children

The contact between Social Worker and children seemed to be fairly low key. Children were sometimes addressed as an introduction to a conversation with parents. But those were mainly comments about children like, "you are looking better".

Most younger children were addressed in passing in the hallway or when she looked into a room.
Social Worker (addressing a girl on the hallway): "Hi, have you been out at the weekend?"

The girl nods.

Social Worker: "What did you do?"

Girl: "Nothing."

Social Worker: "Are you feeling any better?"

Girl: "No."

Social Worker: "Okay." She turns to the girl's doll and comments about her new outfit.

The girl was not very talkative with the Social Worker who did not dig very deeply into anything. On the other hand there seemed to be little communication with younger children (less than ten years of age) on a deeper level.

Some more communication existed with teenage children. The Social Worker visited some regularly and commented that one teenage girl had done a lot of dumping with her. Some other conversations took place in the hallway and they usually dealt with how they were doing currently.

(14-2)

Social Worker: "Hi, how was it this time?"

Norman: "Worst, I threw up thirtyfive times."

Social Worker: "Did you count?"

Norman: "My mother counted but she lost track after thirtyfive times."

Social Worker: "Humm, it's not getting better."

Norman: "No."

Social Worker: "You’re looking well. Are you going home today?"

Norman: "Yes."
This was a somewhat typical conversation in which some general issues were addressed but there was no deeper level of involvement.

6.7.5. Social Worker Relating to other Staff

The Social Workers are hierarchically dependent on their own department in the hospital system. They are peripheral to the medical system, however, they take care of 'other problems' and thus facilitate the treatment. There are no close links to any particular group in the hospital. During breaks Social Workers usually sit together as a group and do not mix very much with other staff.

Social Workers seem to interact with physicians only when some information about a particular family is being passed on or with respect to organizational matters. During rounds the Social Worker seems to be more a listener while the physicians discuss and determine the treatment. There seems to be somewhat more interaction in the social rounds in which the physicians do not take part.\(^7^6\)

The communications between Social Worker and physician seemed to be concerned mainly with organizational matters. This may have been influenced in part by the fact that new social workers were interviewed for a vacant position on the ward. The head of oncology took part in those meetings which had to be scheduled and preplanned. Only in one case the resident gave the Social Worker some background information about a particular family which had just come to the ward. In another interaction a resident guided a father back to the Social Worker and asked that something the father had apparently misunderstood be explained again. When the Social Worker was talking to the parents, physicians

\(^7^6\) I had the impression that the staff members in this round considered themselves more as peers within the hospital hierarchy.
occasionally came in and interrupted the conversation without addressing the Social Worker, who in turn was ignored by parents during their interaction with the physician. The last example highlights that physicians usually have priority in interactions and other professionals often become bystanders.

The most intense interaction between Social Worker and nurses happened during meetings which were set up to clarify the roles between Social Worker and nurse clinician. In some other situation Social Worker and nurse clinician exchanged information about particular families in a casual way. The other nurses seemed to interact little with the Social Worker apart from some chats at the nursing station. Nurses also came into the room and implemented their care for children without much consideration for the interactions between Social Worker and parents.

The Social Worker had been contacted by the Cancer Society about a summer camp for children with cancer. She inquired if nurses were willing to attend this camp and provide care for the children. Several nurses were very interested and this initiated some interactions between nurses and Social Worker who also wrote a notice into the nurses’ communication book.

Communication with other staff seemed to be of a fairly casual nature when they happened to meet at the nursing station, or they were issue oriented when, for example, a walker had been offered the Social Worker asked the Physiotherapist if she was interested. When parents needed more advice the Social Worker also inquired at the appropriate place within the hospital, e.g. regarding parking for parents.

When a child had been on treatment for some time the staff got to know the family quite well and exchanged sometimes the latest news about how they
were doing. In some cases the Social Worker wrote something into the nurses’ communication book, e.g. after she had visited parents whose child had just died. During a conversation at the nursing station the psychologist also asked the Social Worker how a particular family was doing. However, there were no regular communication channels between those two professions.

The Social Worker had some established communication with the volunteers of the red cross parent support program. She advised them who they should see and tried to give their support work some direction. She had a long conversation with the supervisor of this program during which she pointed out which cases should be taken up and why other parents should be left alone. She also highlighted some areas like transportation where the volunteers could provide valuable support.

6.7.6. The Perspective of the Social Worker

The Social Worker seems to be somewhat separated from the medical staff. Although she attended several rounds, even some which dealt with medical information primarily, she did not seem to have much influence on the treatment. The physicians seemed to regard the Social Worker as a relief person who facilitated their work by giving some social support for the family.

Physicians and nurses interrupted the Social Worker when they came into a room and wanted to do something with a child or the parents. However, the Social Worker respected when physicians or nurses were active and was careful not to disturb them. For example the Social Worker waited until rounds were over before she looked into the charts from which she got her information about individual children, (12-3) "they are still in rounds, so I can’t look into the chart
yet". Other physicians and nurses frequently interrupted the rounds in order to get a chart.

The approach of the Social Worker seemed to be very cautious. She was very careful, especially during her initial approaches to parents. She is the member of the staff who has probably most insight for the problems of parents and how individual families cope. However, the Social Workers seem to be bystanders who do not have much impact on the proceedings of the treatment. Although they have an understanding of the different reactions of the family the scope of their support seems to be limited to provide a listening ear and to help with financial matters by establishing contacts with the appropriate organizations.

6.7.7. Observing the Social Worker

It has been mentioned before that the observations of the Social Worker took place at the end of all observations. Since the office of the residents, which I used to store my coat and also occasionally to complete my notes, was adjacent to the Social Workers office, we had often come to talk. A thorough introduction to my research was not necessary any more. This had already been done during our conversations.

Before I began with the actual observations, however, I introduced myself to the head of the social work department in the hospital. After I had explained my study he was very open and expressed that he found it positive that social work would be included. Overall the atmosphere was very supportive and the familiarity with the persons allowed me sometimes more involvement in conversations. Additionally many parents knew me in the meantime and introductions were only necessary for parents who were new on the ward.
Occasionally parents or physicians greeted me in passing which gave my presence more attention. This seemed, however, no complication in this case since the Social Worker and many others had become so used to my presence that I had become a part of the social environment as well. It would have been more awkward if I, a familiar face, would have to be ignored.

The Social Worker usually introduced me to other people by saying, "he is following me". Occasionally this would be put into a context of a study, like (12-25) "He is observing me, he has observed children and parents before", or (13-26) "He is observing me as part of a study, do you mind?" No one voiced any objection to my presence.

Occasionally we talked about my research. The Social Worker I observed was quite aware of my role and my research intentions, since we had talked about it several times before. During our first coffee break she asked (12-7), "Can I talk to you?" to which I responded positively. Occasionally we had conversations at coffee breaks, which the Social Workers shared, about the background of the work and the outlook of various families.

My notebook received some attention, particularly from the other social workers and the social work student who was there part of the time. The notes served as a catalyst to talk more about my research, e.g. (12-23) "What do you do with your notes?" Since we had developed a fairly casual mode of conversation I replied, "I give them to the administration", before I really explained that I would analyze them in order to determine the different perspectives of professionals, children and parents in the hospital setting.

When emotionally intense communications between Social Worker and parents took place and I did not know the parents, then I did not take notes
during the interaction in order to avoid additional stress or a change in attitude for the respective parents. I took some time directly after this conversation to empty my memory and write down everything I had heard. It helped that the Social Worker usually sat down in her office after those conversations to write down some notes herself. This gave me space to do it without interference on other events.

There seemed to be little interference with her work. Only after one interaction with a teenage girl the Social Worker mentioned that she had reacted differently in my presence, that she had already come to her office screaming and that she had done (12-26) "a lot of dumping" with her. However, this teenage girl had seen me before and I had talked to her and her mother from time to time. Her restrained reaction may also have been caused by her mood on that particular day.

At the end of the observations I asked the Social Worker how she found my following her. She said that she was concerned that I may not see a typical week, but that things had worked out quite well. She said (14-34), "It is difficult to see a typical week because weeks are so different. They change more than for example a nurse's week. Sometimes there are many phone calls, sometimes there is more patient contact." I said that the observations had been different with her compared to the other professionals because I knew so many parents already who would involve me into conversations sometimes. I thanked her for giving me the opportunity to observe her work.
6.8. OTHER STAFF

Several other staff members were regularly on the ward or when they were consulted. Their presence was usually related to a specific task. However, they could become an important person for some children or parents although they may not have had much impact with respect to the treatment outcome or the hospital hierarchy. Some were important because of their activities (e.g. technicians) and other were opportunities for alternative interactions.

6.8.1. Technicians

Lab technicians came regularly in the morning to take blood samples from children and they also came when specific tests were ordered. Although their role seemed to be quite limited they could make an impact on the feelings of a child. It depended how they were doing their procedures and what kind of attitude they took. Since they worked in a pediatric setting all day they had some experience how to deal with children. Most of them had fancy band aids with faces or some painted faces on the band aids when they had finished. However, their knowledge of the particular wards and the personalities of the children involved was rather limited. They were her do their job and sometimes they did not give the children very much space to cope with the poke. This in turn did have an effect on how the child would feel that day and how s/he would react to the other staff on the ward.
6.8.2. Housekeeping Personnel

Although the cleaning staff had a limited and somewhat underrepresented role within the hospital setting, they were a regular feature during the day and they had some relieving communications with children or parents. They were not related to any aspects of the treatment. It depended on their personality in how far they would use their role to communicate with children. This also changed daily according to the mood they perceived when they entered a room. Some children had fun with them and played some tricks or made jokes. Their regular presence was also a landmark for the timing of events. One boy noted for example that the man with the vacuum cleaner was there so the quiet after lunch would be over soon.77

6.8.3. Psychologist

The psychologist was called in when staff had problems with the behaviour of a particular child. He served as an emergency relief person for difficult cases and mainly dealt with teenage children.

The other function of the psychologist was a relief person for some staff problems. There were regular support rounds for the nurse which the psychologist chaired. The attendance varied as did the topics of conversation. The activity level and the events on the ward influenced the dynamics of those meetings. However, even during very stressful times on the ward the communication about personal feelings remained very limited.

During the observations there was also a project by a female psychologist

77 This actually seemed to be an organizational oversight, at least it did not make sense that vacuum cleaning of the hallways took place during a quiet rest time for children.
which involved the application and teaching of distraction techniques to alleviate pain during intrusive procedures such as lumbar punctures and bone marrow aspirations. The nursing staff and most parents seemed to be very positive about this undertaking, because it seemed to offer some concrete and helpful activities. However, there were some children who rejected the techniques and their parents then usually became somewhat apprehensive as well.

6.8.4. Dietitian

The dietitian had a fairly unobtrusive role on the ward. However, her services seemed to be appreciated by the parents who regarded this as an additional and mostly unexpected service. The appetite of the children varied greatly during their treatment. This made her role somewhat challenging since food intake remained important. If oral food intake was not sufficient parenteral nutrition would be implemented by a physician who was responsible for this aspect of treatment.

There were also satellite kitchens in the hospital which tried to cater children's special wishes.

6.8.5. Volunteers

There were different groups of volunteers on the ward. One group helped during the daily activities of child life worker and teachers. They also organized the library and made their rounds through the different wards with a cart full of books.

Another group of volunteers was involved in the Red Cross parents' support program. They worked in cooperation with the Social Worker and they

References to their work are made in the chapters "6.2. Hospital Teachers" and "6.4. Child Life".
offered regular coffee rounds for all parents of the hospital. In addition they supplied some transportation and miscellaneous services for families.\textsuperscript{7,9}

Occasionally the Social Worker also organized volunteers for children whose parents were mostly absent. The volunteer then did some recreational things with those children, e.g. playing games or reading a story. Those volunteers were usually active during the late afternoons or during weekends.

Occasionally volunteers were also called "Candy Stripers", because their department had a uniform coat which was striped in candy cane colours.

\textsuperscript{7,9} Some references to their work are made in the chapter "6.7. Social Worker".
6.9. STAFF PERSPECTIVES

There are many professions represented on the ward who interact in different ways with the family and the children. Every one acts within a specific frame of reference and has a particular perspective from which activities are undertaken. Interactions between those professions happen in a casual mode, when different persons meet in the hallway or at the bedside, or in a formal mode during rounds. However, the different professionals seem to have their individual notions about the work of another profession. Their seems to be little knowledge about their actual work and there also is not communication channel set up to for this kind of information. For example one head nurse said that she did not know what the social workers were doing, they would always sit in their offices.

This points out the split which exists between different staff groups, in particular between medical and non-medical staff (s. a. Rosenthal et al., 1980). Within the hospital setting there are two major lines of authority (medical and administrative), and a third supplementary authority (support services).

6.9.1. The Medical Line of Authority

Physicians determine the course of treatment and chose the therapy on the basis of their knowledge of illness and treatment protocols. Nurses, as the largest professional group in the hospital, implement physicians' orders on the basis of their knowledge and experience of care. Both professional groups have their own administrative structures which set policies.

It is interesting to note that with the increase in the hierarchy persons seem to become more remote from the patients. The resident physicians, who
basically run the ward, are responsible for most of the orders. Some of them have actually less experience in the field than nurses, however, they are needed to sign orders and prescriptions. At this level the conflict between different perspectives of the care becomes most apparent. Experienced nurses influence the physicians' decisions, which in turn are frequently predetermined by treatment protocols.

Members of one staff group frequently talk about unsuccessful interactions with members of other staff groups. If problems persist then staff at the lower hierarchy level will involve their own administrative authority, e.g. the head nurse or the director of nursing to influence physicians. Higher level staff will use their authority directly to address problems, e.g. a senior physician may scold nurses, and involve the administrative authority only if it becomes a serious matter of general policies.

6.9.2. The Administrative Line of Authority

There are two lines of administration which have to be considered. One is the general administration which looks after the general organization and manages the financial business. Financial decisions in particular set a framework for care in the setting. Another part of the administration are the professional hierarchies which strive to maintain a certain level of quality of work by adopting professional standards and setting guidelines. They also protect their own professional group regarding organization of work (e.g. hours, funding) and against infringements from other professional groups in the same setting.
6.9.3. Complementary Line of Authority

All non-medical staff maintain their own professional backing and have their own administrative representatives. This group involves a wide range of professionals and it is no wonder that due to their differences in their work (e.g. Social Worker, teacher, housekeeping personnel, child life worker, etc.) which generates somewhat different perspectives and due to their position in the hospital setting as support services which has been attributed with a lower level of importance in the medically oriented setting, they have the least influence in the decision making processes.

6.9.4. Issues

Some issues stand out from the observations of interactions of hospital staff in the context of this study.

The functioning of the hospital system may leave little space for consideration of personal needs of an individual patient. The enhancement of coping processes would require an adaptation to personal needs because different persons react differently toward stressful situations. This requires first an acknowledgement of the personal needs and secondly it requires an adaptation of treatment to the personality involved. This may also enhance the overall chances of a particular child because s/he is enabled to cooperate and mobilize his/her own forces in the fight against the illness. The professionals in the hospital, however, seem to have become parts of a machinery which has become increasingly immobile with respect to individual and personal needs of someone requiring assistance. See in particular the chapter "Nurses".
around its own maintenance. This also means that well meaning persons have little room to manoeuvre because they are trapped in their respective roles.

The decision making processes have become remote from the individual and personal needs of the patient. In fact there seems to be an almost inverse relationship between decision making and knowledge of the personality of the respective patient. The activities in the hospital setting are very much determined by the medical staff and the physicians have a leading position in this respect. However, the time which they spend with children and parents is very limited. Their knowledge about the family and the personalities involved stems from mostly short interactions and the knowledge supplied by other staff. However, it must remain of theoretical nature since the practical experience is limited by a tight timeframe. The school teachers or the child life workers for example, who have little influence on the treatment, spend considerably more time with the children than the physicians. Other staff like the child life workers may gain more experience of the personalities and perspectives of the children simply because they spend more time with them, and also because they have a different professional perspective.\(^1\) However, they remain outsiders in the decision making process.

Despite great personal efforts of staff members there is a lack of a cohesive effort which leads to a compartmentalization of personal needs. It seems that there is a specialist for every problem. This has the advantage that presumably knowledgeable people deal with individual problems. However, it also means the separation of issues which are necessarily connected within the respective person, child or parent. Different professional groups seem to move apart through their

\(^{1}\) Please compare the subchapters "The Perspective of .." of the different professional groups.
Hospital Staff / 241

varying intentions and objectives. Communication between professional groups becomes a major issue which is organizationally addressed by having several meetings (rounds) of various combinations of the people who care for the children. This again means that for example social issues are separated from medical ones and even medical issues themselves are handled in different subcategories. All this puts the onus on child and parents to put everything together into a cohesive effort in order to meet individual needs.

The attitudes of medical staff are determined mainly by their expectations toward the behaviour of children and parents. Especially medical staff act within a very task oriented framework. This means that judgements about other persons are influenced by their the degree of usefulness for the tasks of the respective professional group. Activities and relationships are functional although highly emotional situations are created by illness and treatment. The space for emotional involvement becomes limited.

The scope of interactions may be restricted by the perception of professional usefulness. In order to proceed with one's job in a stressful environment communication becomes functional with respect to a certain professional goal. Utterances are often interpreted in a utilitarian context. During treatment procedures for example emotions become side-effects which are as important as their degree of interference with the operations. This has a distancing effect and may help medical staff to cope with own emotions, but it also stretches the interactive link to patients. Idealized professional goals enable people to inflict

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82 This is addressed in the various subchapters on staff members relating to each other.

83 This is highlighted in the examples given from various staff rounds.

84 See examples in the chapter "Children".
pain for the best of the patient while sometimes the reality of care creates conflict with the ideals which lead to personal withdrawal and burnout.

These issues have to be linked to the perspectives of children and their families, which is done in the following chapters. The interactions of all groups involved in the care of children with cancer generate attitudes and behaviour which are specific for the setting.⁸⁵

⁸⁵ See "The Last Chapter".
7. PARENTS AND FAMILY

7.1. INTRODUCTION

A family is a complex system of social relationships. Attitudes and behaviour are developed within an interactional framework. The structures of families have changed considerably over recent years. Single parent or reconstituted families are numerous while at the same time there are also extended families, which include grandparents and possibly other relatives in their daily lives. A specific cultural background may influence the various roles within the family network.

The families in the hospital reflect the various structures of families which can be found within a society. It was observed, however, that in most cases of hospitalized children the mother became a dominant family figure in their care. This is correlated to the somewhat classical role distributions within a family where mother takes care of household and children and father has a job which provides an income. In cases where both parents were working, it seemed that father and mother each spent about the same amount of time with their child in hospital. Then the amount of their presence seemed to be influenced more by personal dynamics like their emotional state. The parent who seemed to be able to control his/her emotions in the hospital setting or appeared to be outwardly less upset would come more often.

7.1.1. The Case Studies

The parents of children who participated in the four case studies were observed in their interactions while they were staying with their child.\textsuperscript{66} This was

\textsuperscript{66} See also the introduction to the chapter "8. Children".
complimented by interviews and recording of several formal interactions between parents and hospital staff.

The diagrams on the following pages may help to illustrate the structures of the families of the case studies.
Father worked in the family business and there seemed to be a cooperative attitude toward taking care of the children. Father was able to take extended leave of absence from the business while Tony was hospitalized and continued to receive treatment as an outpatient. Support included the extended family. Tony's brother went to his grandparents while both parents stayed at the hospital. Mother was pregnant at the time of diagnosis. The family lived away from the city. Tony responded well to the treatment and was discharged from hospital after three weeks.
Case 2:

Both parents worked and alternatively took care of their children. They lived outside the city and visited the hospital irregularly, however, they tried to be present during phases of intensive treatment. Other family members did not seem to be directly involved. The diagnosis of cancer was made at the hospital while the child had been admitted for another illness. During chemotherapy the child’s situation deteriorated very suddenly and he died on the emergency ward. The parents received considerable support from their community after the death.
Case 3:

The parents had separated before diagnosis and their daughter lived with her father in the city. He came to the hospital daily during her short stay on the ward. Her prospects looked dim even if all medical options would be applied. The parents decided to take her out of hospital and discontinue treatment. Mother arrived from another city later and visited just before they took their daughter home. Other relatives did not seem to be involved.
Case 4:

Both parents worked and lived out of town. They stayed near the hospital for the initial two weeks and then visited their child irregularly, mostly on weekends because they both continued to work. Sisters of the mother came to visit once in a while. The grandparents seemed to be only marginally involved. A friend of the family, who had been working in the hospital, was a more regular visitor. The child stayed in hospital longer than absolutely necessary, because nobody was available to take care of him on an outpatient basis in the city.

The parents split up after the first phase of the treatment. Both children stayed at first with their mother, then they lived with their father.
Three of the families who were case studies for this investigation seem to have a very similar structure on the surface. Two parents took care of their two boys. However, there were differences in the support networks and in the care they were able to give to their children during hospitalization.

7.1.2. Observational Approach

All parents, who participated in the case studies, had to give consent for the observations of themselves and their children. The research project was introduced to the parents who could be considered for the case studies due to their child's age and stage of the illness by the senior physician who was assigned to their case. This usually happened after the diagnosis had been established. The physicians signed a consent form\(^7\) to signal their agreement. Then I introduced myself personally to the parents and gave them a written statement\(^8\) explaining the aims of the research and asking for their cooperation. It was made clear that the study was not involved in any aspects of the medical treatment.

Parents were informed that their consent could be withdrawn temporarily or permanently at any time. Arrangements were made with the parents to ensure that they did not feel bothered by the length of the researcher's presence. I stayed in the background as much as possible to achieve a "wallpaper effect", which means that the researcher became almost part of the physical background. After initial hesitations the observation became part of the daily routine. On several occasions I passively resisted efforts to draw me into a helping network.

\(^7\) See Appendix

\(^8\) See Appendix
which would have influenced coping, communication, or other processes.

When important meetings between parents and staff were set up, I also arranged to take part in them. These sessions involved mainly nurses and/or physicians and parents and dealt with the implications of the treatment.

In addition informal and formal interviews were made with the parents at times which were convenient for them. The category "informal interview" includes all conversations which took place during the observers presence on the ward initiated by himself or by parents. Formal interviews were held upon request of the observer with the parents who were involved in the case studies after the completion of the first treatment phase in the hospital. If possible, these interviews were conducted at the respective family’s home in order to include their perspective within the context of their familiar environment. Three of the four parents participating in the case studies were interviewed during home visits which were tape-recorded, transcribed, and analyzed. A copy of the transcript was made available to the parents for further comments.

The initial contact between observer and parents who were not part of the case studies usually developed in a casual manner. Parents often learned about the research from other parents and became more interested which triggered questions. Some became curious about this person who was taking notes all the time. This initiated many informal conversations and gave me an opportunity to introduce myself.

After an initial contact had been established and parents had been introduced to the research project they were asked if they would like to share their own experiences with the observer who was interested to record their perspective. This lead to several more intensive interviews which lasted between
one and two hours each. Those interviews mainly involved the mothers, because they constituted the prime parental caretaker in most cases. If possible the fathers were also included. While a focus on parents with children who were in the initial phase of the treatment was maintained, experiences of parents whose children were in the final stages of the treatment were also included. In fact three children died shortly after long interviews with their mothers had been conducted.

The sixteen formal interviews involved fifteen different families. Usually they were conducted in a separate room, e.g. residents' office or parents' lounge and involved only mother in nine, father and mother in three, and only father in two instances. One additional interview was made with one mother who wanted to address a matter of her concern in more detail upon her request. Four interviews took place in the child's room. One interview took place at a house where parents, who did not live in the city, were able to stay during their child's illness. Three interviews involved children over ten years of age. The interviews were recorded with the help of a notebook during the conversation. The resulting notes were then reinforced by additional expansions immediately after the session. There were also follow-ups to several interviews when parents told the observer additional experiences.

In addition several meetings of parents were attended with their permission. There was a weekly meeting for parents, which was offered by the Social Workers on the ward. This afternoon meeting was attended by a varying number of parents, but it rarely exceeded a handful. During the study parents organized a self-help group which was part of the Candlelighters.89 Their

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89 The Candlelighters are an organization of parents of children who have cancer, who have parent groups in many North American communities. They also
monthly meetings at the hospital became part of the general observations.

7.2. DISCOVERING THE ILLNESS

From the discovery of the first signs of the illness until treatment and phases of remission parents may already encounter some emotional stress. When the first symptoms of an illness are discovered and the child is examined by a physician frequently a minor illness such as a recurring flu is diagnosed. Many parents, however, report that they initially suspected a more severe illness even cancer. It is not clear whether this stems from a general fear which later proves to be true or if they get some other direct clues. A phase of emotional preparation for the worst is initiated, however, it does not yet relate to information. When the suspicions are confirmed by a doctor, they become qualitatively different.

(MM)

Mother: "And, you know, well and Les thought .... I guess we were both thinking cancer, but you just didn't really know, because we don't know any of the symptoms and stuff and we just kinda poked around at it and knew right away that there was something wrong."

