THE CHILDBEARING EXPERIENCE FOR WOMEN WITH STOMAS:
A MULTIPLE-CASE STUDY

by

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ABSTRACT

Although much research has been done on the daily challenges facing individuals with stomas, the experience of childbearing for women with stomas has not been addressed in the nursing literature. The research question put forth therefore was: how does a stoma affect the childbearing experience?

Case study methodology was used to answer this question. This design allowed the researcher to use a variety of evidence to explore in depth a subject about which little is known. Six cases were selected for the study and data collection and analysis procedures were replicated for each case. An informal interview guide consisting of open and closed-ended questions was used to solicit information from six women with stomas who had experienced childbirth in the past eighteen months, their respective partners, and the physicians who provided their obstetrical care. Data were analyzed according to the major concepts of Snyder's (1979) holistic model of the childbearing experience and findings were presented in six individual case reports. Common issues were identified, expanded, and compared in a cross-case report.
In each case, the stoma affected the woman's physiological, self, family, social, and cultural systems and these interacted to create six unique childbearing experiences. Although all the women delivered healthy babies, two serious physiological implications of having a stoma during pregnancy were noted. These included 2 cases of stomal prolapse and 3 cases of partial or complete bowel obstruction. Both complications necessitated hospitalization and caused anxiety and inconvenience for the woman and her family. However, the findings revealed that many of the technical, psychosocial, and cultural challenges faced by women with stomas during pregnancy are similar to those experienced on a daily basis by any individual with a stoma. It was concluded that women with stomas need pre-natal counselling to learn what to anticipate with pregnancy, labour and delivery, and postpartum and they need to participate in formulating a management plan for their pregnancy and hospitalization. Finally, basic and continuing nursing education programs need to address the affective, cognitive, and psychomotor skills necessary to care for these individuals during their childbearing experiences.
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CHAPTER ONE

Introduction

Background to the Problem

A pregnant woman with a stoma simultaneously faces two physiologically and psychosocially demanding challenges: the daily concerns of a stoma and the developmental crisis of a pregnancy.

A stoma provides a permanent or temporary means of fecal or urinary diversion. It requires individuals of all ages and with a variety of pathological conditions, including trauma, congenital anomalies, inflammatory diseases, and cancer to cope with ongoing physical and psychosocial issues. Although the highest incidence of individuals with stomas occurs with older adults, where colonic cancer predominates, younger adults may also require the construction of a stoma, primarily due to Crohn's disease.

Despite a number of anecdotal accounts in the "self-help" literature, the childbearing experience for women with stomas has received very little attention in the health care literature. The nursing literature, while replete with articles about the impact of a stoma on daily life, does not specifically address the impact
of a stoma on pregnancy. The medical literature, while addressing the medical considerations for pregnant women with stomas, only briefly mentions psychosocial implications. However, according to Rubin (1976), childbearing is a multi-dimensional phenomenon and consideration should be given to psychological, social, and cultural factors as well as physiological ones.

Although the incidence of pregnant women with stomas is currently low, with approximately only eight such women reported in the past two years in the Lower Mainland, the Fraser Valley, and the Sunshine Peninsula of British Columbia, the incidence of Crohn’s disease is on the increase (Kirsner, 1985) and consequently one would anticipate an increase in stomas in women of childbearing age. Nurses need to know how to adapt their care to support these individuals during their childbearing experience. Therefore, an opportunity to investigate the experience should not be overlooked.

Statement of the Problem

Very little is known about the experience of childbearing for women with stomas and therefore a lack of theory exists on which to base effective care planning.
**Purpose of the Study and Research Question**

The purpose of this study is to document and analyze the experience of childbearing for women with stomas. The specific question to be answered is: how does a stoma affect the experience of childbearing?

**Conceptual Framework**

Snyder (1979) describes a holistic model to explore the complexities of the childbearing experience. In her model pregnancy is depicted as a trajectory which begins at conception, ends with delivery, and has specific signs occurring at anticipated intervals (see Figure 1). This trajectory is a perceived phenomenon with the involved individuals having their own perceptions about the course of the pregnancy. The perceptions may or may not be in accord with reality and are dependent on many factors, such as the level of knowledge and the past experiences of the perceivers. The perceptions are also major determinants of behaviour.

A basic assumption underlying the model is that the pregnant woman and those related to her perceive the childbearing experience as an uncomplicated event culminating in a healthy mother and child.
Figure 1. The Trajectory of Childbearing.

alteration in the trajectory can therefore lead to confusion and frustration. The pregnant woman and all those participating in her childbearing experience must then reorganize their behaviour in terms of an altered trajectory.