Despite their suspicions there is no certainty and parents are unable to pinpoint the problem. They may remain in a state of suspected awareness for some time, even when a diagnosis has already been made. Physicians are reluctant to tell them anything until the diagnosis is firmly established and all tests have

\(^{90}\) publish a monthly newsletter.

\(^{90}\) husband

\(^{91}\) See chapter "2. Issues Concerning the Child with Cancer in the Literature".
Parents and Family / 253

been made.

(AM)

Mother: "So then he just, the only thing he said to us was you'll be lucky if it's Mono, that's what he said. So then of course your mind's going what is it, like it's ... And I guess they don't wanna tell you the worst that could be I suppose, I don't know it must put them in a difficult situation too I suppose, but ..."

Many parents also become more suspicious and tense by changes in behaviour and attitude of medical staff. For example, one mother noted that she was called into her family physicians office as the last patient - normally she would have been informed at the phone - and then she noticed that nurses were looking at her and offered her magazines whereas "normally they just let you stare at the wall" (G-3). When the diagnosis of cancer is made parents have lost some of their initial faith in the medical system because many of their fears had not been taken seriously whereas in fact their hunches proved to be right in the end (s.a. Kirkpatrick et al., 1974).

(U-29)

Mother: "We were several times at the emergency until we didn't believe stomach flu any more."

For some parents it can take quite some time until the proper diagnosis is found. One mother reported that it took six months until the final diagnosis of the illness was established (S-20). Those parents enter the treatment process with some apprehensions with respect to the medical system because of their feelings of running against a wall of soothing placebos.

With the official establishment of a diagnosis parents have their worst fears confirmed and experience this initially as a quasi death sentence for their
Parents and Family / 254

Father: "Well basically Anthony had been very lethargic around the first of January 85, and so we got the doctor out to the house and said well it's either Mono or something else. And I had figured that it was something a lot stronger, lot worse than the Mono, because when he says something else either he would say it was Mono, you know or ... But when he said, I guess it was the examination of the large spleen and the large liver that gave lead to him, but before exiting us he wanted to have a confirmed diagnosis. We took him to the hospital and there it was confirmed that he had Leukemia. So basically you go, 'oh my God, he is gonna die'. So that was basically the initial contact. I mean it's the same for many people that cancer is always in the background until it affects a person."

The confirmation of the cancer diagnosis is the confirmation of their worst fears. It comes still as a blow despite some emotional preparation.

Once the diagnosis is established, parents receive more information about the illness in talks to their physician, nurses, and other parents. However, it takes some time until they really understand the implications of the illness.

7.3. REACTIONS TO THE DIAGNOSIS

Several authors report that parents are in a state of shock after they have been told the diagnosis (Binger et al., 1969; Sourkes, 1977; Pichler et al., 1982a). This has been confirmed by several parents in this study (fieldnotes). A shock is usually a sudden and unexpected blow to which a person reacts with certain physical and emotional responses. It is interesting that many parents have in a way prepared themselves for the diagnosis with their own fears or suspicions, which were reinforced by the diagnostic tests which were made or the behaviour of health professionals. In many cases long and agonizing period of waiting trouble parents while suspicions of a severe diagnosis gradually thicken to
Despite all those preparations the confirmation of a cancer diagnosis comes as a blow, sometimes mixed with feelings of relief that the waiting is over and the expectation that something concrete can be done now. This blow is somewhat comparable to a shock because it generates considerable tension and anxiety, however, it did not come totally unexpected. Nevertheless parents become very limited in their capacity to accept new information at this stage, because their emotions bind all their energy. Some parents talked about the initial shock and a feeling of numbness which lasted several days (V-22). This happens at a moment when they are required to handle a considerable amount of new information which is already difficult to understand for a fully concentrated person.

**Mother:** "Oh definitely the first few days are the worst... Somehow I didn’t believe them. I knew he was sick, but a couple of days after he was there, I..., maybe he would have looked like that anyway, but all of a sudden he had these big black circles under his eyes and I mean he looked worse after they had him then when he was at home. And then you think you have to question, I mean you know he is sick but what are they doing that’s making like that’s any better. He looks worse now that he is here. That, you know, is upsetting too."

The harsh treatment seems to worsen the child’s situation initially. The appearance of the child contradicts the notion that things are going to be better, which is after all the goal of therapeutic intervention. All this is part of the treatment process, but it requires knowledge and understanding.

It takes time until acceptance of the child’s condition is reached. However, parents have to make decisions about the therapy and sign the appropriate consent forms right at the beginning. This is a very overwhelming task at this stage, because parents usually do not have the resources to verify the
Parents seem to lose control with the diagnosis and they often feel powerless and scared in face of the unknown fate of their child. These feelings - which may persist to varying degrees for some time - may be mixed with anger due to the seemingly senseless suffering of their child.

(S-13)

Father (after some weeks in the hospital): "I still feel scared like the first day and I feel angry against God that children have to suffer."

The illness does not seem to make sense and there is no rational explanation. Common belief system are frequently shattered. On the other hand it may also be a reaction that parents turn to religious beliefs in order to receive some comfort.

One of the strong feelings in the initial stage is guilt which refers to the puzzling questions "why did it happen?" or "could I have done something to prevent it?"

(AF)

Father: "So that was another question that came up, could I have done anything before, you know, couldn't I have noticed anything before? Why couldn't I have noticed anything before, you know that's always something that's in the background."

Some parents blame themselves for the illness. Those feelings can be intensified by the personal circumstances, e.g. one child with cancer was born after the parents had agreed that the father would go through a sterilization which he had procrastinated. This triggered some angry feelings in his wife, because in a way the suffering could have been prevented.
Generally feelings seem to be reoccurring. They vary in their intensity over time and some things look differently from a retrospective viewpoint. For example some parents said that they stopped feeling sorry for themselves after a while.

Some of the feelings parents have are similar to the stages of grief which have been described in the literature (Kübler-Ross, 1969). They relate to the experience of loss which can either be anticipated (anticipatory grief) or relate to the actual death of a close person. The experience of loss may not only relate to the physical extinction of a person, but may also be a death of one's own hopes and expectations. Children are often the focus of personal hopes. Parents lose those hopes initially when their children are diagnosed with cancer, because they fear that their child is going to die.

Grief has often been described as a set of consecutive stages of feelings. However, parents experience those feelings at different points during their coping processes.

Denial of facts may happen initially and again with respect to treatments or results which show a relapse for example, e.g. "it can't be true" or "maybe there is a mistake".

Anger may be incinerated by mishaps in the hospital and it may also be generalized against the hospital and the staff as the visual representation of illness related issues. Parents have mentioned that they became more suspicious with respect to staff activities and that they had to force themselves to come into hospital.

Bargaining may be revived as a function of hope, when parents search for alternate treatment possibilities.
Acceptance has to happen at various points during the treatment, because situations change and coping issues may repeatedly come back.

The initial coping responses vary among different families. Some withdraw and others try to get every possible bit of information about the illness. Coping with the different issues which arise is a longterm process. Then symptoms of Burnout which include fatigue and unwillingness to do anything may occur.

During the initial phase some parents are kept very busy with all the arrangements which have to be made, e.g. babysitters may have to be found for other children. This can keep parents away from their own emotions for a while.

(Mother: "Neither of us got even a chance to break down. We had to talk to all the different doctors."

The events require coping with organizational matters and all the new information. It takes some time until the diagnosis really settles in. Some parents referred to this as a bad dream which wouldn't go away.

Telling relatives and friends is also one of the initial tasks. They also react differently to the information. Some are understanding but there are also reactions of shock and disbelief.

(Father: "The family sort of understood, but it was just this one person who says it can't have happened, it's not true, they've made a mistake and that was the biggest thing to try to cover that hurdle, try to make him understand."

The reaction of other people can have quite an influence on the relationship between them and the parents. Other people may react with denial or they may
be afraid of the contact because they do not know how to react and what is appropriate to say. In some cases parents may have to deal with the coping processes of their relatives or friends in addition to their own if they want to continue the relationship. This can lead to a situation in which parents feel more at home in the hospital because they can relate better to parents and staff who share some of their experiences.

Coping with the illness consumes a considerable amount of energy. Parents often think about their child, even when they are not in hospital. It can be difficult for them to concentrate on other things like their work.

7.4. PARENTS IN HOSPITAL

When the child is hospitalized parents also are subjected to the rules and behaviours of the new environment. Hospitalization of the child has an impact on the whole family. The timing of daily events and the roles within the family are likely to change. The hospital itself requires some adaptation to its rules and routines. In addition there are many new social relationships and parents find it difficult that they have to share the intimacy of their emotions with so many strange people.

(V-27)

Mother: "Meeting so many people at first is nerve wrecking. You want to shout at them 'leave me alone in my little world'. In the beginning I asked the same questions over and over again. It seemed like every doctor in the hospital came."

The hospital is also another step in the realization of the illness, especially when parents encounter other children with cancer on the ward.

Parents developed certain attitudes and rules of behaviour for themselves
in relationship to others. They formed their rationales for their respective behaviors. Some related them directly to experiences in the hospital and to their own coping processes.

(G 61)

During a conversation in the hallway:

**Father:** "I watched the LP through the door."

**Björn:** "You don't like to be in ..."

**Father:** "Not in the beginning when he is screaming."

**Björn:** "Yes, that's really hard to observe."

**Father:** "Especially after the first time, when there was just as much blood on me than on him. If something goes wrong in the beginning ..." (pause) "I guess I am using that as an excuse."

The final introspective statement pointed at fathers difficulty to see his child suffer which he used at the same time as an excuse not to confront himself with the situation. This evasion, which is very understandable, has some parallels to the behaviour children sometimes demonstrate when they want to avoid painful procedures. Only they are not able to avoid the situation.\(^2\)

Parents also attach symbolic meanings to events and places in the hospital. For example some parents made a distinction between a *good day* and a *bad day*. A good day is when not much treatment is happening, maybe just a blood test. Chemotherapy and other treatments take place on bad days. Similarly locations in the hospital could be attached with similar symbolic values. One family particularly remembered the room in which their son had a seizure.

(Q-23)

\(^2\) See also chapter "8. Children".
Father: "I call it the freak room. That's where he freaked out."

_laughs_

Memories give certain areas their individual meanings.\(^3^9\)

As the treatment progresses parents often wonder if they made the right decision, especially when they become more aware of the side effects and some things do not seem to go that well. They also compare their child's situation with other children.

_V-25_

Mother: "It sounds awful, you wonder was it right to go through all the stuff. Then you look at other kids, become attached, look at George. You wonder if that's going to happen. When you hear that other patients are gone you ask if that's gonna happen to Judith."

....

"In November she had a total relapse. She is not in remission. We try to find an appropriate bone marrow. Her chances are down to five percent. I sometimes think, why didn't she die a year ago. It's a pain in the ass coming in every week. However, her quality of life is good compared with Rita."

The suffering of the child through the treatment is difficult to bear. Parents seem to oscillate between hope and despair. Other children are in worse or better condition, however, parents never know if they represent an example for their own case.

\(^3^9\) Children and hospital staff also did this to some extent. The symbolism for the children, however, seemed to be the strongest (see chapter "8.3. Children's Communication").
Telling Mother

Tanya's mother arrives on the ward. She finds her daughter's room empty. At the nursing station she asks where her daughter is. "Just a moment", the Unit Clerk picks up the telephone and asks for the doctor. He will be paged.

Mother wanders slowly away from the desk. She appears to be very tense. The nurses at the nursing station watch her. One nurse approaches her and tells her that her daughter has died. Mother starts crying in the hallway. One nurse leads her into the parents' lounge and another follows with a box of paper tissues.
7.5. INFORMATION

The benefit of having information versus being left in uncertainty was one point parents stressed frequently, e.g. (I-16) "It made a whole world of difference to get information". Even though the information was sometimes bad news parents felt relieved when they finally knew what was going on.

After they have learned about the diagnosis parents are usually overwhelmed with information about illness and treatment. This happens at a time when they are emotionally very upset and they cannot handle much else. It is required that parents give informed consent to the treatment at that stage. They usually receive a written information about illness and treatment and a form which they have to sign. There is also little time to think because the treatment has to begin right away. The decision comes ultimately down to the question treatment or no treatment.

(V-23)

Mother: "Why read them? Either you treat or you don't treat. I gave them back and read them one year later."

Whereas for most parents it comes down to a pro or contra treatment decision most parents also seem to inform themselves about illness and treatment after they have decided to go ahead. However, informed consent means usually more consent than information at this stage. Parents have to trust others and rely on processes which they do not know in order to keep up hope for their child.

(H-47)

Father (with papers in his hand, during a casual conversation in the hallway): "They want me to sign another consent form to add a fifth drug to his chemo. It's a study from the North American Cancer group."
Björn: "So you better read it first."

Father: "There is no question that I'll sign it. Someone else has signed for the research on the drugs he's getting."

If the primary decision has been made the rest is just a consequence of that step. However, parents cannot calculate the effects of their decisions. They have to trust the judgement of physicians who they may have met for the first time.

The information which parents receive varies with its source and covers different aspects of the illness. Although parents also receive written information, verbal communication seems to be of paramount importance. When they talk to the physician directly many details surface and the amount of information is sometimes difficult to digest, since there are also their own emotions which consume a considerable amount of energy.

Information about treatment, side effects, etc. is sometimes passed on rather carelessly. Physicians may inform parents of side effects of a drug at the bed of the child, which may leave many questions which the child will later ask his/her parents. The drug may also have been given to the child when the physician informs parents and child about it.

(K-69)

Physician: "We're giving three drugs. One is called Daunamycin, which is given through here." (points at the IV line) "It is orange. Daunamycin may cause many problems. He may complain about pain in the jaw, but that's just nerve pain. It can also affect the heart. We haven't had any problems during the last seven years, but I want to tell you."

He explains a little bit about the other drugs and says: "We'll be following him closely and change the dose if necessary."

Parents learn about the effects of drugs and treatments often after they have been administered. Serious side effects are mentioned, however, parents do not
know the actual implications at this point. Connected with the information is the assurance that there have not been any problems lately. This provides a smokescreen for parents which prevents them from asking further questions at this stage. When side effects do occur the physician may say that s/he has told the parents already, whereas parents may feel that they never received such information. Some parents agreed with the notion that they should not be told about all the possible side effects.

(U-36)

Mother: "Who needs to know all the things that could possibly happen to sit at home and think about that."

Parents usually cannot estimate the severity and the chances of these side effects and may put them out of proportion. However, The parental attitude changes over time when they gain more experience with hospital and treatment. There is always a degree of appropriate information which has to be found individually between parents and staff.

Parents also receive information indirectly when they overhear conversations between physicians and nurses. Certain keywords such as the name of their child's illness make them more attentive. They become alerted and anxious when they hear that something is going wrong. One father said that he felt scared when he heard that one nurse said (D-27): "You are putting it into the wrong line", to another nurse who was giving an injection to his son.

A part of parents' energy seems to be directed towards finding out what is going on. However, sometimes they receive conflicting messages from different staff members. One father said that when one resident told him that they may be able to go home the same day, which had to be confirmed with his senior
physician, he would check with the housekeeping staff to find out whether they had received orders to clean the room (H-77). He had learned to verify information by checking if it had been processed within the system.

Parents are very interested in information about the progress of treatment and also seek knowledge about the general outlook. They may pick up ideas from books, talks, newspapers, etc., which are then used to ask questions from the staff.

7.6. PARENTS AND HOSPITAL STAFF

Parents were initially overwhelmed by the number of different staff members in the hospital which intruded into their privacy. Meeting new people became one of the parental duties during the hospital stay. It was an ongoing process due to the staff turnover which presented another problem to parents. They found it difficult to adapt to new staff for themselves as well as for their children. They noted this especially during procedures when children had to get more pokes because an inexperienced person was taking the blood or giving medication.

Many parents seemed to have a positive attitude toward the staff which may have been a part of the relief parents felt when they learned that something could be done for their child. This positive opinion of the staff's efforts continued in some cases even if some things had not worked out and mistakes had been made. However, the attitude also seemed to be related to the course of the illness. When there was little success in the treatment parents tended to become more critical. The time spent in the hospital was also a factor which could increase the amount of negative feelings toward staff. However, parents always seemed to acknowledge the efforts of the individual persons on the ward.
Sometimes parents were very critical toward an individual member of the staff with whom they had had a bad experience. However, mistakes were frequently blamed on the system, e.g. (D-35) one mother blamed the hospital system and not the persons after she had discovered that her daughter had received a too large dose of a medication while neither physician, nor head nurse, nor chemo nurse, had not noticed anything. After such incidents parents become more alerted to possible mistakes in the system. However, since the hospital is often their last resort for the illness of their child they are in a bind situation.

This can increase parents’ anger because it pulls away their basis of hope which relies on the hospital and its staff.

(R-28)

*One mother* said that her daughter’s Hickman line had broken because a nurse had reused the tape which held lines together. "She could have bled to death if they had not caught it."

*She added that she could not stand when something in the hospital went wrong and that it would make her angry and uptight.*

Mistakes of the hospital staff create a new line of stress for the parents because after they have discovered mistakes they feel that they have to check more what is going on. When they discover more errors they become more tense and alert and increasingly develop distrust in the hospital and the staff.

One common complaint of parents was the lack of proper communication and arrangement of schedules which resulted in long waiting times. Parents wondered why they had to come early in the morning and had to make arrangements to get to the hospital in time when nothing happened and they had to sit and wait for hours.
7.6.1. Parents and Physicians

From the perspective of the parents, physicians seem to be the persons who have the key to the solution of the health problems of the child. Because the illness is life threatening they are as a group a last resort of help.

Parents rely on physicians and on the information they pass on. However, passing on information sometimes happens in a very indirect way. Frequently groups of physicians come into the room, look at a child, sometimes without any interaction with the parents, and then continue their conversation in the hallway. Parents then gather fragments from their talk and are sometimes worried what will happen. One father commented about a group of physicians who were talking just outside of the room.

(C-35)

"At first it used to bother me when doctors came in and looked at my son and then went out and talked about him. I knew that because I heard his name once in a while, but I didn't understand a word of what they said. I don't know if they do that for the parents or if it's just their routine."

Although parents get used to this, they are alerted and attentive when they become aware that physicians are talking about their child. Children also receive some information this way.\(^4\)

When things go wrong the tension can trigger anger and create anxiety. However, some parents are dependent on the relationship with their physician because he is the source of treatment and hope. Mistakes, even if they are very serious can be blamed on the system from both sides. This can avert the threat of legal consequences. One father expressed this conflict while talking about an

\(^4\) See also in chapter "8. Children"
incidence where his son suddenly had a seizure.

(L 52)

**Father:** "Dr. Lee came up later and when he came to the room he turned white. He said later that the fluid levels had been wrong. It was a mistake of the intern. He asked if I would have sued if Serge had died. I wouldn't sue if Dr. Lee was involved, because I think he is the best doctor on the ward. He did everything. I don't know if the medical intern is under Dr. Lee so that it would be blamed on him. I wouldn't do anything that would harm Dr. Lee." 

Despite the mistakes which had been made the father did not want to do anything which could have an effect on "his doctor". Many parents feel some kind of obligation to their physician. This may be due to the situation in which parents see the hospital as the last resort for their hopes.

One mother vented her anger about another mistake she had discovered. Her doctor had prescribed the wrong dose of chemotherapy, which the mother had discovered after she had rechecked the prescription in old charts.

**Mother:** "Why do I always have to find something like that? I will not do anything about it because I do not want to hurt Dr. Lee's reputation. But I'm angry."

The parents had to rely on their physician as a resort of help for their child. Therefore they felt powerless when they discovered mistakes. They built up their anger and began to distrust orders which they rechecked to prevent further mistakes.

During one meeting of a parents group one father complained about mistakes which had been made on the ward. In particular he was upset that

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95 The last sentence is an intentional quote which may not be a literal quote.

96 A similar reaction can be found with respect to nurses (see the following subchapter "7.6.2. Parents and Nurses").
physicians apparently failed to diagnose an appendicitis. The father who happened to work in a medical setting himself insisted that the situation be checked out and he claimed that only through his strong intervention something happened which then led to an appendix operation. The parents reacted very concerned and to some extent apprehensive at that meeting. One father asked what other resources were available and that he would not know what to do if he could not trust the hospital any more. Parents rejected the thought of any action about this incidence because they seemed primarily concerned to lose their good standing with the hospital staff and being deprived of their last resort of hope for their child.

Some parent's, however, may become very angry at the hospital staff and the physicians. One father of an oriental boy came to distrust his child's physician whom he accused of not doing enough for his son.

(12-28)

Father: "Saturday my doctor came felt his tummy, said it's bigger, there is something. Sunday he came, felt tummy, yes there is something. On Monday I stopped a resident and told him to check. Why wait three days, why not do something right away? My doctor didn't even write it down. He thinks that Ernie will die anyway. He said can try new drug or not, it doesn't matter. He promised to write a letter for East because only Orientals can be donors for bone marrow. He hasn't done it yet. We try to buy time. Maybe they'll find a new drug or something in the meantime. My son is dying, maybe he has until Friday. Now there is hectic looking around among relatives."

This father wanted to do everything possible to save the life of his child and he was deeply disappointed that his doctor did not share the same opinion. Some mistrust developed in the physician parent relationship and in the end the family even tried to change their doctor which the physicians on the ward did not do
for policy reasons. So the parents must have felt stuck with the illness and the
fate of the child as well as with the care by the physician they did not like.

Interestingly the father of the child who had a seizure due to the badly
monitored fluid levels commented about the father of the oriental child, to whom
he had talked frequently, (12-29), "He is angry at his doctor, but I can
understand". However, this was still no reason for him to question the system of
care like other parents had done.

Occasionally parents received conflicting messages from different physicians.
When one girl's condition deteriorated the hematologist suspected toxicity from
drugs and said that her state would soon be reversed (H-28). However, another
physician who had done a biopsy thought that there was no hope at all. The
mother said that she felt like a yoyo, especially since her daughter had been
transferred between intensive care and the ward several times.

Some parents also wondered about the attitude of some physicians. They
found some of them very factual and unemotional, but they attributed this to
their daily encounters with the children with cancer.

7.6.2. Parents and Nurses
Nurses have a very important role for parents in the hospital. They are the
medical staff who are addressed with many question because they are on the
ward whereas the physicians are rarely available. The Nurse Clinician has an
outstanding role in this respect. She informs parents about illness and
treatment. For many parents she was the important link to the medical
world.

See also the subchapter "7.5. Information". 
Most parents praise the staff for their dedication and the work they did in general, even when they noted that some things did not go that well. One father for example said that he had been annoyed about one nurse, but he still praised the staff as a whole.

(AF)

Father: "She wheeled as I recall Anthony's buddy over the IV cords. I wasn't too impressed with that and that was the only nurse I wasn't too impressed with on that whole ward. And that hospital is just incredible. I mean I got nothing but praise for that staff. You know it's just a really neat place to be, well ... ... considering the circumstances."

This father had witnessed some organizational mishaps as well. However, this did not seem to influence his positive attitude toward the hospital staff in general. Nevertheless mistakes or inappropriate behaviour can make parents apprehensive with respect to a certain member of the staff.

(G-4)

One mother said that there were problems with the many new nurses on the ward and one had given a wrong medication to which the nurse commented, "this was silly of me". The mother found this remark inappropriate and noticed as well that this nurse did not clean the line for two days. She said, "I don't want her to take care of my child again, but who do I tell?"

This mother had concerns about a staff member, but she felt unable to deal with it within the hospital system. Therefore it appeared to be something which could not be solved and the mother felt condemned to remain passive. Some parental concerns can be a pretext for their passivity, for example several mothers were concerned that they would be judged as just a "paranoid mom". (G-5). This also reflected the agonizing fear of not being taken seriously.
Often mishaps were acknowledged and rationalized which served as an apology for the staff within the hospital system. At the same time parents stressed this as an additional argument for their presence on the ward.

(Father: "I mean, they got a lot of patients .... But then that's where the parents probably should come in. They should know what their kids gonna get and they gotta make sure that he gets it. I mean you know there are some days they forgot Tim, like forgot his temperature, forgot to weigh him and what was it ...")

(Mother: "We would just say would you mind taking his temperature, you know, you haven't taken his temperature yet, or can I have him weighed, or just stay on top of things to make sure that everything has been done. There were a couple of days they forgot to test his blood and we figured he didn't have his bloodtest today. You know we'd give them an hour or something if they weren't there on time. Or there was days when they came and said you know Ted's bloodtest, and we'd say no he doesn't have his bloodtest today, they he's off for a special reason, no, no, doesn't he get it on Thursdays? I said no, and then they went saying bye ...")

Some parents become very attentive and keep books about medications and bloodcounts. Those parents are more likely to discover flaws in the system, especially when they have some medical knowledge or have gained expertise with the illness. The discovery of flaws in the system of care influences parents attitudes toward the staff. Some parents expressed that their opinions were not really appreciated. They said that the staff had a "what do you know" attitude.