Along the trajectory factors relating to the physiology of pregnancy and to the self, family and peer, societal, and cultural systems interact to create a unique and holistic experience for each individual woman. These factors are visually represented by a series of concentric circles (see Figure 2). The physiological pregnancy is at the core of the model and represents the physiological adaptations to pregnancy. The woman's self system, the next circle, symbolizes the woman's emotional adaptation to pregnancy and involves a process of incorporating the experience of pregnancy into her self system. To do so, requires working through various developmental tasks such as accepting the reality of her pregnancy; incorporating the growing fetus into her own body image; separating herself from her growing fetus; and finally preparing to assume the maternal role. The ability to successfully work through these tasks and emotionally
Figure 2. A Holistic Model of the Childbearing Experience. Snyder, D.J. (1979). JOGN, 8 (3), 165.
adapt to pregnancy will be influenced by a multitude of factors specific to each individual experience (Rubin, 1976). The peer and family system, the next circle, depicts the network of significant family members and friends involved with the childbearing experience. The structure and dynamics of these interpersonal relationships will affect the childbearing experience and conversely the childbearing experience will affect the relationships. The next circle illustrates the social system within which the childbearing experience occurs and includes such groups as the community where she lives and the organizations where she receives care. All of these social groups will affect the childbearing experience. The outer circle of the model exemplifies the overall cultural system within which the other systems operate. Culture includes all of the attitudes and values related to childbearing. These values provide the framework for the individual woman and her family to define and evaluate their particular childbearing experience. A deviation at any level of the model can alter the trajectory of the childbearing experience and conversely an alteration at any point in the trajectory can affect each layer of the model.
Although all the factors relating to each level of the model must be identified, Snyder (1979) contends that it is more important to consider them in light of how they interact with each other rather than as separate entities. In this way a comprehensive understanding of the childbearing experience as perceived by the woman may be achieved.

This holistic model of the childbearing experience was used to guide the observations and the analysis for the study. For the purposes of this study, however, the family and peer system was adapted to address only issues pertaining to the family. The effects of the stoma, therefore on the physiological pregnancy, on the self system, on the family system, on the social system, and on the cultural system were identified and conclusions drawn regarding how these factors interacted and possibly altered the trajectory of childbearing.

**Definition of Terms**

Childbearing experience: a multidimensional phenomenon, having a definite duration from conception to postpartum, and encompassing physiological, emotional, social, and cultural factors (Snyder, 1979).
Assumptions
The study was based on the following assumptions:

1. Childbearing is a unique and holistic experience for each individual woman.

2. An individual with a stoma has an ongoing need for physiologic and psychosocial adaptation.

Limitations
The limitations of the study were as follows:

1. The women’s perceptions of their childbearing experiences may have been limited by the time lag between the time of the experience and the time of the study.

2. The study may have been limited by the women’s ability and willingness to articulate their true perceptions of their childbearing experiences.

3. The researcher is a specialist in enterostomal therapy nursing but is not an expert in general research surrounding pregnancy and childbirth.

Research Method
Case study methodology as described by Robert K. Yin (1994) was selected for this study. The unique feature of this design is its ability to use a variety of evidence to investigate complex social phenomena.
It is considered an appropriate design when the phenomenon or phenomena of interest is rare, or critical, or revelatory in nature. The case, or unit of analysis, may refer to an individual, a group of individuals, or an event. If the study is concerned with one unit of analysis it is referred to as a single-case study and if more than one such case is included in the study, it is referred to as a multiple-case design.

This study utilized a multiple-case design. Six individual cases were explored, each case defined as the childbearing experience for a woman with a stoma. Very little is known about this phenomenon and case study methodology enabled the researcher to examine data from a variety of sources, including the women who experienced childbirth, their partners, and their physicians. The data for each case were analyzed separately and the findings compared across cases.

Significance of the Study

Scientific Significance

The study contributed to the knowledge about the complex phenomenon of childbearing for women with stomas. Physiological, psychological, social, and
cultural factors associated with this phenomenon were identified and hence nursing knowledge advanced and suggestions for further related research founded.

Practical Significance

The findings will assist health care professionals to care for pregnant women with stomas. They will give the nurse direction in assessing the needs and caring for these women pre-natally, during labour and delivery, and postpartum. The findings will also provide women with stomas, contemplating or experiencing pregnancy, with insight into their condition.

Organization of the Thesis

This chapter has introduced the study by describing the background to the study, the statement of the problem, the purpose of the study and the research question, the conceptual framework, the definition of terms, the assumptions, the limitations, the research methodology, and the significance of the study.

Chapter Two presents a review of the related literature. This review consists of both research and non-research based literature.
Chapter Three describes the application of case study methodology used in this thesis. It outlines the selection of informants, ethical considerations, data collection and analysis, and reliability and validity.