On the other hand parents also appreciated the efforts of individual nurses. Especially the nurse clinician who had kept the parents informed about illness and treatment was usually very much appreciated. But parents also had their favourite nurses and felt relieved when they cared for their children.

(V-26)
Mother: "Some nurses are very businesslike, others care. Betty is the best nurse, however, she will burn out if she continues like that. Marg loves all the kids. If they get rid of the practical nurses they are making a big mistake."

This mother had spent considerable time in the hospital and had developed her preferences for nurses. She was also concerned about the planned staff changes, which would eliminate licensed practical nurses on the ward.

7.6.3. Parents and Social Worker

Parental reactions to the social worker varied considerably. The fact that social workers are not a part of the medical system can be appreciated or render his/her presence into just a byproduct, an additional person. Contact with a person outside of the purely medical world can open up new perspectives. However, when parents are already overwhelmed with the number of different professionals within the setting, they often make a hierarchy according to the medical priorities they perceive as being necessary for their child. This means that contacts with non-medical personnel, which are then considered to be less important, are among the first to be avoided.

The judgements of parents toward the social worker ranged from very helpful to nosy. Accordingly some parents were very open with the social worker, talked to her and received information from her. The social worker was appreciated as being supportive and not pushy. Others were quite apprehensive and felt that she was intruding and checking things according to preformatted questions. This meant that they felt their concerns were not really taken seriously.

See also chapter "6.3. Nurses".
7.7. PARENTS RELATING TO OTHER PARENTS

Other parents can be a good source of support. They can relate to the feelings parents of children with cancer go through. This can be basis for understanding which goes across social and other boundaries. In the initial stages of turmoil other parents who have been through this situation can be very helpful.

(TP)

**Father:** "Well the biggest relief to us was another parent coming up telling yeah, they have been through it. It's all okay, you know, there is all this that can happen. Get all the information. And then we see their little child. This is twelve tons off your shoulders. You know you can make it then. You know... We didn't know that."

Other parents can give hope, especially when parents with a newly diagnosed child are able to see children who have made it. However, some parents need time before they feel able to communicate with others.

(V-22)

**Mother:** "I talked to other parents when I was ready for it. I went to the Red Cross meeting and I thought those parents were nuts because they were laughing."

The communication with other parents can also help to get into other coping patterns and come out of emotional isolation.

While they are in the hospital parents can observe the strain other families go through.

(TP)

**Mother:** "You know, we learned so much from watching the other parents too, you know, just how they reacted... you see good things and you see lots of bad. We saw them fighting in front of the kids.

The Red Cross organized a regular meeting for all parents of the hospital."
Its a pretty traumatic time for them anyhow and then the parents are sitting there fighting in front of them? Maybe the kids are used to that. Tony would be devastated if he ever saw us, you know ..."

**Father:** "... sure could break a family, I know that ...

The bad things they see in other parents may prevent them on the one hand from being too close and on the other hand those examples of behaviour serve as learning process of things to do and to avoid.

Parents seemed to judge other parents behaviour according to their own. For example, one couple condemned other parents because they did not stay with their child in the hospital.

**(S-15)**

**Mother:** "I think it's cruel when parents leave children alone."

They may exchange those views with other parents when they meet or during the long periods of waiting when nothing is going on and parents occasionally get together.

Parents also mentioned that they felt devastated by the fate of another child they got to know, which made their emotional situation more difficult. They sometimes expressed that they had to protect themselves from other parents in order to keep their own spirits up.

**(D-60)**

**Mother:** "You don't want people who are down around."

When they become too close to other parents they feel that they would be influenced too much by their feelings. The resulting avoidance of attachment seems to be somewhat parallel to the reactions of nurses and other staff who
avoid attachment in order to be able to continue work and remain professional. Rationale and context are different, however, the mechanism to remain distant as a protection against emotions is very similar.

During the study some parents got together and founded a parent support group which was connected to the Candlelighters, a self help organization of parents of children with cancer. One part of those meetings was usually dedicated to some information. Members of other organizations, e.g. the Canadian Cancer Society, and also helpful persons, like the psychologist who taught distractive measures for children to alleviate pain, were invited. There was a general exchange of information between parents, e.g. where to get help with rides and medications. In addition they talked about events in the hospital in an anecdotal way.

During one meeting a father vented his anger about the hospital and expressed his concern that (H-52) "the practice of medicine does not allow you to ask questions". He then gave an example by saying that his daughter had complained about stomach pains for three days when the father diagnosed an appendicitis. He then gave the staff an ultimatum calling for a surgeon within thirty minutes. It turned out that the father had been right. This left some parents stunned and confused. One mother said (H-52), "we are in an emergency and we like to believe that everything is taken care of". Others said they felt that the hospital was their last resort and that they did not have any choice. Some other parents mentioned incidents in which their child was given a wrong dose of medication. The next day one mother told me that she probably would not go to those meetings again because they were too negative.

In another meeting parents talked about their relationship with the
hospital staff and they expressed some concern when persons they felt incompetent were handling their children. One mother gave an account of her daughter's first LP during which she had counted eighteen pokes (L-70). In later LPs this was reduced to thirteen pokes. However, parents expressed that they felt it difficult to assume an advocacy role for their child, because they were trying to be happy and have good vibes for the child which would conflict with criticism of the staff in that situation.

7.8. PARENTS AND THEIR CHILDREN
The relationship between parents and their children with cancer goes through a series of changes. At first there is the grave concern which sometimes triggers a lasting feeling of protectiveness (Green and Solnit, 1964). Parents want to do as much as they can for their children, but at the same time parents frequently become the focus of many of the child's emotions, anger in particular.

(K-52)

Mother: "Sometimes when Tina is acting up and screaming at everybody I have to remember what she has been through."

Parents are sympathetic toward their children's needs, however their reactions during different phases of the treatment can be an additional emotional burden for the family.

7.8.1. In Hospital
Children and parents are both initially overwhelmed by the events from their different perspectives. Parents learn cognitively about the seriousness of their child's condition whereas the child experiences threatening events which most
likely are not understood. Parents perception at this stage is limited by their emotions. The child tries to hold on to the parents who are struggling themselves with all the different kinds of information which some described as bombardment. At that point parents are also unable to tell their children what is going on because they do not know themselves.

Parents watch their children anxiously and their empathy for what their child is going through makes them suffer as well. This can be difficult to bear and some parents develop rationalizations, e.g. that their child is too young to remember anything.

(K-51)

Mother (of a two year old boy): "I hope he doesn’t remember anything of this. Sometimes I wonder how much he can take."

Parents watch the struggle of their child while at the same time they have to cope with their own emotions. This can lead to denial of realities, when the conflicts become too strong. The situation may be judge better than it is, especially since there is always an underlying need for hope.

The notion parents have of their child changes as well. When operations had been performed and the child had lost an arm or a leg some parents said that to them their child was not handicapped. One mother said (H-32) that she got angry at a person who suggested special education for her daughter who had lost an arm.

Parents often said that their children were very strong and that they found it incredible what they were able to cope with. The child’s attitude was often related to their own attitude. Predominantly parents seemed to make efforts to present themselves as being strong in front of their child.
Father: "One reason that Simon is strong is that we are strong in front of him."

There can be benefits if parents can guide the child through traumatic situations with their own strength. However, there is always the risk that strength becomes a false pretense. When parents do not feel strong themselves they send double messages to the child when they try to pretend strength. This can lead to a communication breakdown if the trust in the relationship is undermined by false pretenses which are perceived by the child. The child is then left alone with assumptions and often misleading explanatory models.

When parents stay with their child in hospital they often help with daily routines and they also may give their child some oral medication. This can become a source for conflicts between child and parents. From the child's perspective the medication may be a focus of the treatment in hospital. The more a parent wants their child to take the medication the stronger the resistance can be. Some of the medication also has a very bad taste or comes in a form which the child rejects.

Parents said that they had tried everything once, threatening, blocking the nose to get the child to open the mouth, etc. They watched another mother kneeling almost on top of her son on the bed in order to get him to take his medication. Nothing had worked until one father had the idea to take the medication out of the capsule and mix the powder with something else. This finally worked.

Sometimes parents got stuck and very frustrated with their children. Other parents were often a good source of support because they were able to relate to those situations on the basis of their own experiences. They were able to listen,
Parents and Family / 281

give emotional support, and could also make helpful suggestions.

7.8.2. After Treatment

When children are at home again parents usually experienced some changes in their children. Many parents said that their child had become more independent and somewhat stronger. But it was also noted that children displayed more anger and bad temper.

(TP)

Father: "And he is meaner, he's meaner, with other kids, a lot more or less to Denver (brother), you know, before ..."

Mother: "... bad tempered."

Father: "Yeah, he's got a real bad temper now, like kids are fighting he'd come home, now he'd stay there fighting."

Mother: "Sometimes he comes."

Father: "Yes, he is mad at everybody, mad at the world for it. You think that's the reason."

"There may also be a display of separation anxiety which refers to the need of being protected. This can also be the case if parents have stayed in the hospital most of the time during the treatment."

(TP)

Mother: "When we got home the first few times, and we were actually gonna leave, even to run to a store, he would act like he would have been left at the hospital on his own, like not that we had stayed with him, thinking that we were helping him by staying with him all the time. He'd act like he'd been left for a week, you know, by himself instead of feeling secure that we had stayed with him. It seems strange that he reacted like that. He is still like that sometimes."
Many angry reactions relate to the ongoing treatment and to visits to the hospital. Good communication remains important and some emotional reactions can be sorted out when the child receives the appropriate amount of information and has time to cope with treatment and procedures.

(TP)

**Mother:** "But he was reacting so bad that we thought he is gonna get ulcers, he goes on and on if you tell him the day before. You know he'd have temper spells or he'd cry and cry and say mom I don't want it. We thought it's a lot worse, tell him two or three minutes before, cry and get it over with. And Judy (nurse - in the outpatient department) was the one downstairs that's suggesting you tell him before you come to the hospital. You know we are going to the hospital on Wednesday, you know we are just going to have our Vincristine, there's nothing else, or that he is due for an LP then say, 'you know this Wednesday Tony you have to have an LP', and he's been fine."

The information assured the child's relationship with the parents. If the child knows that s/he can trust adults the stress of coping with uncertainty is deleted.

**7.9. IMPACT ON THE FAMILY SYSTEM**

Families are social systems which involve a varying number of persons from different generations. The impact of the illness depends very much on the structure and constitution of the family. In large families older siblings may get a different role by assuming more responsibility in the household and by keeping some daily routines alive. In divorced or reconstituted families issues of the relationship of the former couple may add to the burden of the illness.

The different personalities have also their individual coping mechanisms. When a serious event happens, like the diagnosis of cancer for one child there may be problems with the understanding of the disease and as well with the
coping mechanisms.

**7.9.1. Grandparents**

The changes which are required due to the illness may be hard to understand for grandparents who are usually more remote from the illness.

*(TP)*

**Mother** *(about the grandparents)*: "But now they come to terms with it. They just couldn’t understand that when we came home that Ted was allowed to play outside, playing around with another child. They couldn’t understand that. Like to them he was still really sick and I would say, you know, we have to treat him like a normal child. I mean we have to be careful in lots of ways, with colds and like that. I mean I can’t keep him pinned inside all the time. He has to be out to be able to play with other kids be careful like we don’t know the kids everybody that he plays with, you know, we are still careful, but to a certain extent. And it took them a long time to understand that."

Coping with the illness requires that attitudes have to be changed and that some of the notions of treating grandchildren have to be altered. Changes have to be made in two ways, both child and family have to learn to do things differently in order to avoid infections. This interferes with many wishes.

*(TP)*

**Father:** "That’s the hardest part like he likes going everywhere with somebody, with his grandfather and that, and to get them to understand that no public places period, you know like ..."

**Mother:** "My dad likes to take them somewhere and show them off ..."

**Father:** "Yeah, his grandchildren, everybody should see them."

There are changes in the daily activities and also in social relationships. The longterm effects of this, especially on the child, have yet to be thoroughly
7.9.2. Siblings

Siblings have not been an explicit part of this study and have only in recent years become the focus of more research (Gogan, 1977b; Koch, 1981; Lansky et al, 1982; Cohen, 1985; Asada, 1987; McKeon, 1987; Walker, 1987). They reactions are an important area of investigation which cannot be addressed exhaustively in the framework of this study. Nevertheless some brief highlights may point out several issues which are involved.

The fact that a child has cancer also alters the relationships between siblings. Bearison and Pacifi (1984: 266) state in their review of the literature: "They often feel neglected, jealous, resentful of the attention given the sibling with cancer, and fearful of their own health". The feeling of being left out may be paired with a feeling that a part of one's own development is repressed. Healthy siblings are not allowed to act freely. They have to be considerate of the sibling with cancer and even of their parents.

Some siblings may grow with the experience and assume an adult role within the family. This role suppresses part of their own development as a child, e.g. conflicts with the parents may not be allowed because of the situation and the need to be considerate and protective. On the one hand they may learn to be more responsible for the family, but they also have to submit their own development to the circumstances. In a way the natural development of the sibling within the particular family setting may be put on hold. Reactions vary with age, but the impact of the changes in relationships and the reorientation of the family may have a lasting impact on a siblings life. Some parents talked
about their other children and some expressed that everything was revolving around the sick child which made it necessary for everyone in the family to adapt his/her usual lifestyle.

The sick children usually expressed interest in the activities of their brothers and sisters when parents or the siblings themselves visited. One boy (3 years) also seemed to expressed pride when his younger brother came for a visit and he introduced him (K-2): "This is my Dean." Several stories which children told to each other refered to incidents with their siblings, especially when something unusual had happened, e.g. a brother had broken his leg (X-11).

There were also some stories about younger siblings who were very concerned about procedures and about events in the hospital. However, in one case a father told that a younger brother was very eager to see his older brother in hospital, but then he showed primarily interest for the new toys which had been given as presents. This example also highlights that it is very difficult to interpret children's behaviour without more in depth study.

It is difficult for siblings that the whole family life suddenly revolves around the brother or sister, who gets more attention and more presents. This can lead to jealousy between brothers and sisters. Conflicts between sibling and the sick child are difficult to resolve, because the sick child is under a protective shield due to the illness.

Siblings have shown many reactions to the situation which range from regression to a more aggressive attitude. Their emotional needs are often neglected. They also seem to be neglected in the research about the impact of pediatric cancer on a family.
7.10. PARENTAL PERSPECTIVES

Parents have several crucial roles during their child's illness. They are partners for their child who ideally offer the warmth of parent child relationships and interpret as well the events of the treatment for their child. Parental guidance, however, is seriously challenged by the traumatic events relating to illness and treatment. Parents also have to maintain their family in financial, organizational and emotional ways. This also includes the ties to the family system regarding their other children and their own parents. In addition to all these external demands they have to cope with their own emotions. This puts them in a constant double bind situation.

Certain phases may be distinguished for parents during the course of their child's illness. These may be consecutive or parents may also go through shortcuts due to their special circumstances.

1. Suspected awareness of child's illness
Parents notice the symptoms of an illness. They consult physicians who diagnose a minor illness. The physicians may also diagnose something more severe which they do not tell the parents. The parents become suspicious, but they cannot get any confirmation from the medical experts.

2. Shock and doom
The diagnosis of cancer is established and parents think that their child will die. Their worst fears have come true and they are emotionally upset.

3. Relief
The child comes into a hospital where cancer is treated. Parents learn that there is hope for their child and that there are knowledgeable people who appear to be able to deal with the illness.

4. Increasing awareness
Slowly the parents become aware of the reality of childhood cancer. It has seemed more like a bad dream before, but now they deal with it on a daily basis. They also experience the atmosphere and different stages of the treatment on the hospital ward. Intense feelings come and go. Sometimes there is anger against healthy people or against God. Frustrations with the treatment compound these feelings. There may also be more feelings of guilt, e.g. Could I have detected it earlier? Did I do something wrong with my child, perhaps wrong nutrition?
As the treatment progresses there is also sometimes doubt if the right decision has been taken when side effects of the treatment become more obvious. The question if all this is really true may also come up. The doubts lead to a more critical attitude toward treatment and hospital staff.

5. Adjustment
After some time in the hospital parents adjust themselves and their daily lives to the new environment. They learn more about the illness every day and get to know terms and procedures. They are relieved that something can be done for their child and have some hope that things will turn out well. The hospital staff is regarded as being very helpful.

6. Disenchantment
Parents discover flaws in the medical system and realize that some aspects of the hospital do not live up to their expectations. They become more watchful and control the treatment. At the same time anger against some staff members or the hospital may flare up. Parents may also become increasingly unmotivated with respect to visits in the hospital. They may feel fatigue and some symptoms of burnout.

7. Back to life
When the child is better parents focus more and more on the healthy aspects of life and tend to put away the illness. Dealing with its effects, e.g. extended protection against infections, becomes part of the daily routine. Hospital visits are understood as being necessary, but they are also experienced as a burden and a reminder of the illness. Therefore parents may become more apprehensive toward the hospital.

Feelings are not static. They come and go and come again. One example is hope which may be encountered in various cycles during the treatment. There is hope initially when the treatment begins. It may fade when there are no immediate successes and come again when progress becomes visible. Sometimes new hope can be triggered by information in the media about a new possibility to cure cancer. Such information is eagerly exchanged with other parents.

The illness also separates parents from the daily lives of other people. The number of friends is most likely reduced due to their involvement in their child’s illness. There also is a different level of understanding between people who have experience with cancer and the ones who don’t.
Mother (making two circles with thumbs and indexfingers of her hands): "Here is the world of cancer and here is the normal world and they don’t come together. People have to be educated about cancer."

Parents make a shift in their perspective through their child’s illness. Daily problems seem to be less important and plans are only made for a short range.

Relationships to other people change as well. They are not so directly involved and their problems and attitudes may seem to drift away compared with the task to deal with cancer of one’s own child. Other people have to be kept informed about cancer which can be a burden for some parents who have to go through things over and over again.

(G-6)

"I am tired of explaining everything to other people over and over again."

This can mean that only a group of insiders who can share the perspective will remain in close contact with the parents.

This separation between the parents of children with cancer and other people can also be experienced in language terms. One mother said (F-64) that she found it strange when her girlfriend talked to her about the problem that she was not able to sell her house and used "devastated" to describe her feelings. Daily problems are suddenly seen with a different perspective and priorities change.

At the same time parents also have to digest an incredible amount of new information. They are asked to give consent to procedures whose names are already difficult to remember, let alone all the possible side effects. Parents have to trust important information from strangers which is difficult to understand
Denise Jallais

Lullaby for My Dead Child

You shouldn't be afraid of the dark
Or of worms
Besides
Now you can play with the rain
And see the grass come up

You shouldn't put dirt in your mouth
And sit still waiting for me
Besides
We've given you some flowers
To console you for being little
And dead.

Translated by Maxine Kumin and Judith Kumin
(in Moffat, 1982)
even without emotional turmoil. In addition they have to learn the rules of the setting and get to know the roles of the staff members which seem to come and go in many different configurations without much introduction. All these demands which the situations put on parents seem occasionally overwhelming.

(K-52)

Mother: "Sometimes you wonder if you can bear more, but when it comes you do."

There is no escape for parents and they have to grow with the experience. If they don't, their world can fall even more apart, e.g. the family may break up or individual parents may suffer a breakdown. It takes time for the parents to find their own coping strategies and interactions with other parents can often provide useful insights.

7.11. OBSERVING THE PARENTS

Initial introduction by physicians and other parents helped to establish contacts. It was also important that the observer became a part of the social environment through regular presence on the ward. Curiosity about the constant notetaking aroused interest and frequently became an incentive for an initial conversation.

The next step was to get to know parents and children. Contact to the parents was crucial because I needed their consent in order to be able to do the observations. After the physician had signed his consent form I approached the parents as soon as possible and introduced myself and my study.

The first introduction was verbally and quite short. I then handed a consent form to the parents and asked them to read it and sign whenever

\[100\] See appendix
they felt comfortable to do so. I did not push them to sign immediately because I knew that they had already been overwhelmed with requests for consent to treatment procedures and I certainly did not want to increase the stress. Therefore I left them after the short initial conversation and said: "I will be around. Feel free to talk to me whenever you like."

The timing of my approach to parents was difficult and crucial for the undertaking. Parents have refused to participate in the study because they were emotionally too upset about the situation and about all the new people who intruded in their lives. One mother stated that they had cried a lot initially and it was difficult for her husband to cry in front of all the women (F-77), therefore they wanted to keep to themselves.

Another reason for the rejections may have been the partial emphasis on the parents' concerns in my introductory statement. I was made aware that this could have been perceived as threatening under the circumstances. In future statements I stressed my focus on the children who are in fact the pivotal point of this study. Later I did not encounter any further rejections. Indeed some parents were very open and almost eager to talk to me.

I tried to be present during the time when most activities were happening with the child. Therefore I came in regularly every morning after the children had their breakfast and stayed almost until supper arrived. Sometimes I varied my schedule in order to be able to observe weekend or evening activities. The main focus however remained on the daily activities.

My regular presence enabled me to get to know many of the parents. Most of them had seen me on the ward and some were wondering what I was doing and asked me about it. This initiated conversations about my research and
established some personal contact. Later parents took me aside for a chat or told me things they knew I was interested in. The parents I knew also introduced me to some of the other parents. Generally parents wanted to be helpful because they felt that they were being helped in the hospital and therefore they wanted to do something themselves as well.

When I had gotten to know more parents I also mentioned that I would like to talk in more detail about their experiences. Most reacted openly, but I usually had to mention it again before an interview could be arranged. After I had introduced myself in one of the Social Workers' parents' rounds one mother said spontaneously, that she would have needed someone like me in the beginning when she had no one to talk to.

Sometimes I found the notebook to be a handicap during those conversations because it limited the opportunities to react directly and develop good eye contact, because I was also involved in writing. With some parents these interviews became almost a question and answer session when they waited politely until I was finished with my writing.

During conversation parents often asked about my personal background, if I had children and why I was doing the research. When I shared this information at their request, it seemed to establish more closeness. The very personal information I received from the many parents made me on the other hand also feel quite close to them.
8. CHILDREN

8.1. INTRODUCTION

The observations of children had two different modes. A detailed analysis was done using individual case studies covering the time span of the first phase of treatment. Observations of appropriate cases were begun as early as possible after the diagnosis and hospitalization.\(^\text{101}\) In addition many observations of incidents and activities took place involving other children who were on the ward during the time of the study. As has been stated before, the observations focused on children up to 10 years of age.

8.1.1. The Case Studies

Four separate case studies were conducted.\(^\text{102}\) The selection criteria for the cases were age, stage of illness, early access.

1. **Case 1:**
   A three and a half year old boy, diagnosed with Leukemia; his parents, either together or individually, were constantly at the hospital. He was discharged from hospital after almost four weeks and was transferred for treatment to the outpatient clinic. Initially he was admitted into a 2-bed room where he was the only patient, and was later transferred into a 4-bed room which he shared with a total of five different children during his stay in hospital.

2. **Case 2:**
   A two and a half year old boy, initially diagnosed with Pneumonia, was admitted to a different ward where he was diagnosed with cancer. His parents were both with him initially, then they visited irregularly, because

\(^{101}\) The chapter "4. Conducting the Inquiry" explains the methodological considerations in more detail and the chapter "5. Participant Observation, a Personal Account" highlights practical experiences which were made during the observations.

\(^{102}\) Additional information about the family background of those cases can be found in the subchapter "7.1.1. The Case Studies" in chapter "7. Parents and Family".
they were both working. He stayed six weeks in hospital - almost two weeks on a different ward initially - and then was transferred into the Intensive Care Unit when his condition deteriorated drastically. He died five days later.

Including the intensive care unit he stayed at three different wards in the hospital. On the ward where he received cancer treatment, he stayed for four days in a single room and was then transferred to a 2-bed room which he shared with one teenage girl who died a few weeks later.

3. **Case 3:**
A five year old girl was diagnosed with cancer of the liver; she lived with her father who visited regularly; after the parents had learned that even with treatment she only had a ten percent chance she was taken out of the hospital.

She stayed one week in the same 4-bed room which she shared with three other children.

4. **Case 4:**
An almost seven year old boy, diagnosed with Leukemia; both parents were with him during the first days, then they visited infrequently. They were both working and their home was several hours away. He stayed almost two months on the ward until he could live at home again.

The first two weeks he stayed in two different 2-bed rooms, which he shared with a total of three other children while being four days alone.

The remainder of his stay he spent in the same 4-bed room which he shared with a total of thirteen other children.

These children were closely observed during their treatment on the ward and also during their visits for ambulatory treatments when possible. The third case study was considerably shorter than the others and is due to the circumstances a special case.

While conducting in-depth observations of those four children, many interactions with other children were recorded as well. This involved particularly children who were in the same room. Visits were also made to other children when the case study child was asleep.

The in-depth study of children in case studies also generated a better understanding of other children’s reactions, because I had been introduced to the world of the children on the ward as a quiet observer. My role seemed to be
perceived as non-threatening and children who had been on the ward for some time often spontaneously talked to me.

8.1.2. Observational Approach

The observations of children varied according to their respective ages. I introduced myself to the child in question and requested his/her consent to my presence after I had received consent from the parents, but it was up to the child to give or withdraw final permission. The individual child was given the opportunity to decide about my presence each time I entered the room. In most cases the first introduction was done by the parents or health professionals known to the child.

Being with the children without communicating with them might have been perceived as disturbing. Therefore I sometimes engaged in minor activities with the child such as playing games, casual conversations, etc. if the situation required this. However, it was always my aim and attitude to stay in the background as much as possible and perceive communications, events, etc. from the perspective of the child. I was present on the ward at regular times during the week. A typical observation day began when medication was administered and breakfast was given until supper was served. This seemed to be the timeframe for most important interactions, which was confirmed by occasional observations during evening hours and on weekends.

While undertaking observations focused on individual children other events on the ward were also recorded keeping in mind the perspective of the child. Other children, especially those who shared the room with the case study

\footnote{See "Children's Consent" in the Appendix.}
8.2. THE SCENARIO

8.2.1. Diagnosis and Treatment

The diagnosis of cancer is usually made after an ordeal of many intrusive diagnostic measures. Several parents have reported that a diagnosis has been made after symptoms of an illness have been observed for some time. In some cases even other diagnoses of less severe illnesses have been made (s.a. Kirkpatrick et al., 1974). Children are not feeling well at this stage and their situation seems to be compounded through the diagnostic procedures and the confrontation with strange persons in different medical settings.

There are many different forms of cancer, and treatments even within one category of illness change according to a number of medical protocols. However, there are some common issues in the process of the treatments which shall be outlined briefly. Initially there is a diagnostic stage which involves numerous intrusive procedures in order to determine the kind of cancer and its spread within the body.

In order to diagnose the illness several blood tests are made and when cancer is suspected the bone marrow and the central nervous system are examined for the degree of their involvement. In addition biopsies may be conducted in order to examine the cells of a tumor. Blood examinations are usually repeated several times during the process of diagnosis when the child goes from the family physician to the local hospital until the arrival at the specialized medical unit in the treatment hospital. Also laboratories at different
locations sometimes repeat bloodcounts and other diagnostic measurements in order to rely on values which are done according to procedures of local standards. All this means that the child is subjected to many pokes and unknown but painful procedures in unfamiliar settings. It is no surprise that children are usually quite withdrawn initially.

Then the sick child usually remains in hospital while the treatment is administered. Usually a combination of drugs (Chemotherapy), which can have severe side effects, is given. The most obvious, but physically the least serious, is the loss of hair. Other common side effects are nausea, mouth ulcers, skin rashes, and generally feeling very miserable. Chemotherapy usually makes the child feel worse than before and require that additional drugs are taken to lessen the side effects. Radiation is also frequently given during the course of the treatment in addition to chemotherapy.

The initial phase of treatment can last from a few weeks to several months depending on condition and physical reaction of the child. After the first phase of intensive treatment a child is usually discharged from the ward and receives further treatment in the ambulatory unit as an outpatient if he/she is doing well enough. There the child meets a new set of persons and many of the intrusive procedures like blood tests and bone marrow aspiration are repeated in regular intervals.

At some point the child can go home and take only pills, however, bloodtests are made in regular intervals. If the child stays in remission chemotherapy is continued in intervals which are set by the treatment protocols. There may also be other treatment phases during which the child is readmitted to hospital. Chemotherapy is generally given in hospital and the child usually
stays overnight when the drugs are administered intravenously.

When the child gets an infection or does not seem to do very well he/she is admitted to the hospital for appropriate treatment, because the chemotherapy also influences the ability of the body to fight off infections. This may delay treatment and lead to additional complications. If there is a relapse of the cancer, then the initial treatment is repeated in a modified version.

The treatment usually covers several years and includes additional supervision for some time. It has been mentioned before that the study focuses on the initial phase of the treatment. In order to assess the impact of illness and treatment on children, a child’s perspective has to be taken into account.

8.2.2. A Child's View

The illness does not seem to make the child very concerned initially. The physical symptoms, like feeling more tired or weaker, appear gradually. They do not seem to be of great importance for young children. Even adults are not communicating serious concern in the beginning.

The importance and the threat of the illness in the child’s mind, is generated through the circumstances like the many visits to different medical institutions and the number of tests and intrusive procedures. Interestingly, frequencies and sizes seem to be a measure of importance for children, e.g. the more persons are doing examinations or the larger the syringes are the more serious it appears to be. The illness may be regarded as being concentrated in a number of treatments, such as Lumbar Punctures or IVs, which can represent all the bad things associated with the present situation. Adults’

See Image 9 "Children’s Talk" as an example.
Children's Talk

One mother listened to the talk between her three year old son, who had undergone treatment for Leukemia, and her nephew in the back seat of the car. Grandmother had just died and they were passing a cemetery.

Her son said, that was perhaps where really sick people go and they get great big needles, but when they get better they come back.

Mother said that you don't come back when you go to heaven, that's where you stay.

Her nephew said, maybe she is peeking her head through the clouds looking at us right now, she will be waving at us. We'll look at the clouds and we will see her happy.
attitudes also seem to change with the increasing number of treatments. The child can perceive parents' anxiety and sadness.

Children find themselves in a strange environment whose rules are unknown. This environment also seems to be hostile because it afflicts pain and the personal space is constantly being intruded upon by strangers. Especially young children have little or no resources to put all the events into a meaningful context. In addition to the illness the child also has to find coping strategies with respect to the new environment with all its new rules and different levels of interaction.

8.3. CHILDREN'S COMMUNICATIONS

The methodological framework for this study is based on the theory of symbolic interactionism. The symbolic interactionist's view attributes a self to children which enables a person to make interpretations and generate meaning in interactions with others (Blumer, 1969; Denzin, 1973). In order to understand children we must look at the symbols they use, because they reflect those interpretations.

8.3.1. Nonverbal Symbols

Children often use nonverbal symbols as answers, especially when they feel insecure, which can be observed when children meet strangers or even adults whom they have not seen for some time. In hospital, encounters with strangers are frequent and a child can never be sure what the person is planning to do with him/her. When children do not feel well they withdraw and spoken language becomes even more restricted.
Some nonverbal communications can be quite clear and direct, i.e. when a child nods or shakes his/her head as an answer to a question.

(M-4)

A Child Life Worker (a substitute for the regular staff member) enters the room and comes to Anthony's bed. She says: "Do you wanna come to the playroom?"

Anthony shakes his head.

Child Life Worker: "Can I bring you something?"

Anthony nods.

Child Life Worker: "A book?"

Anthony shakes his head.

Child Life Worker: "Toys?"

Anthony nods.

Child Life Worker: "I'll see what is there."
She leaves the room.

The communication was reduced to a short but clear exchange of information. The boy did not want to talk and communicated with nonverbal symbols giving "yes" and "no" signs.

When the child did not talk to someone verbally two reasons seemed to be the major cause. On the one hand children were often reluctant to talk to someone because they did not know that person's motivation. Children often experienced that someone came into their room and talked in a friendly way only to perform a painful medical procedure. On the other hand silence served as a method to retain some control in the situation. It was a way to influence interactions when children felt very powerless in the hospital environment. Ann Hill Beuf (1979) noted that institutional requirements undermine the patient's
sense of self-determination. Children were often put into situations in which they had nothing to say. For example the planning of procedures was generally done without consulting them.

Communication can still work if the nonverbal symbols are understood. The interpretation of nonverbal symbols may, however, not be straightforward in every case. Shaking the head can also mean "I don't know" or "I am not sure". Sometimes meaning may also be communicated when no apparent reaction is visible. A three and a half year old boy would communicate "no" by shaking his head, but he would never nod to say yes. When he was asked if he wanted something and he did not shake his head it would mean "yes". These symbols can only be understood if one spends time with the children and gets acquainted with their personal characteristics.

Nonverbal symbols can also be used to avoid communication. Signs which usually mean "I don't know" like shrugging one's shoulders, can also mean "leave me alone". Both aspects are involved in the following interaction with a teacher:

(M-13)

Teacher: "Do you know if you will be staying a few more days?"

Anthony shrugs his shoulders.

Teacher: "Do you live far from the hospital?"

Anthony shrugs his shoulders.

Teacher: "Do you think we could get mommy to get some books?"

Anthony leaves his shoulders pulled up.

The teacher turns to another child.
In this case, the teacher did not get the information and had to wait for another opportunity to talk about it or get it from somewhere else. Nonverbal signs are sometimes difficult to interpret because they may have a variety of personal meanings. In addition adult and child may have different intentions and may therefore not be able to understand each other fully. Another interaction between the same persons can illustrate this.

(N-2)

**Teacher:** "Do you like Arithmetics?"

*Anthony* shakes his head.

**Teacher:** "What do you like best?"

*Anthony* lifts his left shoulder.

**Teacher:** "Do you like Arts?"

*Anthony* shakes his head.

**Teacher:** "Do you like lunch?"

*Anthony* shakes his head.

**Teacher:** "Hmmh, I have to do some more thinking."

In this interaction Anthony gave two kinds of nonverbal symbols, shaking his head (meaning: "no") and lifting his shoulder (meaning: "no, not really", or: "I am not sure what you mean, I don’t really want to talk about it"). The first symbol is more absolute than the second one although adults tend to interpret them similarly as "no". Anthony did not want to talk. The teacher tried different questions and got closest with the open ended question, "what do you like". The question "do you like lunch?" which was meant semi-ironic in order to trigger a positive comment was probably understood by Anthony with the
addition of "now" (he just had breakfast) or his response meant the final "leave me alone, I don't want to talk". The teacher concluded the interaction in an open ended way which left Anthony some space. Frequently adults ended with a value judgement or a teasing statement to another adult like "he is not a big talker". Such statements may further exclude the child because they can signal insensitivity for the child’s situation and are reflections of the coping processes of the adults.

8.3.2. Verbal Symbols

Children frequently attach their own names to things as a playful approach to cope with strangeness. One boy, almost seven years old, named his IV pole "Fonzy". A nurse picked this up and when the IV was pulled out, she pushed IV pole out of the room and said to the boy: "Say good bye Fonzy." In this way she was able to relate to the language of the child.

Children learn concepts from encounters with things or incidents and their association with verbal utterances. Through listening they learn words from the sounds they hear. A later repetition of that verbal sound serves as a reminder of the incident or the thing it was primarily associated with. The meaning which is generated this way may be quite different from an adult’s interpretation and understanding. One girl, for example had heard that she would get a "bow and arrow". The verbal sounds had been picked up and put into her context of understanding. She was quite disappointed, however, when she received a "bone marrow" instead.

This may be part of an adult-adult collusion against the child, see the subchapter "8.11. The Perspective of Children with Cancer".

term frequently used for "bone marrow aspiration"
Children use "I" when they talk about things they did. Sometimes this is associated with pride when they refer to an achievement. Adults, however, frequently use "we" when they talk about something which is actually happening with the child, i.e. a nurse said to child "We are going to get blood today". Adults put themselves verbally onto the same level as the child who is actually subjected to the procedure. Even if such statements are intended to include the adult and demonstrate empathy, the child is experiencing and feeling the procedure. The nurse who makes a similar statement may not even be present during the procedure. It is likely that some children experience this as patronizing.\(^7\)

Some parents also use "we" when they talk about their child, i.e. "we are starting to lose hair". It may even be used in the communication with the child, i.e. "are we sleeping?" The depersonalizing aspect of this euphemism becomes apparent in a child's rejection of mother's statement.

\(\text{(E-47)}\)

**Mother (to Tim, 3.5 years):** "We should give Lester your Lego, see if he can put it together, shall we?"

**Tim:** "I want to."

Tim stressed the "I" and highlighted his self in opposition to his mother's statement. He showed that he was aware of his self determination and refused to be included into his mother's utterance.

Another frequently used statement of adults, 'can you do this for me?', is

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\(^{107}\) There is a parallel in education at school when teachers say for example, "let us put all our books down". Please also note the use of "we" by hospital staff to indicate a position within a group, e.g. "6.3.4. Nurses' Position in the Hospital"
related, i.e. a nurse said to a child "Can you swallow this pill for me?" This reflects something which is probably quite real for the child, that he/she is not doing something for his/her own good, but rather to please the adults. The child has to get over the unpleasant encounter in order to be able to continue a good relationship. It is interesting to note that the adult's attitudes are also expressed retrospectively, i.e. one nurse said: "He took one (pill) this morning for me". This means that it is not only a mere trick to get a child to do something, but it also reflects an attitude of adults toward children.

The use of "we" and "do something for me" seem to be culturally accepted forms of communication with children in North America, not only in the hospital context. However, in a situation where the self of the child is already restrained in many ways, the use of depersonalizing language may be received as just another effort to patronize and decrease personal space.

Like adult language the symbols children use are reflections of the meaning they associate with things. As has been stated before the process of interpretation is something personal. With respect to children those interpretations also have parameters within their age-related categories.

8.4. CHILDREN'S UNDERSTANDING
The understanding of events and the meaning which is attributed differ considerably between children and adults. The understanding also depends on the child's age and personal experiences. When complicated concepts are not understood, they are put into the simpler context of the child's basis of understanding. For example, a boy (3.5 years) said to his father: "I didn't do anything to my hair, someone just took it." He did not yet establish the causal
link between loss of hair and medication. He also rejected his own responsibility for this event and therefore the responsibility for the loss of hair was deferred to "someone" else. The link between loss of hair and medication was established after he had witnessed the loss of hair of other children. It has been reported that children of this age group may regard their illness as a form of punishment for something they have done wrong (e.g. Bearison et al., 1984).

Symbols are markers for importance. Some symbols are visible things such as the color of a medication, i.e. Tim (3.5 years) said (looking anxiously at his IV): "I am not afraid of the water, what's that pink stuff?" The clear fluid was regarded as water and the color of the other medication made him anxious. It marked something different and possibly something important. The threat of the whole IV may become focussed on colour.

Other symbols were associated with procedures. The "band-aid" was very important for children, because it marked the end of a procedure. Some children screamed "I want a band-aid" at the beginning or in the middle of a procedure as a sign that they wanted to be finished with the injection, LP, etc.

Persons can also symbolize certain activities which are judged as good or bad. Young children sometimes began to cry when they saw the chemo nurse, although she might have just passed by. Some children also began to cry when a nurse looked at the IV, because it reminded them of the painful poke and they were afraid that something painful was about to happen. Persons are judged by their activities, i.e. Tim (3.5) said about the Ambulance drivers: "Those are nice men, they don't do nothing, they just drive." They were not judged to be threatening, but one could never be sure what a nurse would do next. All these judgement required concrete experiences. Tim for example had to
experience what the ambulance drivers did before he came to his conclusion.

Several signs and symbols are associated with persons or with the organization of the hospital. For example (U-21), a mother was passing by wearing a face mask and Anthony (7 years) commented: "I thought she was a nurse". In another situation a child looked to see if the lights in the corridors were on again as a sign that the quiet time at lunch was over. At that point another boy indicated that the quiet time would be over soon, because he heard that the floor in the hall was being vacuum cleaned. This happened regularly during the quiet time, which seemed to be an organizational flaw in the hospital system, because it disturbed silence and relaxation. However, it is interesting to note how these events became markers for children which helped them to structure events.

Children also got to know the hierarchy of the hospital and importance is given to persons accordingly. This was probably influenced by the attitudes of parents and hospital staff. For example when a doctor was called something serious may have happened and children sometimes showed signs of anxiousness and began to whine.

The meaning attributed to an event depends on the information children receive and also on how much they are able to digest at any one time. Hospitalization is also an educational challenge, as there are so many new things to learn.
8.5. INFORMATION

Children get their information from different sources. Initially what is going on seems to be beyond their comprehension. They are interested in and experience the concrete things that are going on. Their illness consists largely of needles, pokes and bad tasting medicine.

The information they receive helps them to organize their environment and put everything into a meaningful context. Information is passed on to children in three different ways:

1. Information is communicated directly in interactions.
2. Children observe incidents or listen to conversations.
3. Children experience procedures, e.g. LPs, etc.

Adults passed on information in direct communication with children when they felt that it was necessary to inform the child about something which was about to happen, or when children asked questions because they needed clarification about something they encountered. Initially children’s questions were directed at the general exploration of the present circumstances.

(C-73)

Tim (3.5 years): "Why are we still here?"

Father: "This is going to be our home for a while."

Later those questions became more concrete and addressed information about treatment or procedures, i.e. Tim: "Do I have to get more shots?" Another interaction of the same child, about two weeks later, shows that he has learned about the proceedings although the terminology may not yet be quite accurate.

(G-37)
Tim: "When is my blood gonna come?"

Mother: "You don't get any blood today."

Tim: "The book."

Mother: "Oh, you mean the results!"

This interaction took place in the outpatient department where bloodtests, LPs, etc. are made for those children who were healthy enough to remain outside the hospital. They may also receive blood or chemotherapy. After the blood results arrived they can usually go home, if nothing else is scheduled. This is probably the reason of Tim's question. However, he may be misunderstood since "blood" may be taken as a reference to blood transfusions.

When children ask questions they deal with concrete issues such as: "Why does he only have one leg?", or "Why does he have a bag in front of his tummy?" Questions serve to clarify meaning. However, also form links to their own situation, i.e. a child's question "why did that lady go home?" may be rephrased as "how do I get home?" With more experience in the setting routines are addressed: "When is my blood coming?", which was used as synonym for bloodtest results. The longer children stayed in hospital the more they became knowledgeable about the terms which were being used and they also seemed more interested in what was happening with other children.

(G-38)

Tony (3.5 years): "What are they doing with that boy?"

Father: "This is a girl. She got a shot in the bum. You finished all that."

Tony: "I'll get chemo."

Father: "Every two weeks."
After more than four weeks in the hospital Tony had learned some new expressions and knew his treatment routines.

Children may get things "wrong" because they do not understand the words or the concepts. If children do not understand they make up their own explanations, or put things into their own context. Even well informed children may get some concepts wrong, which becomes apparent in the following conversation between two children, Rick (7 years) and Mike (10 years).

(W-5)

Rick: "I am getting a Hickman line."

Mike: "You got a line."

Rick: "That's a Central Line."

Mike: "What happened to your other line?"

Rick: "It got infected and they pulled it out. Now they put a Hickman line into my stomach."

Although Rick knew differences between various catheters - he had experienced many - he still thought that the Hickman line would go into his stomach instead of into his blood vessels, which is in fact the case. Since he had to be fed via catheters the concept of getting food into his blood was not in his frame of reference yet. Many adults would probably also have difficulty with this.

Distinguishing between different things becomes quite important once children have learned their meanings.

(R-23)

Rick's IVAC beeps.

Anthony: "Your IV is talking to you."
Rick: "This is not an IV."

Anthony: "I know."

Rick (points at the different lines): "This is a central line and this is an NG."

The personification of things was something children seemed to use to make their environment less frightening. The IV became somewhat like a person. Rick knew differences which Anthony did not know at this point, although he did not admit it. Through the distinction Rick made he passed knowledge on to Anthony. Children were an important source of information for other children because they could easily relate to their respective views.

If the parents were there their child would ask them the question, even if the nurse or the physician who were actually the addresses of the question were present.\footnote{This may even apply to the initial contact between children, as shown in the chapter Children Relating to Children.}

\begin{itemize}
\item The nurse hangs a bag with liquid onto Tim's IV-pole.
\item Tim (whining to his father): "What is she doing?"
\item Father: "She is just hanging it there. It's for later. You don't get any more pokes, she'll just hook it up."
\end{itemize}

It put parents on the spot when children trusted them to provide major information. Frequently timing or procedures changed and parents were not aware of it. However, the child was usually the last link in the chain of information and procedures. If plans were altered the parents were held responsible, because they had told the wrong things. For example a child's mother had been told
that her son would be able to leave hospital in about a week, which she had
told him (P-32). It turned out that he had to stay considerably longer. On the
one hand this increases children’s feeling of ambiguity toward statements of
adults and on the other hand it also leaves a feeling of being cheated. Children
may quote adult’s statements in their conversations, when they fit into their
scheme and they want to make a point. In the hospital setting this made a
learning process necessary in order to be able to determine who could make
certain statements. However, because the illness involves a great deal of
uncertainty the child received many conflicting messages, which in turn increased
confusion and frustration.

The acquisition of information is a dynamic process. Initially parents are
the main partners and sources for information. The younger the children are the
more they remain connected to their parents and will even avoid talking to
medical staff directly. Gradually children discover the different sources of
information in the hospital setting and their relative reliability. Older children
may even use information from alternate sources against their parents, e.g. "But
the nurse said...", if it fits into their context.

The passing of information also depends on the relationship. Sometimes
there may be a mutual understanding that a conversation can only go to a
certain point at which one has to stop in order to preserve the mutual
pretense.¹⁰⁹

(N-14)

Jim (ca. 8 years): "Why did they kick me out of room 10?"

¹⁰⁹ The mutual pretense has been described by Glaser and Strauss (1965) in
the context of awareness of death and has also been examined in
Bluebond-Langner’s (1975) study of terminally ill children.
**Mother:** "Because you were too far away."

**Jim:** "Why?"

**Mother:** "Because they want to keep an eye on you."

The conversation stopped at this point. Jim was not doing very well and the nurses had moved him to a different room which was closer to the nursing station, so that they could observe him more easily. Jim was inquisitive about his situation, but only up to a certain point. Direct questions about his state were left out, possibly in an attempt to protect his mother or himself, which would be an example of mutual pretense awareness. Even though information is available the social situation may prevent the sharing of knowledge, because it believed that it would to affect the relationship.

Children receive most information through the observation of others and by listening to conversations. The name of the illness will be mentioned at some point, e.g. one mother tells another "he has Leukemia" and other conversations may deal with the treatment of Leukemia. Children picked up considerable information about their illness and the treatment processes the longer they stayed in the hospital. They were also quite attentive to what was going on in their environment and what happened to others. They became particularly aware when someone talks about them.

(E-49)

**Tim** plays Lego on his bed while his mother talks with another mother.

**Mother:** "We have been here two weeks yesterday. We'll probably be in here for six weeks."

**Tim:** "No, three weeks."

**Mother:** "Who told you?"
Tim: "My Dad."

Tim had been following the conversation although he seemed to be involved in his play. He corrected the statement of his mother immediately when he thought it was not right and contradicted his expectations. This interaction also shows that children, as well as parents, receive different information from different sources. This can create confusion and distrust. Children tended to give that information validity which come closest to their own expectations and wishes. Tim wanted to get out of the hospital and he took the information which suited that desire best. He may encounter a double disappointment later when it does not become true.

Children received considerable information from the conversations which they could overhear. When doctor or nurse informed the parents about something at the bedside they also told the child at the same time. This fact seemed to be ignored frequently because quite a range of different conversations took place at bedside. Doctors told parents for example about possible side-effects of the drug the child was taking.\(^{110}\)

Children made implications from their observations. They drew conclusions for their own behaviour in order to prevent the same things which happened to others from happening to them.

(E-71)

**Father (comments about another child in the room):** "He is doing better, he is taking his medicine."

**Tim:** "Does he go to the treatment room?"

**Father:** "To get his IV."

\(^{110}\) See subchapter "7.5. Information" in the chapter "Parents".
Tim: "I take my medicine right away when the nurse brings it, so I don't even taste it."

Tim wanted to behave right so that he would not have to get an IV. He even used an idea which he had heard from his parents, "swallow quickly then you don't taste it", in his own words to indicate that he would do everything in order to avoid getting an IV. Tim had learned about procedures through his own experience and the treatment room had the stigma of pain and discomfort.

Children's observations can be very astute and pick up details as well as their implications.

(H-38)

Nurse 1 (looking into the room): "Is Simon Miller here?"

Nurse 2 (standing at the bedside of a child): "Tony? He is right there." (looks at Tony).

Nurse 1: "Oh yes, I weighed him" (leaves).

Tony (to his mother): "Maybe she weighed another child?"

A reference was made to Tony, using the wrong name. He picked this up and made his own logical implications: maybe the nurse was completely wrong. As a matter of fact mix-ups may actually happen when children have similar names.

Children looked very much at details and considered the literal meaning, depending on their age. Anthony (7 years) said for example: "She said everybody was in the playroom. Everybody? I don't believe her." In this case he considered the implications and took them almost like a joke. However, when those implications are not clear for the child wrong conclusions may be drawn, i.e. regarding the treatment.

Information seemed to be very important for children. They wanted to
Children know what was going on with themselves and what was happening with other children on the ward. Information about death was usually hidden. However, this may cause some concern in children and it may also be reflected in their behaviour. A Child Life Worker reported, that a six year old boy (Rick), who had been on the ward for some time, had been "difficult" for three days after another younger boy (George) had died. When the Child Life Worker mentioned George's name Rick asked if George was dead and said that another boy had told him, adding, "but he often lies". After the Child Life Worker had told him that George had died, Rick asked if he was in heaven or hell and how he died, if he "dropped dead" and if "blood gushed out of his mouth". After they had talked about it for a while he was notably more relaxed. It is interesting that the incomplete information Rick had received before had apparently left him with considerable ambiguity which made him somewhat restless. He needed confirmation from a reliable source. His concrete questions how it happened have probably been influenced by television. However, they also show that concrete images are quite important for children.

Children's statements can reveal the information they have. For example a seven year old boy, who had been in hospital for a couple of weeks answered to the question if he knew why he was here, "I came here because I had a sore throat and my mother told me my blood wasn't working well" (W-41). Is this accepted as sufficient reason for being put into a hospital and being subjected to many different and uncomfortable treatments?

Frequently the children actually began to understand something when they could perceive the physical symptoms. On the other hand much information of the adults passed by because children were not yet able to perceive what it
meant. When a treatment occurred it may come as something new, although adults may think that the children have been prepared. Children associated their own meanings to events. However, if adults cannot not establish the link with a child's perception they lose an important contact with the child.

Young children seemed to have a higher tolerance for ambiguity of meaning. They had to cope with a considerable amount of information which they did not understand fully. In some cases they were not able to find explanations of events which were concerning them directly. Even when a physical symptom appeared, such as the loss of hair, they tolerated this without exactly knowing why it happens. It may have seemed less important than the pain of some treatment procedures. The degree of emotional upset probably depended on the perceived threat of the event which was influenced by the discomfort and pain it caused.

(R-17)

**Anthony** (7 years): "My hair is falling out."

**Nurse:** "Do you know why it is falling out?"

**Anthony** *(shakes his head):* "No."

**Nurse:** "Because of the medication they give you. Do you know what happens after it falls out?"

**Anthony** *shakes his head.*

**Nurse:** "It grows back."

This boy was wondering about what happened but did not seem to be very upset about it. He received some information which seemed enough for the

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It is interesting to note the language here; "they" refers to an unidentified place in the system, although the nurses actually give the medication.
moment, but it does not mean that the issue is resolved. The nurse also mentioned that the hair will grow back which indicates the temporary status of this event.

The treatment procedures are probably the most dramatic interactions children encounter while they are in the hospital. They provide information and experience about the frightening aspects of the illness.

8.6. PROCEDURES

Treatments vary in their emotional and physical intensity. The reaction to a procedure is influenced by the personal perception and the situation. One child may perceive taking pills as an easy task and another child may not. The many intrusive procedures represented the most obvious impact of the illness for the children, because something was physically done which caused pain. This also triggers considerable emotional reactions.

Children frequently got injections for tests or to receive medication. For some children the needles seemed to represent a summary of all the fear and agony which was connected with their treatment and they fought them with all their energy, even though they may have somewhat understood their necessity as in the case of teenagers. Some children, who appeared to be very calm and collected normally, started screaming and kicking when it came to an injection.

When parents were present they sometimes had to cope with an additional reaction of the child toward them. This could reflect the contradiction that emotionally close persons took part in seemingly hostile activities. Children seemed to hold their parents responsible for not protecting them.

Every child went through many intrusive procedures with different persons
and they frequently developed some preferences for who was doing it the best way. The same child could react very differently to the same procedure when it was done in a different way by another person. Children acted out less when they are reasonably informed about what was going on and when things were done quickly and precisely at the same time.

(N-13)

Two nurses enter the room and approach Anthony's bed. One of them is the Chemo Nurse who gives the chemotherapy injections.

Nurse: "Anthony, you gonna have an injection."

Chemo Nurse: "It's not an IV, it's just a push, just like your bloodwork."

They go to either side of the bed.

Nurse: "Do you wanna sit up or lie down?"

Anthony: "Lie down." He lies back.

Nurse: "I have to put my arm across you."

The Chemo Nurse puts her tray with syringes down and ties an elastic band around Anthony's arm while the other nurse explains that this is done to "pop up your veins". Anthony says "ow" because the tape squeezes his skin.

Chemo nurse: "I am sorry that I twitched you; can you put your shirt up?" She explains that there is medicine in some syringes and that she has to flush in between. She cleans the skin with a swab, counts "one, two, three" and inserts the needle into the vein. Anthony wiggles his legs a little bit and looks at the syringe.

Chemo Nurse: "That's your medicine. It feels a little bit cold...then I flush again....does it feel funny?...then there is the red stuff, when you pee it will be a little bit red, it's not your blood, it's your medicine."

Nurse: "You didn't even say 'ow'."

Chemo Nurse: "There's a flush."

Anthony watches her closely.
Nurse: "So you got Jim as a roommate."

Chemo Nurse: "Ok, one, two, three." She pulls the needle out and presses a little swap on the injection site.
"That's it. That's it until next week."

Some other explanations followed. This procedure was done swiftly and did not provoke much anxiety. The child received information about what was being done and became quite interested in the process. He was told that an injection would take place and that it would not be a permanent IV. Little time elapsed with preparations where anxiety could increase. The nurse tried to distract Anthony with her comments. This may or may not be accepted by the child, but in this case it did not trigger any noticeable reaction. The procedure was quickly over.

The next day the same child received another injection, intramuscular and by a different nurse. The child's mother was present and nurse and mother began to talk for approximately fifteen minutes while the nurse held the syringe in her hand. With the syringe in his view for such a long time the child began to fight against the injection and had to be restrained during the procedure.

Pressure was often applied when the child did not cooperate. This also involved the parents who tried to make their child compliant with all the treatments and procedures which the hospital offered. The child on the other hand frequently tried to exert counter pressure and exhausted all possibilities in order to avoid something unpleasant and make his/her self come to the surface. This could happen with all procedures or even when medication was given. They were all considered part of the treatment.

(D-10)

Tony is lying in bed and his parents are standing on each side of the bed. Father has a spoon with medicine in his hand. There is no other
patient in the room and the door to the hallway is open. Tony wails and cries "I don't want it" or "Why do I have to take it?" Father repeats "You have to take it." and "Because it makes you better."

Tony: "Why do I have to take the medicine?"

Father: "You answer me this time." (he closes the door, comes closer to Tony and leans over him)

Father and Mother (strictly): "Don’t throw up! If you throw up you have to take more!"

Tony (whines and puts his hands to his mouth): "I don’t want it."

Father (strictly): "Put your hands down or we have to hold them down!"

Mother gives Tony some juice from a cup. After drinking Tony continues to whine.

Father (strictly): "Right now!"

Tony: "Where is the snow?"

Father: "It rained. We'll talk about it later. Do it right now or we'll get a nurse.

Tony cries louder.

Father (turns to the door): "I'll get the doctor."

Tony (yells): "No!"
He opens his mouth. Mother sits down on the bed and Father puts the spoon into his mouth. Tony chews with a disgusted face and swallows the medicine.

Mother (hands Tony a cup with a straw): "Here take some jello."

Tony sucks a little and whines.
Father goes to the sink and rinses the spoon. He says quietly: "This is the worst tasting stuff I have ever tasted."

The parents used increasing threats and Tony used different avoidance strategies, i.e. involving into a discussion "why do I have to take the medicine?", distraction "where is the snow?", or physical resistance by covering his mouth with his hands. In the end the child gave way to the mostly emotional threat of the
parents. This threat also involved hospital staff as a deterrence. On the other hand the parents knew that the medication tasted horrible.

The threat of the adults and the counter activities of children increased with the intensity of the procedure.

8.6.1. Getting an IV

Intrusive procedures pose a threat to physical integrity and may change the feeling for oneself. This is compounded when visible signs of the procedure, i.e. an IV, remain. The lines which are attached to the body become a handicap for mobility and are constant reminders of the intrusive procedure.

In addition treatment procedures may take place without much consideration of the child's state of mind or whether he/she is involved in something else or not. Frequently the child is left overwhelmed with the events. This can be very traumatizing, especially when it is the first time this procedure is encountered, i.e. an IV.

(S-31ff)

Ellen is standing on the side of her bed and eats her lunch. Two nurses approach her and tell her: "We are going to start an IV on you to put some fluids in you."

Nurse 1: "Come up to the bed hon."

Ellen sits on her bed and nurse 1 takes one of her socks off. Ellen smiles uncertainly. Nurse 3 enters the room and brings some bags with fluids which she unwraps on the bed. Nurse 2 leaves the room.

Nurse 1: "You're gonna lay down sweetie."
She helps Ellen to lay down. "Will you stay nice and still for me?"

Ellen nods.

See also chapter "8.8. Children and Hospital Staff".
Nurse 2 (comes back to Ellen's bed): "Have you had an IV before?"

Ellen shakes her head.

Nurse 2: "It will be a little poke."

Nurse 1: "Will you hold nice and still for me?"

Nurse 2 holds Ellen on one hand and her left leg. Nurse 1 counts "1,2,3" and inserts the needle into her leg. Ellen moans and holds her doll tightly. Nurse 1 tries to find a vein without success and pulls the needle out again. Nurse 2 moves closer to Ellen's head. Ellen puts her arms around her. Nurse 2 goes back a little "I'll give you a hug in a minute", and holds Ellen's right leg, while nurse 1 moves to the other side of the bed. Nurse 1 inserts another needle without counting and finds the vein.

Nurse 2: "Okay, it's all in. I am going to tape it up."

Ellen strokes the back of nurse 2 while both nurse bend over her leg and attach a cast to it. After they have finished nurse 2 lifts Ellen up and gives her a hug. Ellen is still holding on to her doll.

Ellen (begins to cry): "I want my Papa."

Nurse 2: "He'll be back later."

Holding Ellen in her arms she rocks a little and tells her about a box with goodies. Ellen cries "Papa". Nurse 1 strokes Ellen's hair away from her face.

Nurse 2: "Did you see the little baby in the other bed?"

Ellen cries with her face down on the nurse's shoulder.

Nurse 1: "What toy can I get you?"

Ellen (continues to cry): "Nothing."

Nurse 1: "Look at this book. Look who is here!"

Ellen does not react.

Nurse 2 puts Ellen on her bed and says: "Look, I wanna show you something", but Ellen cries "no" and holds on to nurse 2, who lifts

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113 I wondered why they attached the IV to her leg instead of her arm, which would make her less handicapped.

114 In some departments nurses have a 'treasure box' which contains small toys for children who have been through a procedure.
her up again. Nurse 3 brings an IV-pump.

Nurse 2: "Look what Conny brings." (The IV-pump beeps) "Oh listen!"

Ellen continues to cry and does not look up.

Nurse 2: "Okay, I have to go now." She puts Ellen, who is still crying, down on her bed, says "I know" and leaves the room together with nurse 1. Nurse 3 sits down on Ellen's bed and takes her into her arms. Ellen puts her arms around her. A physician enters and talks with nurse 3 about medication and "she is having a CT-scan later". Nurse 3 talks to a mother while Ellen is still on her lap with her face buried.

Nurse 3: "Shall I read you a story? She pauses and looks at Ellen who is holding on to her. "Do you wanna look TV?" (no reaction) (a little while later) "Okay, I think we'll put you on the bed." She lays Ellen on the bed who attempts to hold on to her. Nurse 3: "I am not going anywhere."

Ellen curls up and holds her doll tightly. Nurse 3 leaves the room. Another child cries in the background. The nurse returns after a while, makes some notes on a chart, looks at the lunch tray, "Do you want some lunch?" lifts the lid, "Ate it all", and leaves the room carrying the lunch tray.

This had been Ellen's first IV. There had been no preparation. Ellen was on her own faced with a number of people who inflicted pain and restrained her movements. She was overwhelmed and her reaction to the shock (crying) came out after the actual procedure was over. Nurses then tried to remedy what they could. However, no one had time for Ellen. After a while she was abandoned. It is also important to note that sometimes children had an after-reaction, which meant that the reaction to the pain could appear up to several hours after the incident was over.

In this scene some statements were made as efforts to calm her down which proved to be untrue, i.e. a nurse said "I am not going anywhere" shortly before she left. Such statements can undermine the trust in communications. In
passing Ellen was also informed that other events were going to happen, i.e. "she is having a CT-scan later", whose implications she did not know. This incident is also an example how children received information indirectly and how statements were made from an adult perspective to facilitate the completion of the procedure. However, little was done to prepare Ellen for procedures and relate information to her understanding.

The emotions may become still more intense with the increasing scale of treatment and reactions.

8.6.2. Lumbar Puncture (LP)

Lumbar Punctures (LPs) are procedures which are routinely done to examine the involvement of the central nervous system (CNS) and to inject certain drugs. A needle is inserted between two vertebrae in the lower part of the spine. The child has to sit or lie in a curled position and is usually held tightly by a nurse so that he/she cannot move very much. The LP of a 3.5 year old boy can be as follows:

(E-59ff)

10:48

The father carries Tony to the treatment room and lays him on a stretcher in the middle of the room. The room is bare and has bright lights. There is a white sheet on the stretcher and a tray with instruments stands at the bottom side. The Chemo Nurse and Nurse A are standing on one side of the stretcher. Father leaves the room immediately after he has put Tony down. Mother came with them and leaves the room a moment later with tears in her eyes.\textsuperscript{115} Nurse B enters the room.

Tony (screams loudly): "Dad don't!" - "Mom don't do that!" (after

\textsuperscript{115} Parents and child had experienced an unsuccessful lumbar puncture which had been a traumatic experience for them.

\textsuperscript{115} Parents and child had experienced an unsuccessful lumbar puncture which had been a traumatic experience for them.
"I want my mom and dad!" He screams as loud as he can with his eyes wide open.

Nurse B: "They are waiting. You'll see them when we are finished."

Tony (screams loudly): "Don't, don't!"

Head Nurse (enters the room and says to the chemo nurse): "Don't you wanna try it with the parents?" (she turns to Tony) "Shall I get your daddy?"

The Head Nurse leaves and the Senior Resident looks into the room. He leaves after the Chemo Nurse told him that she will page him when she is ready. Tony's mother comes in with the Head Nurse. Mother sits down on the stretcher and Tony curls up in her lap. The Chemo Nurse takes Tony's hand and looks at it.

Tony (stares at his hand and screams): "Don't, I don't want it!"

Nurse A and Nurse B hold Tony's arms and legs. Mother tries to turn Tony's head away from the arm to the other side.

Tony (screams): "I don't want a poke!"

The Chemo Nurse inserts the needle and Tony shouts: "Ow, ow!"

Head Nurse (standing at the foot-end of the stretcher): "It's okay to scream."

The Head Nurse waits for a moment and leaves the room. Tony's screaming turns into crying and then into sobbing.

Chemo Nurse: "That was easier. You are getting used to it."

Tony: "I don't want a machine. I don't want them to push that green thing."

Mother: "The button?"

11:02

Junior and Senior Residents enter. The Junior Resident prepares a syringe behind Tony's back. The Chemo Nurse tapes the IV lines and a small cast to Tony's arm.

Tony is referring to an IV-pump (IVAC) which has a green button with a light for "power" and a red and white button which blinks (white) when the IV is dripping and lights "Alarm" (red) and beeps when the machine gets wrong or no drop signals.
Tony: "I want my dad."

Mother: "There are just a little more jobs to do." (she rocks slightly with Tony on her lap)

Tony: "I wanna get out."

Mother: "We have to sit here for a moment. We have to get your medicine in and it's in already. We can still walk around."

Tony: "Why don't I have it in my foot?"

Mother: "Because you are a big boy and you have it in your arm."

Nurse A distributes face masks to nurses and physicians.

Tony: "Why does this man have that thing on?"

Mother: "So that there are no germs. Do you want one too?"

Tony: "No." (cries a little, sobs)

Nurse A gives mother a mask, mother: "Oh I get one too." The Junior Resident injects a sedative into the IV-line. Tony is not aware of this.

Tony (whining): "I want my daddy."

He becomes sleepy while the physicians and nurses wait.

Mother: "I am just gonna lay you down because it's too heavy on my arm."

She lays Tony onto the stretcher so that he lies on his right side. She asks Nurse A for help who does not react. Mother sits down on a chair on the right side of the stretcher. Nurse A pulls Tony's pants down and holds his legs. The Junior Resident washes his hands.

Tony (afraid): "What are they doing?"

Mother: "Anne (Nurse A) is going to wash you."

Tony (whines): "I don't want a needle."

The physicians and Nurse B prepare needles, syringes, etc. for the procedure.

Tony (whines): "What are they doing?"

Mother: "Go to sleep it's just Anne."
Junior Resident: "We just gonna clean your back."

He rubs some liquid on Tony's back. Tony's wailing increases. The Senior Resident puts the freezing in with a Metajet$^1$ which gives a clicking sound when it stings.

Tony (screams): "Ow, put a band-aid on!"

The Junior Resident rubs more cleaning liquid on Tony's back, who screams louder.

Mother: "They are just cleaning. Close your eyes or I'll have to go."

Tony (screams): "What are you going to do? I don't want a needle!"

Mother: "You don't get a needle."

The Junior Resident inserts a needle and puts some more freezing in.

Tony (screams): "Ow!"

Senior Resident: "You won't feel it Tony."

Tony (screams): "Ow, I want a band-aid!!"

The Junior Resident inserts a larger needle in between the vertebrae. Mother gets up for a moment and looks where the needle is going. Another nurse looks briefly into the room. The doors bangs. A clear liquid is dripping out of the needle. Mother gets briefly up again and takes a look. It is quiet. Everybody is concentrating on the needle. Nurse B comes into the room. The Senior Resident says to Tony: "You won't feel anything." Tony whines a little bit. Mother speaks softly to Tony. The IVAC beeps. Nurse B lets some liquid go through.

Tony: "I want a band-aid on my back."

The Junior Resident screws a syringe on the needle and slowly injects a yellow liquid.

Tony (louder): "Ow, ow, what are they doing?"

Mother: "Don't start crying or I'll have to leave."

Tony: "I don't want her to hold my legs."

Mother: "Ssshh Tony." (after a moment) "What band-aid do you want: a happy face, a witch?"

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$^1$ A Metajet shoots the medication quickly under the skin.
Tony: "I want a witch." (begins to whine louder)

Mother: "Don't." (pause) "What kind of band-aid do you want: a bear, a pumpkin?"

The Senior Resident leaves the room. The Junior Resident finishes the injection and pulls the needle out.

Tony: "What are they doing?"

Mother: "It's all done."

Nurse A and mother pull up Tony's pants. Tony cries.

Nurse A: "Shall we give him his shot in the bum now or later?"

11:35

Tony's father enters and carries Tony into his room and lays him on his bed.

This was not the first LP Tony had to go through. His first LP had actually been quite traumatic. His IV had come out and there had been a lot of screaming and blood. His parents were somewhat reluctant to encounter something like this again and left the room. This, however, increased Tony's anxiety and the head nurse, who had heard the screaming in the hall, suggested they call the parents into the room again. Only Tony's mother came, because his father was still influenced by the memory of the first LP where he had been present. Tony actually received two treatments, an IV and an LP. Tony's anxiety focused on certain objects, for example on the IV-pump, "I don't want a machine. I don't want them to push that green thing." He had obviously observed IVs before and knew that when the green button was pushed the machine would start to work. Pushing the button seemed to represent the threat of body intrusion.

After the IV had been put into his arm the physicians enter and a new
wave of anxiety hit Tony, "I wanna get out". While the nurses and physicians were preparing themselves for the next procedure he showed interest for the things he saw, i.e. putting on the face masks. He got different messages which were meant to calm him down, but he did not get any information about what was actually going to happen. When the next procedures was about to begin his anxiety increased and he wanted to be finished with the procedure. The sign for the termination is the band-aid, therefore he screamed "..put a band-aid on!" The adults tried again to calm the child down, however, their statements were inaccurate and did not tell the whole story, i.e. "..just cleaning.." or "You don't get a needle". Such statements may have a serious impact because they come from the mother in an emotionally tense situation. This may start a cycle in which the child expects help but receives statements which prove to be wrong. Then child begins to distrust those statements in general, especially when they are repeated in similar situations. Several manoeuvres were made to calm the child down, however, the adults were tense as well which was reflected in their voices. The child received a message which was supposed to give comfort with an emotionally tense expression in the voice. This is an example of a double-bind communication which conveys conflicting messages in one interaction. In the end the adults relaxed and tried to talk more to the child - from their point of view - in an effort to distract the child's attention, i.e. "what kind of band-aid do you want: a bear, a pumpkin?" At that point the child was ready to do anything to get out of the situation.

The experience must be worse for children if there is no preparation for the procedure. There may be no time allocated in a tight schedule or it may be just because of the way the hospital organization works. The planning of
procedures seemed to be fairly tentative. Even when children and parents were informed that a certain procedure would happen, it did not mean that it would be conducted at the set time. For example, a lumbar puncture which had been scheduled for the morning finally took place in the late afternoon. The child had received some sedation and a physician said to a colleague: "By the time we get ready we might as well give him another sedation because now I'll be away for an hour. Feel free to do it." The patient becomes just another case in the daily routines and treatments are juggled between schedules and not planned according to the individual needs of care. It also shows how concerns for an individual get very easily lost within organizational matters.

For children and parents the perspective is quite different, because the procedure is a major event. They spent considerable time waiting with increasing frustration and agony. A nurse commented to me about the attitude toward planning which is stated in the example above: "That's why parents complain most about waiting." Nurses were often aware of the situation, but there was little they seemed to be able to do about it. Finally the procedure was initiated when the physician standing at the nursing desk said with a half-loud voice to the child's nurse, who was sitting on a table in the hallway completing charts: "If you wanna take him to the room!?

(K 28)

4:25

The father lifts Sean up from his bed and carries him to the treatment room and puts him down on the stretcher. The nurse goes with him.

Nurse: "Oh we woke you up, how about some music?" (She winds up a musical toy)

Father (to Sean): "Tomorrow will be a better day."
Nurse: "Are you here for a minute?"

Father nods and the nurse leaves the room briefly and returns. The physician enters the room with papers in her hand (a treatment protocol) and asks: "How old is he, two and half?"
Father confirms this and the physician says: "Ten milligrams" and puts the papers away. Father leaves the room.

The nurse takes Sean's diaper off and turns him to his side while the physician is preparing syringes on a tray with instruments. The nurse hold little glass bottles and the physician draws liquid from them into syringes. Sean watches and whines. After completion the physician turns to Sean.

4:35

Physician: "I am going to clean your back."

Sean turns so that he lies on his back and struggles against efforts of the nurse to turn him to his side.

Physician: "Maybe if you (bend) him up and roll him up."

The nurse manages to turn Sean to his side, holds him down with her arms around his neck and his legs, and bends his body so that he is curled up with his back toward the physician, who begins to clean his back with a sterilizing liquid.

Sean (screams): "Mommy, Mommy!" and tries to turn himself around.

The physician tells the nurse to turn Sean further until his back is straight while Sean tries to struggle against the nurse. The physician inserts the needle and Sean is struggling harder and cries. The needle bounces up and down with Sean's back and some drops of blood are coming out.

Nurse (with a monotone voice): "Good boy, good boy."

The physician moves the needle back and forth, waits, pulls it out and tries again. Sean screams and tries to turn around, while the nurse, who bends forward, is holding him.

Physician (taking out the needle): "Maybe we sit him up."

The nurse releases her pressure on Sean and helps him to sit up. Sean cries a little less. The nurse then holds him bent forward in a sitting position.

Physician (rubs again some liquid onto Sean's back): "I am just cleaning."
She inserts the needle and pushes it a little deeper. A few drops trickle out of the needle.

"That's it."

She takes small test tubes from the tray with instruments and catches the liquid which is dripping slowly from the needle. Then she screws on a syringe filled with a yellow liquid and pushes it slowly into Sean's spine. Sean's whining increases.

**Physician** (repeats several times): "It's all finished." As the syringe is empty she pulls the needle out.

**Nurse:** "He needs a new diaper."

**Nurse and Physician:** "Good boy."

4:47

**Nurse** *(lifts Sean up and holds him in her arms):* "Good boy, your daddy will be proud of you."

She tries to pull the IV pole towards her. The physician helps. **Father** enters the room.

**Nurse** *(to father):* "It's over." *(to Sean with higher voice reflecting surprise):* "Look who is here! Is this mommy? Is this Santa Claus?"

**Sean** *(sternly):* "No!"

**Nurse** *(with the same high voice):* "Someone is going to hold you."

She gives Sean a new diaper and then lifts him into his father's arms.

**Physician:** "He was really good."

**Father:** "It didn't sound like it."

**Physician:** "He was very very good."

**Nurse:** "Yes it hurts."

*They leave the room.*

At first the nurse tried to distract Sean with some comforting words when she said apologetically "oh we woke you up" with a slightly higher than usual tone of voice and wound up a musical toy. The procedure had yet to be set up. The physician checked how much medication she was supposed to give.¹¹⁸ Then the

¹¹⁸ At this point I felt somewhat concerned, because powerful drugs given into
instruments were set up while the child watched how the syringes and needles were being prepared which increased his anxiety. No explanation was given to the child. When the nurse tried to position him he struggled against this because by now he was really scared.

In addition the child had been sedated. Children can react very dramatically to different sensations in their body. Sedation may be compared to being drunk when the perception is limited to tunnel like sensations where only a small focus is possible. Movements into specific directions may be difficult which can trigger frustration and anger, especially when a threat approaches. It may be experienced by the child as being forced into a nightmare from which he cannot escape, not even by waking up.

Father left the room because he did not want to be part of Sean's bad experiences. He thought that this would enable him to continue to relate positively to him. Sean was forced into the procedure, but he mobilized his energies to fight against it. The nurse was struggling with his movements while the needle was already inserted. The stereotype "good boy" sounded emotionless and empty. The physician said "it's all finished" before the procedure was actually over. All those phrases had the intention to calm Sean down, but they sounded hollow. After the procedure was finished nurse and physician praised Sean again "good boy", which again sounded rather as a mechanical expression of their own relief than to reassure Sean. Efforts by the nurse to

\[\text{(cont'd)}\] the central nervous system can have quite an impact. I hoped that the physician had the right protocol in her hands and knew what she was doing. I also wondered what impression the father got from this.

\[\text{119} \] During this part I became quite annoyed with the procedure and felt at the same time scared that the needle would hit the stretcher and injure Sean's back.
children cheer up Sean with humour which was meant to be child appropriate triggered only anger.

When Sean was praised for his conduct during the procedure "he was really good", the father's reacted skeptically because he had perceived the anguish "it didn't sound like it". Father had probably watched the whole procedure through a slot between the two entrance doors which permitted limited vision into the room. It seems that all communications were only futile attempts of a cover-up, while important messages and honest information were avoided.

Lumbar punctures or other treatments may involve several pokes. Especially when there are unsuccessful attempts to reach the spinal fluid, the pokes during an LP may reach two digit numbers. It is obvious that those intense situations and the communications in them can have an influence on a child's relationship with other persons as well.

8.7. CHILDREN AND THEIR PARENTS

The relationship of children with cancer and their parents changed during the illness. Children seemed to need the relationship with their parents on the one hand and on the other they held them responsible for some of the things which happened to them during the treatment. When children were alone in the strange hospital environment they frequently missed their parents.

When parents came for a visit the reactions of the children varied between ignoring the parents by looking away or forms of slight aggression (i.e. making complaining noises when parents tried to talk friendly or jokingly to them), and a bright smiling welcome. However, I rarely noticed open expressions of joy and physical contact like hugs, stretching arms towards parents, etc. This
is somewhat different from other observations which have been made in a hospital setting (Beuf, 1979). This may have been due to the awkwardness of the situation that everything was quasi public in the architecture of the setting. It may also have been a characteristic of those families who were possibly not very expressive in their emotions. Open joy, apart from a faint smile, was rarely shown when parents came to visit.

Younger children sometimes ignored their parents when they came to visit. They even displayed signs of aggression when their parents approached them. This was a way of holding the parents responsible for what was happening and it was an effort to punish them. It is as if they wanted to say, "You have been away when I needed you, now I am going to let you know". This was a somewhat contradictory behaviour, because children missed their parents when they were not present. Children even became quite anxious and wanted to know, what parents were doing when they were walking around in the hospital, who they talked to, etc. Children were especially concerned when they became aware that their parents were talking to members of the medical staff.

Children often acted out their anger and aggression toward their parents. In a way they seemed to be held responsible for the suffering. This could be quite hard for the parents, since they did not seem to get positive emotional feedback, which they may have expected for their care. When parents stayed with the child power play and displays of complaining behaviour seemed to be more frequent. Children seemed to use the parents as an emotional retreat for negative emotions which have been generated by the present circumstances. Children reacted frequently with power struggles in many different situations.

(N-37)
Mother and Anthony talk about dental care.

Mother: "You have to keep your mouth clean."

Anthony: "No!" (presses his teeth together).

Such a display of unwillingness and resistance may be common with children, however it seemed to increase in the situation in the hospital. It can be interpreted as a way to maintain some self determination. Those reactions could be considerably stronger when the parents took part in medical procedures, i.e. giving medication.

Children usually established good relationships with other parents or regular visitors of other children. They were more likely to become "parent substitutes" than nurses who were associated with unpleasant feelings relating to hospital and treatment procedures.

8.8. CHILDREN AND HOSPITAL STAFF

Initially children were withdrawn and reluctant to establish any communication with hospital staff. This was true especially for young children. Some children were also very polite and used the behaviour they were educated to use with strangers. Initially they were not able to distinguish between the different professional roles in the hospital. Everyone could be regarded as either nurse or doctor. After they had encountered some intrusive procedures they withdrew more and were afraid of closer contact to hospital staff. The more time they spent in the hospital the better they learned to distinguish professional roles. Children established relationships and drew conclusions about the importance of persons which was not necessarily related to the hierarchy in the hospital. The persons who administered painful procedures stood out in the perception of children, e.g.
the Chemo Nurse.

In general they developed a somewhat suspicious attitude toward hospital staff, because children could never be sure about their intentions. Someone could just want to talk or niceties were only said as preparation for a treatment. This made mutually open relationships difficult.

8.8.1. Children Relating to Nurses

Nurses seemed to represent most activities of the hospital. They gave injections and medications, took part in the various treatments and looked after the child when the parents were not present.

'Nurse' was used as a collective term for various professions. Initially the Unit Clerk was a nurse as well as the technicians. They all wore similar uniforms. Distinctions between the various subgroups were developed gradually. The Unit Clerk would become "the nurse in pink" or "the nurse at the desk", although her duties were not clear to the child. Preferences toward individual nurses seemed to be influenced mainly by personality factors, e.g. when a nurse was regarded as "funny" in a positive way, or by technical aspects of their work, e.g. how injections were given. Children preferred to get injections from specific nurses. Because children were quite sensitized due to the many injections they received during the course of their treatment, they also had gained experience with respect to how things should be done.

Children and nurses had a limited perception of each other. Nurses implemented the medication and were therefore connected with pain and injections. Some nurses had a difficult time establishing a unstrained relationship with children.
Nurses assumed a triple role, they were the persons applying the treatment, they were educators, and they related to children on a personal basis. However, these different roles were sometimes conflicting and children often did not know which role a nurse had. Children developed apprehensions to a person who was afflicting pain and they often looked suspiciously at nurses even when they were socializing in a friendly manner. Children learned to look for signs of an impending treatment, like moving an extra table close to the bed or bringing suspicious packages, which could contain sterilized instruments, into the room. The role as an educator, which meant in this context the teaching of behavioural rules, had its own problems, because there was little consistency among the nurses. For the children it must have seemed like having more than twenty parents. The lack of consistency also enabled children to play with the rules and and make tricking nurses a sport.

Nurses clearly enforced their own agenda with the children and intruded without respect for the child's activities. They were intruding in at least two ways

1. the physical intrusion with injections, IV's, body care, etc.
2. the intrusion into the personal sphere by applying whatever measure seem necessary for the treatment without much consideration for the child's privacy.

Children's reaction toward nurses seemed to be influenced by two major areas of concern. One was a reaction as a defense against the various intrusions and the other was an effort to have a relationship out of the need to relate to nurses as an important group within the hospital setting. In a way children wanted, like the nurses themselves, good relationships however, this was made very
difficult by nurses' roles in the delivery of treatments, by the lack of open communication, and by the changes in staff.

Good relationships need time to develop. This requires some time in order to get to know the environment, the persons, and their activities and involves an actual time period which persons spend together. This time seemed to be missing and this created a lack of insight for each other's interpretive frame of reference. Attitudes and reactions were interpreted on the basis of one's own knowledge which did not necessarily incorporate the other person's reality. In addition children learned to distrust communication from the experience that nice words were often paired with nasty deeds which made good relationships even more difficult.

Nurses had to care for several children at the same time and children experienced the care of so many nurses that it became very difficult to establish personal links. Nurses just became representatives of hospital and treatment. It is no surprise that all this made children reluctant to establish closer personal contact with nurses. As one expression they also tried to avoid physical closeness, e.g. reject getting a hug from a nurse.

8.8.2. Children and Physicians

Children learned quickly that physicians were important, because they made all the decisions. However, this importance was generated by others. Everyone within the hospital looked up to the physicians as the persons with the responsibility for the treatment. For children they were more distant because they rarely had

\[120\] A very nice literary description of the process of getting to know each other can be found in the little prince's relationship to the fox in Saint Exupery's *The Little Prince.*
time to stay a while with the children. They came to examine children, checked out the situation, or answered questions of the parents. Their visits rarely lasted longer than one or two minutes if they were not doing a physical examination or giving a treatment, i.e. LP etc.

Children learned from their parents that they had one specific physician as "our doctor". If the parents were not there children sometimes did not know who "my doctor" was, because many different doctors and medical students visited and examined children. They were all "doctors".

(X-3)

**Anthony** (seven years) had been in the hospital for several weeks. One day he looked at the little sign at the end of his bed and read his name. He found another name under his own.

"Who is that?"

**Björn:** "That's your doctor."

**Anthony:** "No, every doctor who comes in is my doctor."

Although he had spent considerable time in the setting, he did not know that he had become the patient of a specific physician. In fact other physicians, especially medical students, had spent considerably more time with him than "his" doctor.

Doctors were somewhat distant for children and therefore they did not necessarily get the correct answers when they asked the child something. For example, when the physician asked "how are you" or "how is your tummy" the child may have said "fine" although he/she was in pain.

Medical Students often spent more time with an individual child when they made a physical examination. If no threat was perceived, e.g. no impending injection, a child was more likely to open up and talk, ask questions, become
interested in the various instruments, etc. During those interactions the child heard many explanations about the intent of the examination, however, information dealing directly with the illness was excluded, because Medical Students seemed reluctant to talk about it. On the other hand groups of physicians and Medical Students frequently exchanged information in conversations which could easily be overheard by a child. A meaningful conversation about the illness between physician and child seemed to be the exception.

8.8.3. Children and Child Life Worker

Child Life Workers spent longer intervals with the children. They were somewhat like islands on the ward, especially because they did not inflict pain during treatments. In the play area children met each other and could play with a variety of toys. It is no wonder that some children developed a special relationship with the Child Life Worker and they sometimes even wanted her to be present during an injection and hold hands. Once children knew the role of the Child Life Worker they generally seemed to be looking forward to activities with her. Children with more ward experience sometimes asked nurses where she was when they could not find her.

The play area was a semi open area on the ward which was at times quite crowded. Frequently games were interrupted by medical staff for treatments and examinations, but also to establish a more friendly contact. They saw the children in a more relaxed mood and tried to catch a little positive feedback, i.e. a smile from a child. Nevertheless this could also interrupt the flow of

\[121\] For a more detailed account of the work of a Child Life Worker look at chapter "6.4. Child Life".
It was not always perceived as a retreat and sometimes children rather took some toys and played in their own room.

Doctor games and giving injections to dolls played a major role in play activities. It enabled children to act out some of their experiences and apply their knowledge about the medical procedures. However, the play area also was a center for social contact between children and a space where they exchanged information.

8.8.4. Other Staff

Children saw a number of persons regularly, depending on the type of cancer and their physical condition. All children had regular encounters with technicians who took bloodtests. They were known and children looked at them anxiously when they entered the room. If there were more children in the room they never knew who they are going to poke this time. However, all staff contributed to the hospital atmosphere. The technicians knew the children even less than the nurses and most of them did their job in a rather technical manner which offered little relief for the children.

Another staff member was the cleaning lady who was not threatening, because she did not take part in any treatments. With jokes and a little bit of teasing housekeeping staff were able to create a more relaxed atmosphere for a few moments. For example one cleaning lady sometimes addressed me as "my boyfriend". One day the following conversation developed.

(Y-14)

\[122\] See also the comments on privacy in the subchapter "6.3.6.3. Understanding Children".
Martha (to Björn): "How is my handsome boyfriend today?"

Allan: "I am gonna kill him."

Martha: "Why?"

Allan: "Because he is my boyfriend!"

Martha: "No."

Allan: "He is my boyfriend!"

Martha: "Okay."

Allan: "He is yours."

Martha: "Oh, come on!" (to Björn): "Whose are you, his or mine?"

Björn: "Mine!"

They all laugh.

Allan reacted openly and displayed considerable humour. He also felt encouraged by this interaction to relate more positively to some other persons a little later that day.

8.9. CHILDREN AND SCHOOL

The attitudes of children toward hospital school varied. A reluctance to go to school can come from a variety of things. Sometimes an aversion was expressed openly, but it may nevertheless be difficult to interpret the underlying feelings.

(O-5)

9:50

Child Life Worker and volunteer enter Allan’s room and come to his bed.

Child Life Worker: "Hi Allan! You didn’t go to school?"

See also the chapter "6.2. Hospital Teachers".
Allan shakes his head.

Child Life Worker: "Did no one take you?"

They pause for a moment and leave the room and talk with the nurse in the hallway. The nurse comes to Allan's bed.

Nurse: "You can go to school now."

Allan: "I don't wanna go." He begins to cry.

Child Life Worker (standing at the door): "I can go with you for a while."

Nurse (wipes away Allan's tears): "Let's go for a little while."

Child Life Worker: "It's just Monday."

(brief silence)

Child Life Worker: "Let him come around and we'll see." (leaves)

Allan tells the nurse that he has already done his work with mom.

Nurse (talks softly to Allan): "maybe you show her and tell her that you've already done it, because she doesn't know." (pause) "I come with you."

Allan: "I don't wanna get dressed."

Nurse: "Let's go and show her otherwise she will ask where you are."
She gives Allan his pants and closes the curtains at his bed. She helps him to get dressed and brushes his hair.

9:59

The nurse and Allan leave the room.

Nurse (puts her arms around Allan's shoulders): "Show her what you did with your mom."

They arrive at the classroom where the teacher greets Allan.

Teacher: "Hello Allan! You can sit here."

Allan (does not move): "I already did it with my mom." He begins to cry and steps backwards. The teacher offers him another place where he can watch some pictures (slide show with audio tape).
Teacher (to nurse): "Can you stay?"

Nurse: "I have to take care of another kid."

Allan cries.

Teacher: "You need a hanky. Too bad that Jim is gone."  

Allan cries "ouwie" and holds his throat with his hands. The nurse puts her arm around his shoulders and talks softly with him. She gives him a tissue, squats down next to him, and points to the tape recorder. All of the nurse helps him to put headphones on. The teacher switches the recorder on and Allan can see pictures while listening to a story. The nurse stands up and stays for a moment behind him.

Nurse: "Are you okay?"

Allan: "No."

The nurse stays for a while behind him and strokes his back. Then she says "I’ll come back, okay?" and leaves the room while Allan continues to watch the story.

This whole episode may have been related to the fact that he had just returned from a weekend pass with his mother and aunt. On Friday it had been mentioned that he probably could leave the hospital and come back as an outpatient. However, both parents worked and lived out of town. Therefore he had to stay in hospital on his own. Neither teacher nor nurse knew this and were therefore not able to relate to the child’s immediate history and feelings. The nurse, however, could have picked up from the nursing notes that Allan had cried last night and calmed down after a nurse had talked to him for a while.

In addition the child had been moved from one room to another without giving him notification although he had just arrived back the evening before. His

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1 2 4 Jim was another hospitalized boy of similar age who came to the same class.

1 2 5 This part of the conversation could not be understood.
Children / 348

nurse commented that she had to get his things from the other room in the morning because they had not been transferred (O-16).

Another reason for his reluctance may have been his dislike of school. Quite a while later this boy commented that he hated school. Interestingly he seemed to like doing schoolwork with his mother.

The interpretation of the cause for his feelings is difficult. In this case adults have reached their conclusions without trying to understand the child’s feelings. Relating to each other’s emotional state sometimes requires spending some uninterrupted time together. Within the given time frame of hospital routines, however, the necessary space for individual coping processes and feelings was often not available.

When he came to school the next morning he began to cry again. After he watched a story on the recorder the teacher made an effort to involve him into the school activities, not without obstacles.

(O-33)

After Allan sat down at the table the teacher shows him a puzzle. Allan shakes his head.

Teacher: "What’s your favorite?"

Allan: "Nothing."

However, the teacher did not push him to do much work and after a while he participated in school activities.

Children need time to be able to orient themselves and even when they have spent considerable time in the hospital their emotions may make them preoccupied so that they are not able to do much else. This can also change their attitude toward school from day to day. School is also a place where they
engage in common activities with other children. However, to be able to do this they must have established relationships with other children in the hospital.

8.10. CHILDREN RELATING TO CHILDREN

Children who have spent more time in the hospital were interested in new children, especially when they had interesting new toys. However, when children were admitted they were usually rather shy and withdrawn. Sometimes parents or relatives served as mediator and interpreter for children.

(L 22)

Anthony lies on his bed and watches his aunt and mother draw pictures. Randy enters the room on a tricycle and drives right up to Anthony's bed.

Randy: "Hi."

Anthony does not react.

Aunt: "Maybe in a couple of days."

Randy tells a story about a toboggan ride to Anthony's aunt while Anthony observes him.

(L 28)

One and a half hours later Randy walks into the room and approaches Anthony again.

Father: "Give him some time, maybe tomorrow."

Randy (disappointed): "I have been waiting so long."
He leaves the room.

(L 31)

During the next morning Randy comes again to Anthony's bed. Anthony does not react, but his father greets Randy.

Randy: "Can I play with your GI Joe?"

Anthony shakes his head.
Father: "Try again tomorrow."

Randy (annoyed): "I'll try again and again and again until he leaves."
He leaves the room.

Later those two children happened to be in the same room and then they played frequently with each other. Anthony’s parents were not present very often which made it more necessary for him to relate to other children. However, the first apprehension seems to be quite typical. It could be observed in different forms with other children as well. Adaptation requirements and constant presence of parents inhibited relationships initially.

The notion of mine or yours also develops over time in the hospital. With personal toy this is quite straightforward. Children can be very possessive about their toys and this is especially so when other children are present whom they do not know and did not chose to be with.\(^1\)\(^2\)\(^6\) However, when they get to know other children and become more familiar with the environment, they also discover their toys and their curiosity leads to an exchange of toys. This process seems to be more inhibited when parents are present. Children withdraw more to their own things.

The notions of "mine" and "yours" also involve the physical environment after it became somewhat familiar. There is talk of my IV, my bed, my table, etc.

(N-30)

Randy wants to test a pencil and begins to write on Albert's bed. Albert pushes the paper away and says: "not on my bed".

\(^{126}\) D.H. Lee (1975b) described this as "solitary togetherness" when children are put into a bed in the middle of a company they did not chose and cannot change.
Albert had already acknowledged the hospital bed as his.

Age played a role in the relationship of children although children with different ages played together in the play area. Children of similar age seemed to relate better to each other. Between younger and older children there was sometimes a hierarchy, similar to children behaviour outside hospital settings. When parents were present children sometimes talked to them instead of talking to the person they wanted to communicate with. This could also happen between children. The parents then assumed the role of a safeguard and a translator.

(O-18)

Bob (3.5 years) and Anthony (6.5 years) are lying in their beds. Bob's father is sitting on a chair between their beds. Bob whispers to his father.

Father (to Anthony): "Do you like to watch He-man?" (pointing with his head at Bob) "He is shy."

Anthony nods.

Father (to Bob): "Yes, he does."

Bob (speaking softly to his father): "I have a Greyskull castle."

Father (to Anthony): "He has a Greyskull castle."

Anthony: "Me too."

Father (to Bob): "He has the castle too."

...

This continued for a little while and the father continued amused until they both finally talked directly to each other with a little help from Bob's father:

Bob (to his father): "I want to play with him."
Father (to Anthony): "He wants to play with you, do you want to play with him?"

Anthony lifts his left shoulder.

Bob (to his father): "I want to play with cars."

Father: "I can take them out but you have to do some things for yourself."

The strange environment and initial shyness created this situation where the father had to act as a mediator and translator to overcome the apprehension to talk to each other directly. The children could understand each other quite well when one of them spoke. However, once created they accepted the interaction via a person who could be trusted.

Younger children seemed to relate to other children simply because they shared the same environment. Daily events and toys were the main topics of conversations. Communications about their own situations revolved around concrete aspects of the treatment, e.g. the number of injections, IVs, rather than dealing with issues of the illness in more abstract terms.

Older children occasionally talked about their illness. However, the fact of their illness seemed to be a bond between them, rather than conversations about it. Peer relationships appeared to be very important in this situation because children were able to relate to each others perceptions on the basis of a common experience.

8.11. THE PERSPECTIVE OF CHILDREN WITH CANCER

Children with cancer had a twofold dilemma, they had to deal with their illness and they had to cope with the changes in their physical and social environment. In addition it was very hard for them when no apparent meaning for many
events was communicated to them. They were forced to make up their own interpretations.

The true impact of the illness became a reality for children with the onset of the treatment rather than with the first symptoms of the illness. Their physical environment changed and children as patients were subjected to many new rules and role expectations.

A sick person is expected to fulfill certain social role obligations. Talcott Parsons (1964) described the sick role with four points:

1. Exemption from blame for the "sick" condition,
2. Exemption from other roles - such as that of student or worker,
3. The obligation to get better.
4. The obligation to cooperate in the therapeutic process.

This model has been criticized for a lack of consideration of different types of illnesses (Beuf, 1979; Schreier, 1981). It also does not reflect the role expectations for a patient within an institution nor age related differences. However, the model may serve to highlight some role related issues.

Cancer is a special case of the sick role in several ways. In their desperate search for meaning children sometimes drew their own conclusions about the blame for their condition. Parents may be held responsible or own behaviour preceding the treatment (Schowalter, 1970; Bluebond-Langner, 1978).

Since the treatment of the illness constitutes a long term process, exemptions from other roles are only temporary. To participate in other activities, i.e. school, is considered to be important and also reflects the hope of adults for a complete rehabilitation.

Getting better is a long-term process and since the harsh treatment
worsens the physical situation of the patient temporarily an obligation to get better is connected to a larger framework of treatment and care. Adults rationalized treatments with the expectation that it will get better. However, children were usually not able to share this because they experienced the situation differently. They were subjected to traumatic procedures and felt worse rather than better. This created a conflict of meaning between what they were being told and what they experienced.

Cooperation with the therapeutic process may be in conflict with the role of the child-patient who is not supposed to understand the context and its implications and therefore has to be forced for his/her own good. A certain amount of difficulties with a child's behaviour may be tolerated as part of coping processes and may be considered as a challenge.

The younger children were the more likely they were forced into a treatment since they reacted more on an immediate level of emotions rather than according to the more distant values of "being better, healthy etc.". Ann Hill Beuf (1979) noted that children have a double disadvantage. They do not know what is wrong with them and they cannot assess the quality of the interventions of hospital staff.

After the successful completion of a whole treatment phase a child has gained some experience and may be more able to tell if it works or not. However, evidence if the treatment actually works is difficult to obtain since it is beyond the realm of direct experience. Children with cancer remain connected with the hospital for a long period of time, they have to continue to take a considerable number of drugs, and they still feel miserable sometimes. Since no complete recovery is achieved but rather a somewhat ambiguous state of
remission, children as well as their parents remain in a position of uncertainty, which leaves the search for meaning unresolved.

Children had a particularly difficult time understanding why all this was happening to them. They seemed to form their concept of the illness from the experiences which they had during the treatment. And they were also able to perceive that this illness was different from others from the reaction of adults, particularly their parents, and from the new medical procedures to which they were subjected. They were forced to participate in threatening and painful procedures in an unfamiliar environment. Adults, including the parents, participated in a more or less forceful way to ensure that all procedures could be performed. At the same time, as research indicates (i.e. Spinetta et al, 1975), those procedures do not necessarily become less anxiety provoking over repeated exposure. In fact sometimes anxiety increases.

Children had a difficult time with their relationships which seem to be thrown out of balance. On the one hand there was the sheer number of new persons which a child encountered in a hospital setting. Every relationship has individual characteristics and obligations. At the same time the child has lost some of his/her self determination as a patient in the health care system, which gave more power to persons other than oneself. Treatment requirements increased the disregard for the child's personal needs. The child was not treated as a person any more (s.a. Bartholome, 1982), but rather he/she became subjected to the effects of decisions without a chance to participate.

Verbal statements frequently did not match with the emotional context in interactions. This became especially apparent during intrusive procedures where

\[127\] See also chapters 8.2.1. and 8.2.2. as well as Bluebond Langner 1975.
Children received many conflicting messages. Communications of adults became goal oriented and tended to ignore the child’s emotional state, thereby removing the child further from the context of a mutual relationship. This loss of context left the child increasingly alone with the search for meaning and the need for emotional nurturing. Conflicting messages and attitudes increased a general distrust in the relationship to other persons.

The relationship between parents and their children with cancer also faced serious challenges. Parents and child were on a different level of experiences and looked at the situation from very different angles. If they cannot communicate well they will move further apart. Communication, however, was handicapped by differences in emotions which were paired with the differences in judgements of what was good or should be done. If parents see themselves as the enforcers of prescribed procedures, which they believe are for the good of the child, they risk losing the contact with their child which is of paramount importance for his/her well-being.

Children frequently encountered adults as a united front against them. Adults worked together and forced children into painful procedures. However, there was not only the physical pain. It seemed as if there was no way out. In several interactions it must have become apparent for the child that there was a collusion of the adults. This collusion took place in two forms. One was the direct cooperation to perform a medical procedure. The other was more subtle and reflected coping behaviour. When a child acted out adults occasionally made joking remarks about the child which reflected a misunderstanding of the child’s situation, but they made provisions for an adult to maintain his/her role, e.g. when a nurse was unable to cope with a child’s behaviour she may tease this
child indirectly with remarks addressed to another adult.

Children had to cope with the physical symptoms of their illness, the discomfort of the treatment, a deterioration in their relationships, severe limitations of their personal sphere, and an enormous amount of new and ambiguous information. However, there were also gaps in the information which children had to fill with their own interpretations. In addition there was a lack of consistency in the attitudes of the adults who nevertheless - from the child's perspective - seemed to be united to enforce the suffering. This additionally defied attempts to make sense of the events.

During the treatment an adversarial relationship seemed to be created between children and adults. A lack of communication created distrust from the children and reinforced the adults' view that children were not open to cooperation anyway. The organizational framework of the setting supported both views by keeping staff busy with organizational matters and by creating inconsistent relationships for children. This was very unfortunate for children because they lost self-determination and became an object in a system which was almost impossible to understand. This may also have an effect on the recovery because the child's own willpower and resources remain largely unused in the important fight against the illness.

With increasing survival rates the physical and psychological long-term effects of the illness gain more importance. Studies indicate that the distrust of close relationships and other psychological difficulties may have a lasting effect (O'Malley et al, 1979; Bearison and Pacifici, 1984).
8.12. OBSERVING THE CHILDREN

The first contact with children I was going to observe usually took place in the presence of the parents. I usually introduced myself to the parents while the child was present. However, before I actually started to observe children and spend time with them, I introduced myself personally to them as well.\textsuperscript{128} I kept my introduction short and I pointed out that they could always tell me when they did not want me in the room. When I came into the room I asked them if I could stay with them for a while. Parents sometimes added something to my explanation in their words.

In one instance I introduced myself to a girl after I had talked to the father while his daughter was not present. The girl was quite open to my presence in the beginning and asked me to paint her fingernails, which I did.\textsuperscript{129} However during my first encounter with her she received her first IV. After that she shied away from me whenever she saw me despite efforts of the father to explain to her that I did not have anything to do with the IV.\textsuperscript{130} She would sometimes watch me and when I looked at her she quickly looked or walked away. I was not sure if this was a game or whether serious feelings were involved, but because I did not want to risk being an additional burden I refrained from doing more observations of this child.

It sometimes happened that children did not want to say good-bye and when the parents started to tell them, "Say good-bye to Björn", I usually said,

\textsuperscript{128} Examples of introductory statements can be found in the appendix.

\textsuperscript{129} "So much for unobtrusiveness", I thought.

\textsuperscript{130} This child lived together with her father after her parents separated. The reaction may also have involved some projection of anger onto me due to her present experiences and her relationship with her father.
"It's okay". Good-byes and thinking of a longer time frame of hospitalization was sometimes difficult for children. For example one boy (almost seven years old) shook his head when I said good-bye and told him that I would come back next week (it was Saturday). When I came back on Monday and asked him, "Can I stay with you for a while", he nodded.

Rejection of my presence did not often occur during the observations of children. It was rather attachment that I had to deal with, especially if the parents were not present very frequently. Children asked where I was and when I would come back. One boy named me "my buddy" and took my hand when he wanted to go somewhere and he felt insecure about it. He also hid behind me during games with other children. For another child I was "that man". In a way I must have represented some security for the children due to my constant and quiet presence. However, I do not think that their reactions to hospital staff and medical procedures were greatly influenced by my presence.

At first children seemed to ignore me and they looked at me quite rarely. Then they began to look at me when other persons talked to me. After that I sometimes perceived that they watched me while I was writing. I sometimes responded quietly in looking at them briefly or with a brief smile. Later they looked back to see if I was following when they had to go somewhere. They also sometimes looked at me when a staff member talked to them as if they wanted to make sure that it was okay to talk to that person. Sometimes children played with me or commented about the things they saw.

Gradually I became an institution. Children commented when I was late in the morning. They also knew my ways and where I was usually sitting. When a volunteer visited a child I was observing at that time and asked if he
could sit down on the chair standing at the bedside, the boy pointed at me and said: "No that's his chair" (U-6). Other children knew who I was with and directed me to the child I observed at that time.

The children became also more interested in what I was doing. My most obvious activity was writing.

(V-19)

\textit{Björn} \ is writing into his notebook at the nurses station.

\textit{Anthony (approaches him)}: "What are you doing?"

\textit{Björn}: "I am writing."

\textit{Anthony}: "Why are you not doing it in the room?"

\textit{Björn}: "I'll come later. I am just writing about the meeting I had."

This shows that children were not only aware of my activity, but it also took place at a certain place. This is quite common in children's perception which deals very much with the concrete. Children became also interested in the content of my writing.

(V-20)

\textit{Anthony (takes Björn's pen and pretends to write into his notebook)}: "Look I writed something."

\textit{Björn}: "I can't read it."

\textit{Anthony}: "You got your glasses." \textit{(he points at the page of the book)} "What does it say?"

\textit{Björn} reads about things Anthony has just done.

\textit{Anthony}: "You're writing everything."

This situation came up only after I had spent considerable time with this child.
My quiet presence led to a situation where the children put me on the same level as themselves. One conversation showed that I must have been regarded as maybe a tall child.

(V-29)

Anthony: "I don't know what I am having for supper tonight."

Björn: "You will find out."

Anthony: "Do you know?"

Björn: "No."

Anthony: "What will you have for supper tonight?"

Björn: "I don't know. I have to go home."

Anthony: "Will your mother cook it?"

Björn: "My wife."

Anthony: "No, your mother."

Anthony did not want to accept that my situation was not the one of a child any more. I was accepted on a close level. This also enabled me to communicate with children using their symbols.

(V-37)

Anthony (walks to another child’s bed limping a little): I walk funny, you know why?"

Björn points with his forefinger at his leg (the way children do it when they play injections).

Anthony nods.

Interacting with nonverbal symbols gave me access to children’s symbolic level of communication.
Children’s relationship with me also changed over time. At first there seemed to be a little apprehension, which is quite understandable under the circumstances. Then there was a period of testing where children seemed to find out more about what I was doing. They sometimes asked their parents or they asked me "What are you writing?". Later they regarded me as their friend and expected me to be present.

(Y-39)

I am walking down the hallway. Anthony sees me, comes closer, and takes my hand.

Anthony: "Did you come to visit me?"

Björn: "Yes, I was just looking for you."

Anthony: "You are my friend." (to other boy in passing) "He is my best friend."

We go to his room.

Anthony reacted in a very friendly manner because he knew me as a non-threatening person and because I fulfilled his expectations. If I would have said "No, I am going to visit someone else", he would have been disappointed and his expression of positive affection to myself would not have taken place. The circumstantial context has to be taken into consideration when an evaluation of children’s utterances takes place. It is also important to note that this appreciation from the child took place while I did not take any direct action toward the child. It was the permanent and unthreatening presence which drew emotional attention.

While observing the children I was concerned if the attitudes of other persons toward children would change. Sometimes I thought that staff, especially
nurses, might interact less with the children because of my presence. One person was there all the time so the social side seemed to be taken care of. If something was wrong I probably would have alarmed them. One nurse left the room after she had given an injection to the child and said to me: "You'll call me if anything happens". This gave me a role without choice which I did not want. However, I think that the interactions which took place were not very different from the interactions which occurred without observation. The interactions of staff with other children in the room while I was observing a child or happened to visit in another room did not seem to be very different.

During the observations I made an effort to put myself in an unobtrusive position. I usually placed myself so that the children did not immediately see me when they looked up. This was sometimes not possible, especially when there was limited physical space. This was the case during procedures in small treatment rooms, but it also could happen in the child’s room.

When visitors were with the child I did not want to interfere with too much personal closeness. Therefore I sometimes sat under the TV where I could be out of the way. The persons in the room would then frequently look into my direction, but since I did not move much I became almost a part of the physical environment. Sitting under the TV sometimes created a problem because I could not understand all of the conversations when the volume was turned up.

Some visitors included me in their interactions with the child and made comments in my direction or asked the child to show me something he/she had done. This made my presence more obvious to the children and at the same time I received a closer introduction to the child’s sphere of action.

Teenage children seem to be more aware of the implications of cancer and
probably think about it more in terms of their life-plans. In a reference to my presence one boy made this apparent. I had explained my study to this boy and his father and the father had told me something about his experiences with cancer in the presence of his son. Later a nurse commented on the University T-shirt which the boy was wearing and he said pointing at me with his head (P-50): "I'll do what he does". This probably reflected not only interest into University life and a hopeful outlook for the future, but also an interest in my study.

It was an experience for me that the presence of a person who did nothing to alleviate pain and suffering, but who was consistently there, could generate attachment and comfort.
9. THE LAST CHAPTER

The initial momentum for this study came from a personal experience with cancer in the family. The experience initiated a search for more information about coping processes and issues which arise within a family when one member is severely ill.

The literature on childhood cancer addresses issues such as coping with terminal illness and treatment, telling the truth about the diagnosis, and dealing with personal emotions. However, the studies and reports, particularly in the earlier literature, often reflected the individual positions of the authors as they were involved in the processes of care for the children. Studies of professionals tend to address emotions like anger, grief, fear in their behavioural appearances and categorize behaviour into models of coping mechanisms which suit statistical analysis (Neff, 1978; Katz et al., 1980; Farley, 1981; Kupst et al., 1982b). However, these processes are not static but evolve from the dynamic interactions of persons in a particular situation and therefore valuable information is lost. Anecdotal reports from parents on the other hand give insights into personal experiences and their dynamics, but they are mostly tied to individual situations (e.g. Ludwig-Klein, 1980). In recent years more research was conducted, often on an interdisciplinary basis, which addressed issues of the family as a whole and the relationship between family members and hospital staff (Zucker et al., 1982; Copeland, Silberberg, Pfefferbaum, 1983; Chesler, Barbarin, 1984; Thiel, Knispel, Wallis, 1985). In addition a more comprehensive look has been taken at issues of communication which also address the possible ambiguity in meaning (Comaroff, Maguire, 1981; Susman et al., 1982; Gutheil et al., 1984; Chesler, Paris, Barbarin, 1986). This research project has made an effort to generate
understanding of the perspectives of all persons involved in the care of children with cancer as well as making an analysis of the interplay of roles within the setting.

Communication between those involved can be regarded as essential for all coping processes. This is addressed in the literature which discusses in depth the implications of "open" or "protective" communication.\textsuperscript{131} The question "what kind of information should be given to parents and/or children?" is addressed. However, it has rarely been asked how information should be given and what is actually communicated in a hospital setting.

In this study an effort has been made to generate an understanding of the different perspectives of the persons involved with childhood cancer. The research examines the conditions which influence communication and investigates the background of interactions between persons in a hospital. This has been done using the conceptual framework of symbolic interactionism which regards communication as social acts between persons who generate meaning in the process.\textsuperscript{132} Understanding of the processes then requires closeness to the perceptions of those involved in order to gain insight into the interpretations.

Most important in this context is the transfer of meaning between the different persons and their interpretation of information. This relates to their perception of communication which is influenced by their position in the setting. Three different questions were addressed in particular:

1. \textit{What is the form and content of interactions of persons involved with children with cancer in a hospital setting?}

\textsuperscript{131} See chapter "2.6 'Protective' and 'Open' Approach".

\textsuperscript{132} See chapter "3. Conceptualizations" for a more detailed description.
2. **What is the mutual understanding of meaning among the participants in interactions?**

3. **How does communication relate to the coping processes?**

The validity of the conclusions of this investigation are ultimately limited by the conceptual framework\(^1\) and the particular setting within the given timeframe of the study. Generalization with respect to other settings must be carefully examined in order to avoid conclusions merely on the basis of appearance of analogies. This is implicitly true for all scientific research projects, but seems to be disregarded frequently especially when more abstract quantitative measures dominate the conduct of an inquiry. The objectivity of this particular study lies in the explicit processes of interaction between the persons within the setting and the reflection of the observer's role as a participant. Following the symbolic interactionist frame of reference, observer as well as persons under study have become objects in the process of this investigation. Great care has been taken to state explicitly the conceptual frame of reference, the conduct of the investigations, the influence of observer bias, analytical schemes and contextual components. This reflective process generates meaning and makes the objective contribution to our knowledge. It should also enable the critical reader to follow conclusions and reexamine results in new investigations.

Although it was a goal of the study to obtain a comprehensive and holistic understanding of the communications in the hospital setting, the various perspectives of the persons involved were discussed individually in the previous chapters in order to learn more about the roles and the interactive processes between groups. It was necessary for the understanding to get closely acquainted\(^1\)

\(^1\) This is really a dialectic relationship because the theoretical background also enables formations of concepts and interpretation of meaning.
with the role of one person which was achieved by following him/her through daily activities. In addition changes of perspective in the setting were made possible through my association with different roles. This meant that I - as a participating observer - was able to go through various positions in the professional hierarchy as well as investigating the roles of parents and children. The observations focused on one individual group at a time in order to obtain a thorough understanding of roles and outlook professionals, parents and children. The observations have been reported in the previous chapters in the same sequence in which they were conducted.

9.1. INTERACTING IN A HOSPITAL SETTING

In the context of the first question it quickly became obvious that communication changed with the roles of a person in the setting. The attitude and the expressions as well as the content of information changed depending on the participants of the interaction. The closer another person was perceived to be, the more openly information was passed on. The reverse was equally true and therefore most information was held within the boundaries of one’s peer group. It seems that confidence was graded according to the closeness of a person to one’s own thinking patterns, which were directly related to the role of a person in the hospital setting.

This created several group and subgroup distinctions. Professionals communicated differently with members of their peer group than with members of another professional group or to parents and children. Medical information was shared freely among physicians who also consulted each other in individual cases. They made decisions about treatment procedures. Nurses would then be informed
about planned procedures and were given the task to implement the necessary preparations. Other professionals like social workers, child life workers, teachers, and therapists were only informed about individual treatment plans at weekly rounds. They looked up current information in patient’s charts or in the Kardex at the nursing station which was used as a planner for daily events.

Parents were usually informed about those procedures in general terms in order to ensure signatures on the respective consent forms. Generally this had to be done by physicians who spent a very limited amount of time in interaction with individual parents. Even if other staff members, e.g. nurses, knew about treatment plans they would avoid talking about it because they would interfere with the role of the physicians.

Children were generally left out of the mainstream of intentional communications. They usually got most of their information in unintentional ways by observing others or by listening to conversations between adults. Much of the information was present on the ward and could be perceived by listening and interpretation of staff behaviour. Children’s degree of information was often underestimated by adults who rarely informed children directly. The much researched question whether to inform or not was often irrelevant, because the information was usually present, but it was passed on in peculiar ways and was sometimes ambiguous in its meaning. When children perceived that procedures were set up they were still left with the uncertainty if it really would concern them. In addition they received little help in understanding why these things had to be done.

One striking example can be found in the process of how information

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1 See discussion about "open" and "closed" communication in the review of the literature (2.6. 'Protective' and 'Open' Approach).
about a brain tumor, which was discovered during a diagnostic procedure, was communicated. The information was passed on freely among nurses on the ward, communicated somewhat less openly between nurses and physicians, avoided in interactions between nurses and parents - despite direct questions - and ignored in communication with the child.\textsuperscript{135} This happened because it was the role of senior physicians to pass on the appropriate information to parents. Therefore parents and children were left alone with their anxious uncertainty until the physician had time for them.

All this reinforces the symbolic interactionist view that meaning is generated in social acts which are influenced by the context in which they take place. An institution as complex and specialized as a modern hospital requires a very large number of individuals with highly developed professional and technical skills if it is to function effectively and maintain acceptable standards of medical practice. The administrative and functional setup of hospitals is as has been shown compartmentalized in such a way as to reflect and enhance the roles and functions of the various specialties and sub-specialties. However, it is reasonable to ask if and how such compartmentalization affects communication within the total setting. One of the efforts which became apparent during the present study was that it offered an opportunity for hospital staff to shift responsibility for their individual interactions to their role in the setting and avoid emotional closeness to parents and children. Individual problems become organizational problems and individual professional groups became responsible for certain issues. If parents find it difficult to cope with the illness, they can be referred to the Social Worker, who may be able to relate to some of the emotional issues, but

\textsuperscript{135} See chapter "6.3. Nurses", particularly "6.3.3. Information".
has little influence on the proceedings of the treatment. If children show
behavioural distress, they may be placed at the Child Life department or
referred to a psychologist who is not even a regular member of the team on
the ward. As a consequence, the various social roles in the setting made direct
processing of information and addressing of personal issues complicated and often
inefficient.

Many activities seemed to be implemented from the perspective of the
setting rather than reflecting the needs of the child and his/her family.
Treatments were done when they fit into the organizational framework rather
than from considerations about appropriate timing for the individual patient. For
example children were woken up from badly needed sleep because some procedure
had been scheduled. An appropriate timing for a patient would include a
recognition of necessary regeneration processes and engage cooperation with the
procedure through planning and information. The timing of procedures on the
other hand was not very reliable either. It depended on the availability of
persons and instruments. Large machines, like the computerized scanners which
were being used by many patients from different wards required scheduling. But
procedures like lumbar punctures or bone marrow aspirations depended primarily
on the availability of the physicians to perform them, because the necessary
materials were already stored on the ward. In those cases the timing depended
on the planning ability of the physicians and on the persistence of nurses to get
the physicians to perform the procedure. This led to a focus on organizational
solutions where individuals were treated in their roles as staff member, parent or
patient.

It is strange that the professional subsystems often seemed to be
functioning in a mutually counterproductive way, which created more work. For example, when physicians were called from one ward to the other for consultations and attended many different meetings, the nurses had to keep reminding them to perform a procedure like a bone marrow aspiration. Physicians rarely communicated their timing to nurses. It was relief for the nurses when the physicians actually performed the procedure by which time the considerations about implications for the child were subordinate. The efforts which were required to coordinate events took away energy from coordination with the patient. In this organizational fragmentation the implementation of a comprehensive program of care can easily go overboard. The different professionals in the hospital seemed to be engulfed in their various subsystems of the whole organization which can have a detrimental effect on the care for personal concerns. Role behaviour which is defined within the professional categories made relating to each other more difficult, because it increased the degree of compartmentalization and made it necessary to spend considerable energy to pass on information in a way which does not upset the hierarchical patterns.

All this happened while highly elaborate interprofessional communication systems had been set up in the hospital. There were numerous forms, which had to be filled out, and many meetings which involved professionals in various configurations. These communication system reinforced the status quo of interprofessional communication. It seems that these processes have been developed to the extent where they feed their own needs and risk bypassing individual needs for care. Various aspects of this conclusion have also been discussed by other authors (Menzies, 1970; Cousins, 1979).

This is not to say that the individual persons impeded the processes on
purpose nor did they intend to communicate insufficiently; rather these things seemed to happen because staff members got caught with their role within the organizational web. Well meaning persons performed acts that were painful and irritating in a physical and emotional sense, because of the concept that it was good for the patient and therefore necessary. The fragmentation of services worked together with this conceptualization to keep hospital staff away from the full perception of the impact of their activities for the child. In addition there was the notion of professional distance which also served as a pretext against close involvement with the child. Hospital staff, especially the medical staff, seemed to be caught in various self-protective mechanisms which guarded them against a full perception of the world of the children in their care.

The gap between the personal situation of the children and the staff's perception of it was compounded by a lack of interprofessional cohesiveness. Professionals of various areas had different goals and perspectives which became functionally organized according to a medical model of treatment. The staff members who could contribute to a greater understanding of a child's behaviour, like the Child Life Worker, were only used for a functioning of routines. When children felt unhappy, they were brought to the play area so that the child life worker could deal with them. However, when the child life worker stressed the importance of informing a child about treatment procedures it rarely seemed to be followed up. Their role was not powerful enough to enable them to create changes in the application of treatment and care.

Communication was usually regarded as a functional tool to transport necessary information, but even this must fail if the receptive states of parents and children are not taken into account. The frame of reference of health
professionals was functionally organized according to their respective duties. This was often in conflict with the more emotionally involved experiences of children and parents, who struggled with their respective immediate coping processes. It affects understanding, when for example the expressions of pain and discomfort are basically regarded as an interference with necessary routines.

All this became an obvious gap between the perspective of child and parents, and the perception of the medical staff. This barrier to understanding was reinforced by professional rationalizations of emotional non-involvement with the family and by organizational functions such as the limits on interactive time. The set-up of the hospital environment generally seemed to be very restrictive toward openness in communication and mutual understanding. It became evident that the development of appropriate communication skills within a hospital setting should be addressed in further research and staff training.

9.2. INTERPRETATION OF MEANING

The interpretation of meaning as a product of interactive processes is related to the roles and resulting perspectives of the persons in the setting. This resulted in difficulties in the conceptualization of each other's frame of reference.

Initially parents were overwhelmed with the many tasks of coping with their own emotions, trying to understand the illness and its consequences, making decisions about the well-being of their child, familiarizing themselves with a new environment and making adjustments in their own lives. At the same time they had to give up much of their control and yet still feel responsible. My observations confirm findings in other reports (Koch et al., 1974; Ludwig-Klein, 1980; Greenberg et al., 1984) which indicate that this state of turmoil, which
peaks initially, influences the ability to receive and digest information. Unfortunately this happens at a time when parents have to make important decisions regarding the care of their child. Hospital staff may know about these issues, however, the agenda of hospital procedures and notions of professionalism rarely allowed the space which is necessary to become communicatively connected in a way which enables persons to convey empathic understanding. Therefore these issues remained remote problems which were only addressed if they seemed to become a factor in the administration of treatments.

Professionals tended to rate individual behaviour according to its degree of interference with medical care. Individual needs were mostly treated within the context of medical treatment. Parents on the other hand were seeking for answers and expected solutions from a system which they had difficulty understanding. Children encountered contradictions in the expressive behaviour of adults and between verbal communications and their own experiences. The three groups of persons, professionals, parents and children, seemed to keep up a mutual pretense awareness\textsuperscript{\textsuperscript{136}} regarding their respective roles, but there seemed to be few communicative bridges. Others (Bluebond-Langner, 1978; Bearison et al., 1984) have also reported that children realize how parents and staff want them to behave and maintain a mutual pretense in order to fulfill those expectations and keep the relationship from breaking down. This also means that the perception of each others' roles set a framework for communication and limited the extent of mutual understanding.

Differences in the perspectives of various professionals were noted, however, their degree of perception of emotional needs of parents and children

\textsuperscript{136} See discussion about mutual pretense awareness in the literature review (2.5. Awareness Context and Knowledge about the Illness).
was inversely related to their standing in the hospital hierarchy. For example, the child life workers, who seemed to have more insight into children’s perceptions, had little impact on the decisions of care. Meaning as a product of social acts thus became a product of role relationships which set the parameters for interaction.

Physicians had a powerful role in the setting because they prescribed and determined the medical treatment. Individual treatment plans were deduced from generalized results of medical experiences with a particular illness. Often the individual assessment led to an ambiguity with respect to the general treatment for this particular illness which could lead to trial and error proceedings trying to find the right balance of powerful drugs. Severe side effects of those drugs are known, but it is very difficult to predict how an individual child will react. In their communication with parents physicians tried to find a fine line between informing the parents and not making them overly concerned. On the one hand they had to provide information to satisfy parental curiosity and to cover themselves legally, and on the other hand they wanted to establish a smooth conduct of treatment. This was a difficult communicative task because complex medical information had to be translated into manageable terminology and at the same time an assessment of a family’s overall needs was required in order to make referrals to appropriate specialists. However, interactions between parents and physicians were usually very short and had a lecturing character, but involved little feedback from the parental perspective.

The organizational background also affected the interpretation of information which was communicated between the various persons involved. Health professionals in the hospital and parents found themselves on very different sides
of issues. This was reflected in many interactions during which mutual expectations were inhibiting a thorough understanding. For example, there were cases when parents wanted to ease up on treatment when physicians - due to their role - wanted to continue with the medical proceedings which they deemed appropriate. There were also reverse cases when parents wanted to do everything possible disregarding skepticism of physicians. Ironically all parties had a common goal, the well-being of the child. However, the interpretation of well-being varied considerably.

The most powerful professional groups in the setting, physicians and nurses, seemed primarily concerned with the physical side of the illness and its implications for treatment. Their main issue seemed to be how the physical indisposition illness could be removed so that the child can be returned safely to his or her family. Parents on the other hand were concerned about the effects of illness and treatment for their child and their own lives. At first many of these effects had to be understood cognitively based on the information which was provided by hospital staff. They were experienced later when side-effects were actually perceived. The visible effects of treatment, which were often perceived as a deterioration of the condition, also increased concerns. However, the impact of hospitalization and changes in family routines became part of the experience almost immediately. Parents’ experiences formed an individual link between hospital and family. The parental viewpoint seemed to be dominated by a notion of well-being which included their own family experience as well as their hopes and expectations.

As has been mentioned above, children seemed to left out of the mainstream of interactions concerning treatment and decision making processes.
They were left in a vacuum between their experiences and the pieces of information which they could gather. They were left alone with the task of interpretation. When children are left alone with the interpretation of meaning they are denied participation in meaningful communication. From a symbolic interactionist's point of view they are not given access to the social acts which generate objective meaning, which in Mead's terminology would constitute a conflict between the "I" and the "me", because "me" is reflected in a different, adult context, whereas "I" cannot make the connection between those differences in interpretation.

Children have not yet developed a high degree of abstraction in their thinking. The child's perception of well-being is related to concrete situations in which they really feel good and are able to participate in activities together with their peers. Their concerns were very immediate, but the experience of hospital and treatment constantly attacked the child's sense of being well or whole, which increased the discrepancy in the perception of adult communication.

Meaning is generated in interactive processes which relate to social roles as well as to individual perception. Perception - as a developmental process - is formed by making experiences and taking roles. Again should be regarded as a developmental process which is formed in individual experiences by taking of roles. Additionally the position within social organizations determines outlook and behaviour. Information can be interpreted quite differently by individuals when their perception is strongly connected with one particular role which they are not able to change. Taking up roles of others is very restricted in the hospital setting which makes understanding a difficult task.
9.3. COPING PROCESSES

If we look at the relationship between communication and the coping processes, we have to distinguish between the actual issues which concern the person involved.

- The **professionals** have to cope with illness as part of their daily job routines related to their respective activities. Their viewpoints differed and were either leaning toward a medical model or directed more at social and emotional issues. Staff members had to deal with illness related issues on a daily basis and in this context they also had to be able to handle failure of treatment and unsuccessful personal interventions. In addition they had to cope with the requirements and functioning of the hospital setting.

- The **parents** have to cope with their own anxiety which relates to their notion of the illness. They also had to cope with their fear of losing their child and feelings of failure and powerlessness. Their parental responsibilities were changed while they watched dramatic treatment procedures and the suffering of their child. At the same time they had to incorporate a considerable amount of new information concerning illness, treatment and the functioning of the setting.

- **Children** experienced the physical pain of illness and the treatment by many unknown adults. They were also struggling to make sense of the events which they experience and witness. This led to conflicts of meaning when events or experiences did not match the information they received.

Coping does not mean the same for those groups of persons, because they were concerned with different issues. In addition there were some individual differences between the persons involved. Their coping energy was directed at different
issues. Therefore it does not surprise that their understanding of each others’ processes remained limited. However, these differences became almost entrenched in the organization of the setting. This meant that openness in communication remained limited to preconceived notions of each others role, affecting mutual understanding. Several examples have shown that professionals in the hospital setting tended to judge behaviour of parents and children according to its functioning for smooth proceedings in the treatment process. For example the quiet and withdrawn behaviour of a child could be regarded as positive coping behaviour whereas the child was in fact very depressed. The opposite has also been observed, that acting out behaviour as a response to the often painful treatment was regarded as disturbing.

The idealized professional goals among helping professionals are personal care for individuals in need. They stem from concerns about providing appropriate help. However, several health professionals also seemed to experience a discrepancy between the rationale for their profession and the practical aspects of their work. This can lead to disenchantment and burnout.\textsuperscript{137} The turnover on the Oncology ward was very high among nurses. Its reasons may be found in the nature of illness and treatment, which does not necessarily lead to full recovery. The effects of the treatment often made the child feel worse and in many cases their benefits were perceived as doubtful, even by the persons who administered the medication.\textsuperscript{138} To keep up their goal of beneficial care nurses also wanted to experience positive results of their activities. They tended to cling to success stories, but the reality on the ward was that they saw all the

\textsuperscript{137} See also "Issues Concerning the Child with Cancer in the Literature".

\textsuperscript{138} Comments from nurses regarding medication (in: "Nursing Aims") can be taken as one example.
difficult cases. This was different in the outpatient department, where ambulatory treatment was given for children who were in remission. Beneficial results became more obvious when nurses could see children who had been without symptoms of the illness for longer periods.

Parents expected help and information from physicians. This put them in a bind with respect to the relationship with the professionals in the hospital setting. Since the hospital setting became the focus of their hope, parents tried to comply with rules and regulations. For example, several parents listened to the information given by physicians without fully comprehending them. Giving information was a necessity for physicians in order to obtain informed consent. Even when they had not understood the information many parents maintained the pretense of having been informed and mostly did not challenge medical staff.\textsuperscript{139} Parents were busy to keep up their coping facade in front of hospital staff and even in front of their own child. Their behaviour contributed to the cover-up of information. Some did this overtly by not speaking about the illness and others developed various forms of protectiveness for their child.

The children were constantly trying to keep up with events, which was made more difficult by the lack of support in making sense of their experiences. Young children especially organized their world very much on a symbolic level. They tried to generate their own interpretation for the experiences they made. For example a band-aid, which was applied at the end of a painful procedure became a very important symbol of relief. This symbolism extended to many senses and experiences. A person could be rejected due to his/her smell or behaviour.

\textsuperscript{139} For specific examples see chapter "7. Parents and Family", particularly "7.5. Information" and "7.6. Parents and Hospital Staff".
Often a friendly facade was maintained with persons to whom they felt great apprehensions. This is quite understandable because any child wants to relate to his/her environment. This was often misinterpreted by hospital staff as forgiveness for infliction of pain. Some children felt very proud when they could trick staff into a false interpretation of events, which seemed to be a power play with a trace of revenge.

It is most tragic that children were usually left alone with the interpretation of events. The majority of hospital staff interacted with them in the treatment related context and parents were preoccupied with their own coping and the efforts to keep up a consistent facade. Such behaviour left children alone with their efforts to conceptualize and interpret and they had to generate their own meaning. This resulted in misinterpretation of symbols and further trauma for children, because it made it very difficult for children to direct self within an organized perspective. It also denied children the social support for their own coping processes.

9.4. ADAPTING TO THE SUFFERING
Looking at the information which has been gathered one can conclude that the social organization of the hospital did not seem to reflect the needs of the individual persons who worked in it nor did it seem to relate very well to the personal needs of the patients in the focus of all care. One has to ask how a system of care, which seems to be counterproductive to individual needs, could have developed. The answer lies possibly in the unintentional collaboration of the two lines of authority within the setting. The administrative authority established structures from organizational, financial, and legal considerations. Policies were
made which create generalized solutions for individual problems. For example the fear of legal implications led to policies of less access to information (e.g. charts) or admission of parents to treatments and examinations. The medical authority was put under constant pressure to ration timing and energy. However, this does not mean that there was more time for consideration of individual cases. The opposite is true. Physicians found themselves burdened with more demands to deal with an increasing number of patients and issues which means that less time was available for interaction with individual patients.

The increasing number of issues came also from the medical approach itself. The knowledge about the physical side of illnesses and the human body is growing and changing rapidly. This requires an ongoing updating of individual knowledge about treatment and consumes considerable time. The perspectives of both authorities combined then generate structures which become removed from personal needs of patients and the people who work in the setting.

Adults failed to relate to the world of children because they were so wrapped up in their own conceptualizations. The health professionals had a powerful agenda which evaluated events in useful and "difficult" categories, thereby limiting understanding. Behaviour was evaluated by the degree of interference with procedures.

Every group of professionals in the hospital also had an educational agenda which was linked with the tasks of the respective roles. Children and parents were educated to behave in a way which was perceived to be beneficial for the treatment. The educational goals differed between the various

140 There is also a link to more generalized expectations of patient behaviour which have been reported in the literature (see chapter "2. Issues Concerning Children with Cancer in the Literature")
professional groups and they were additionally influenced by personal experience with children. For example there was a noticeable difference between the attitude of nurses who had their own children and nurses who were not parents themselves. Generally speaking, it seemed that professionals in the hospital setting were so connected to their professional and organizational roles that they often failed to create meaningful relationships on a personal and emotional level.\textsuperscript{141}

Parents were engulfed in their own coping problems which made it difficult for them to relate to the world of their children. They were also torn between their own coping strategies, the demands of the hospital, and the needs of their child. When their child acted up and rejected approaches by health professionals, parents were usually embarrassed and sided with the health professionals. This was reinforced by their hope for recovery which was linked with the success of medical treatment. They found themselves in a double bind situation in which they could rarely compromise.

Talks between adults frequently revealed their collusion when they made smiling remarks about the child's behaviour in his or her presence. This was part of adults' coping behaviour, because professionals and parents seemed to feel awkward in face of the treatment which the child had to endure. They understood some reasons for the child's behaviour but they could not quite accept that they also shared responsibility for it. It seemed to be relief for them to acknowledge "difficult" behaviour of the child on a superficial and sometimes ironic level, e.g. by saying "he is not a big talker" when the child did not respond.

\textsuperscript{141} See also Menzies, 1970.
Children learned many things while they were in hospital. New language patterns and behavioural rules provided many learning challenges. They learned to adapt and got to know the rules of the setting. However, children must suffer emotionally if they are deprived of nurturing relationships and have no release for their feelings. In addition many communications in the hospital were aimed at making children quiet and conform. For example, miniaturizing issues ("just a little poke") provided conflicts with a child's concrete experience, leading to distrust and a feeling of rejection. In addition children received contradictory emotional messages when adults expressed their emotions nonverbally. This became most evident during medical procedures when charged voices uttered soothing words.

Treatments and painful procedures are necessary components of the medical treatment of the illness. If the intensity of the feelings are not acknowledged, then the experiences of the child may be denied at the same time. Therefore it seems important that a child is carefully prepared for the pain and inconvenience and that the completion of an uncomfortable or painful medical procedure can be acknowledged as an accomplishment by all who are involved. This would require that communication acknowledges and addresses the situation as well as individual feelings.

The clashes between the demands of adults and children's own needs may have an impact on children's relationships to other people as well. In the hospital setting children seemed to become more suspicious and distrusting, because they frequently encountered situations in which they did not know the real agenda. Staff as well as parents were greeted with apprehension. Even casual chats could be preparations for an intrusive procedure.
Symbolic interactionism has been criticized as neglecting the influence of power in human interaction (Joas, 1987). This criticism can be reiterated with respect to the findings of this study when the abilities of the self to interpret significant symbols in communication with others is very much influenced by power which is linked to the roles of persons within the hospital setting. The possibility for the child to negotiate the relationship to objects of reality with others were very limited. Through the roles which were adopted in a hospital setting children were forced to remain isolated and had little chance to establish objectivity in the interpretation of meaning. Meaning is then generated as a subjective byproduct of interactions but is not the product of a negotiated process, which leaves considerable room for ambiguity. Therefore the concept of power emerges as one of the brokers in interactions in the setting.

Children were overpowered by the professionals in the hospital and at the same time they were forced to relate to them. This led to frustrations and counter aggression. The most vehement struggles arose in treatment situations which highlighted the "bad" parts of hospital life and were very intense experiences. For some children there were also events which could provoke their collected feelings, which was a projection from a combination of feelings they had encountered in the setting. Some children saw their only opportunity to act out some of their feelings as active or passive resistance to rules and procedures. This meant that an overpowering attitude was also counterproductive because it spiralled the struggle due to the increasing resistance of children, who experienced that their true emotions were not addressed.

Children were given little chance to contribute to the healing process themselves. The medical treatment took over and influenced children's energy and
resources. Their relationships to others in the hospital setting required their submission to strange and hostile rules and procedures. Space for their self determination was restricted to resistance. However, all this was officially being done for their own good. It is obvious that this notion does not take into consideration that the children themselves are growing and developing persons who are able to direct self purposefully. This was also highlighted by the lack of personal space for children in their role as patients. During many procedures children were not given opportunities for cooperation but rather they were forced into these situations. This began with persuasion and could result in situations were they were physically restrained. The submissive role of a patient seemed to be increased because of the fact that these patients were children who did not seem to "understand". 142

The failure to establish cooperation with children, which is really a failure of the adults, also may influence the process of recovery. Several books and articles have been written143 about the importance of turning the sick person into a fighter against the disease and to mobilize valuable energies. The treatment in the hospital fails in this respect. This study cannot contribute any conclusive data about the degree of benefits of the emotional involvement to the success of fighting the illness; however, several counterproductive communication patterns were found. If in fact the underlying hypothesis is true, then these communication patterns become even more important for a successful fight against the illness. This directs attention to an important field for additional studies, especially with increasing survival rates.

142 See for example comments like, "You can't argue with them anyway", in subchapter "6.3.6.1. Treatments".

143 see for example Norman Cousins (1979).
Remarks of professionals indicated that they felt that children were not really able to cooperate, because they would not understand anyway. However, no real efforts were made to connect to the world of the children. Efforts were rather directed at achieving compliance with the procedures than involving the children's self. It caused problems for medical staff when children acted out their emotions. This increased the struggle between fighting organizational delay and coping with the aggravating emotional reminders of the impact of one's own activities.

Three different sources were responsible for the lack of collaboration with the child. First, the organizational structure of the setting left very little time for emotional concerns. In addition the responsibilities and perspectives were split up among different professionals. There was no connected and comprehensive view of the child as a whole. Second, the application of a medical model reduced a person to a system of physical functions. These became even more highlighted as the treatment dangerously interfered with them. Monitoring the physical person became the exclusive concern of the hospital system. Third, the setup served as a protective mechanism against personal emotions. Emotions were regarded as interfering with professional care. Cancer and its treatment evoke many emotions, however, a professional attitude means keeping distance and doing a job. This was implemented by splitting up responsibilities as part of a coping pattern which offered a protective shield against personal involvement.

The mechanisms mentioned above consumed considerable energy within the ongoing activities of the hospital system. Much time had to be spent in organizing and implementing communication between the various professional levels. The information was split up and transmitted on various levels in such a
way that the official levels became fragmented and lost importance. Much of the background information about children and their families was passed on directly at informal levels within a professional peer level. However, the hospital hierarchy also tended to inhibit full communication among all professional groups.

The hospital setting seemed to be focusing so much on the medical fight against the illness, which was paired with restrictive organizational requirements, that the growth of the child as a whole person was lost. At the same time the system of care has been developed into a framework in which everyone suffers. Staff, parents and children became victims of the organization and the power play between different professional perspectives, which consumed considerable energy and produced many activities which revolved around interprofessional and organizational issues. The rationalization for this lies in "the best interest for the child", which is however narrowly defined within a medical frame of reference. Contact between professionals and parents or children became functional according to established roles of the setting. This means that personal needs were often left unresolved while communication happened in the context of mutual pretense awareness according to the cultural rules of the setting.

9.4.1. Implications
The processes of interactions between hospital staff, parents, and children with cancer have been analyzed and documented in this study. It has been shown that role behaviour influences perceptions and interferes with communication and interpretation of meaning. Behaviour was often evaluated as a functional act within a given context rather than an expression of self. This means that individual needs could not be addressed sufficiently, which is particularly difficult
for children. They suffered from the effects of illness and treatment, the separation from regular activities, from a lack of support in their coping processes. In addition they were often left alone with their struggle to integrate their experiences in a meaningful way.

Children experienced the threatening and painful treatment procedures which were nevertheless presented as if they would be beneficial. However, the communicative link was often severed because children were denied access to the social acts which generated interpretations of behaviour. The resulting conflicts of meaning only increased the intensity of feelings of frustration and loneliness.

These processes are of particular importance for children, who are shaping their social behaviour on the basis of their experiences. If they make strong emotional connections between the intense physical pain and the conflicts in the relationship to other people, they may find it difficult to form trusting relationships later on in their lives. This becomes an even more important aspect with increasing survival rates due to progress in the physical treatment of their illness. Research on the impact of childhood cancer on trust and closeness in relationships on a long-term basis as a new and important area of study has just begun.

This research project analyzes some of the elements in the interactive processes involving children with cancer in a hospital setting. However, more research is needed, to look at the issue of trust building, to generate knowledge about the interpretive processes of children who are being pushed into physically and emotionally painful situations, to learn about the effects of various levels of communication on coping processes and the emotional consequences of cancer survival, to find social and individual solutions to communicate successfully in
hospital settings. It is emphasized that behavioural rules and social roles of the hospital setting as a cultural entity should be taken into account, because they generate an important interpretive context for interactions involving children with cancer.

The successes of medical treatment and increasing survival rates also mean that the impact of the trauma of childhood cancer on relationships has to be taken into consideration. This addresses especially relationships to other family members and close friends. It has been noted that the situation of siblings of children with cancer, who were not in the focus of this study, needs more attention of researchers.

Many developments have taken place in the hospital care for children in the recent years, especially with respect to parental presence. However, the increasing technological control over illnesses and the organizational structures which manage the treatment can also have a counterproductive impact on personal care. The management of treatment in the hospital settings seems to have become the real focus of many efforts, which makes individual care much more complicated. Much of the possibilities for personal contributions to one's own recovery seem to be taken over by medical and organizational strategies within the hospital environment. A need for new approach exists which takes the whole environment of the child and his/her family into account and concentrates on all aspects of the healing process. This would involve redirecting the focus from the needs of the setting to those of the individual child and his or her personal situation. It is the challenge for the modern hospital to find the right balance between the benefits of medical advances, organizational requirements and the care for a unique and individually growing person.
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Appendices / 398

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10.2. CONSENT LETTER PHYSICIANS

PATTERNS OF COMMUNICATION BETWEEN CHILDREN WITH CANCER
AND THEIR CARETAKERS

Supervisor of research: David Kendall, Ph.D.

Doctoral student: Björn Ratjen, M.A.

RE: (name of patient)           DATE:

Dear Dr.

Cancer has a considerable impact on the lives of children and their families on both physical and emotional levels. It is sometimes very difficult for medical personnel to assess the impact of their treatment of the illness on the individual child and his/her family. The cooperation of children and families, however, is an important factor with respect to the success of all treatment efforts. Cooperation is nearly always dependent upon the establishment of successful communication between the various parties.

It is the objective of the proposed study to use established participant observation procedures in order to understand and analyze verbal and nonverbal communication patterns between children with cancer, their families, and hospital staff involved in their care. Special attention will be given to communication related to the illness, taking into account the differing goals and approaches of
these three groups of persons. In particular, answers to two questions will be sought:

1. How does communication about the illness take place?

2. Which factors facilitate/inhibit communication between the different individuals involved in personal intervention related to cancer in children?

We are particularly interested in developing insight into the nature of the communicative interactions between children with cancer and others concerned with their care and treatment, and presenting these findings in a form that would be helpful and useful to both medical personnel and parents. The information provided by this study should make possible the development of new models of care for children with cancer, particularly those which facilitate coping.

The method of participant observation will be used to observe three groups of persons: health professionals, parents, and their children with cancer. Observer participation will be kept to a minimum possible. Preliminary observations of health professionals as a group have been conducted in a pilot project.

The study will include case study and cross-sectional elements. Children of different age groups will be observed during different phases of their illness in a case study approach. Three phases of the illness will be regarded as important with respect to the observations of individual cases:

1. diagnosis until first remission
2. first relapse until second remission
3. multiple relapse until remission or death.

This study will focus on communications on the hospital ward where children with cancer are treated. Children will be selected according to their age and phases of the illness. Two age groups will be distinguished:

1. preschool children including infants and toddlers (up to 4 years), and
2. schoolage children (up to 10 years).

An even distribution will be sought across the age groups and phases of the illness in six case-studies.

Observations of each case are estimated to last three to four weeks depending on the progress of the treatment. Should the treatment last considerably longer, the case-study will be transferred to the general cross-sectional observations limited by the overall timeframe of the study. The
cross-sectional part of the study will consist of general observations of the events on the ward while the investigation is taking place.

It is planned to get in contact with parents and children as early as possible. The best point for this seems to be the establishment of the diagnosis.

We would like to ask you for your cooperation in this study which has been approved by the appropriate research committees. You could help by establishing contact between the investigator and parents of patients fitting into the categories mentioned above. Parents will receive a written statement listing the aims of this research and asking for their consent to participate.

It is understood that the consent to participate in the study can be withdrawn at any time temporarily or permanently without further implications. Would you please sign below if you consent to participate in this study. An additional copy is attached for your convenience. I will get in touch with you during the next days to answer questions you might have and to arrange possible procedures.

Thank you very much

Björn Ratjen

I consent to participate in the study described above

........................................
Signature
10.3. CONSENT LETTER FOR PARENTS

PATTERNS OF COMMUNICATION BETWEEN CHILDREN IN HOSPITAL AND THEIR CARETAKERS

Supervisor of research: David Kendall, Ph.D.

Doctoral student: Björn Ratjen, M.A.

DATE:

Dear Parents,

The hospital environment is always a new and awkward experience, especially when it concerns your child. Many parents have similar feelings of not knowing what to expect. However, for the best possible care, it is important that a hospital and the attitudes of the hospital staff are adapted to the needs of children as patients and their parents. This is why your experiences are very important.

In order to learn more about your experiences with the hospital and your child's illness as well as your child's experiences I would like to ask you to participate in a project which I am undertaking at Children's Hospital.

I wish to ask you to allow the presence of an additional person (myself) during treatment procedures and hospital routine involving you and/or your child. I will record almost everything that is happening with a special focus on communications in order to obtain a maximum amount of information about issues of concern. In some situations audiotape recordings might be used in order to have a better account of the actual situations. However, your permission will be asked in every instance. The notes and audio recordings taken will be strictly confidential and will be evaluated in a way which ensures your anonymity.

The notes and observations including your concerns will later be evaluated in order to understand parent's and children's concerns and to develop better models of care. After completion of the observations you may be asked to comment on your experiences and on the conclusions drawn from the observations in order to ensure a fair representation of your concerns.
Please be aware that you can withdraw your consent at any time for a specific situation or permanently without any implications for your child’s wellbeing.

This study does not interfere with the treatment of the illness nor does it involve or comprise any part of the medical services your child may receive in Children’s Hospital. The study has been approved by research committees of Children’s Hospital and the University of British Columbia, but it is not part of any hospital activity.

We would greatly appreciate your cooperation which may help other children in a similar situation as yours.

If you agree to participate, please sign below. Your copy of this document is attached. The researcher will contact you to answer any questions you might have and will make every effort to arrange everything as conveniently as possible for you.

Thank you very much

Björn Ratjen
(Researcher)

I consent to participate in the study ........................
10.4. CHILDREN'S CONSENT

The following statement is just an example of an introduction to children. It had to be adapted according to the circumstances and the age of the child. Often parents also introduced me to their child. However, it was important to me that the child was able to give his/her own consent.

Hallo, my name is Björn. Your name is ........? I am interested how children feel while in the hospital and that's why I would like to spend some time with you, if you don't mind. I want to learn more about you and other children in a similar situation.

Because there is so much that I see and hear, I try to write everything down so that I can remember it later. That's why I have a little book with me all the time. Everything I write down is secret. This means that no other person will know what you have said except me.

I will be here on the ward almost every day, and you can always tell me if you want or do not want to see me. I am not taking care of you like the nurses and doctors, I am just here to look around and see what happens, and I will write it down occasionally.

You don't have to do anything special for me. You can always tell me if you want me to leave. Is this ok with you?

Do you mind if I come in and sit with you for awhile?
10.5. ACRONYMS AND MEDICAL EXPRESSIONS

All: Acute Lymphocytic (or Lymphoblastic) Leukemia

AML: Acute Myelocytic Leukemia

ARA-C: (a chemotherapy drug)

BID: two times daily (Latin: bis inter diem)

Blasts: blast cells, abnormal immature blood cells

BP: blood pressure

CBC: counts of blood cells

CCABC: Cancer Control Agency of British Columbia

CNS: Central Nervous System

CPR: Cardio Pulmonary Resuscitation

CT-SCAN: Computer Tomogramm

Hickman Line: intravenous catheder

Hodgkin's Disease: a form of lymphoma usually in adolescents

ICU: Intensive Care Unit

IV: used for intravenous lines, infusions

IVAC: name of intravenous pump

LP: Lumbar Puncture

L.P.N.: Licensed Practical Nurse

Lymphoma: cancer of the lymph-system

Neuroblastoma: cancer of the nervous system

OR: Operating Room

O.T.: Occupation Therapist

Physio: Physio Therapist
PO: taken orally (Latin: per os)

R.N.: Registered Nurse

Sarcoma: Osteogenic Sarcoma or bone cancer

TID: three times daily (Latin: ter inter diem)

TPN: Total Parenteral Nutrition

QID: four times daily (Latin: quater inter diem)

Vital signs: bloodpressure, temperature, pulse, respiration