Chapter Four presents the findings in the form of six individual case reports and a cross-case report.

Chapter Five discusses the findings, draws conclusions, and describes implications for nursing practice, nursing education, and further research.

Summary

This study used a multiple-case study method to explore the complex phenomenon of childbirth for a woman with a stoma. Very little is known about this phenomenon and the findings will contribute to the advancement of nursing knowledge and assist health care professionals to plan effective care strategies.
CHAPTER TWO

Literature Review

Introduction

This chapter reviews the research and non-research-based literature pertinent to the experience of childbearing for women with stomas.

Very little is known about the childbearing experience for a woman with a stoma. The medical literature, while addressing the medical considerations for a pregnant woman with a stoma, does not address the psychosocial implications. However, a review of this literature will ascertain what is already known about the problem. The nursing literature, while addressing the physiologic and psychosocial needs of individuals with stomas and the implications of chronic illness on pregnancy, does not specifically address the issue of childbearing for women with stomas. A review of these two bodies of knowledge may provide further insight into the implications of a stoma on pregnancy. Non-research-based literature, on the other hand, contains a number of anecdotal accounts concerning pregnancy and stomas and a review of these articles may help to define issues related to the problem.
Selected areas for review will, therefore, include: the presence of stomas in women of childbearing age; the impact of living with a stoma; stomas and pregnancy: medical reports and anecdotal accounts; and pregnancy and chronic illness.

The Presence of Stomas in Women of Childbearing Age

Women of childbearing age may have urinary or fecal diversions for a variety of pathological conditions. A urinary diversion requiring a stoma is most commonly indicated when the bladder must be removed due to disease or trauma. The most common urinary diversion under these circumstances is the ileal conduit (Benson & Olsson, 1992). A segment of distal ileum is resected with its mesentery intact, the proximal end closed, and the distal end brought to the abdominal wall as a stoma. The ureters are then anastomosed to the newly formed conduit. Since bladder cancer is the usual indication for a urinary diversion, and is generally a disease of people over the age of 50 (Catalona, 1987), it is not a likely indication for a stoma in women of childbearing age. However, in younger women, urinary diversions requiring a stoma are indicated for such conditions as bladder trauma,
congenital disorders, neurogenic bladder dysfunction, and inflammatory disorders.

The most common fecal diversions are the colostomy and the ileostomy (McGarity, 1992). Colostomies are usually performed in the caecum, transverse colon, left colon, and sigmoid colon and ileostomies usually performed in the terminal ileum (McGarity, 1992). Both colostomies and ileostomies may be either temporary or permanent in nature with a temporary diversion performed as part of a staged procedure with a view to its ultimate closure.

A permanent colostomy is most frequently indicated when an individual requires an abdominoperineal resection of the rectum for colorectal cancer (Kodner, Fleshman, & Fry, 1989). However, the incidence of colorectal cancer does not rise significantly until the age of 40 to 45 which is beyond the usual childbearing age (Haskell, Selch, & Ramming, 1990).

A permanent ileostomy, on the other hand, is most commonly constructed for Crohn’s disease (McGarity, 1992), a chronic inflammatory bowel disease which has an incidence of 1 to 7 per 100,000 persons and a peak prevalence prior to age 35 (Mendeloff, 1985). If the
disease does not necessitate the removal of the entire colon, colostomies are constructed. Unfortunately, Crohn’s disease can affect any part of the alimentary tract from the mouth to the anus, and a bowel resection with ileostomy or colostomy may not be a cure (Janowitz et al., 1985). Other segments of the bowel may become active, including the ileostomy itself, and therefore surgery is only performed if medical management is unsuccessful.

Until recently, total proctocolectomy with permanent ileostomy was standard surgical treatment for ulcerative colitis, another inflammatory bowel disease with an incidence of 4 to 7 per 100,000 persons and a peak prevalence prior to 35 years of age (Mendeloff, 1985). Unlike Crohn’s disease, ulcerative colitis is confined to the mucosa of the rectum and colon and a total proctocolectomy is considered a cure for the disease. Although proctocolectomies with permanent ileostomies are still performed, an ileoanal reservoir, a continent diversion, is currently being constructed in most patients who have ulcerative colitis (McGarity, 1992). The colon is resected but the rectum and anal sphincter are preserved after stripping away the
mucosal lining. An internal ileoanal reservoir is then constructed from a segment of distal ileum and anastomosed to the rectal stump (Baba et al., 1985). Crohn's disease is not considered a good indication for an ileoanal reservoir since the disease may afflict the reservoir itself and require further bowel resection (Janowitz et al., 1985).

Both Crohn's disease and ulcerative colitis share many clinical and laboratory features, often making a differential diagnosis difficult (Kirsner, 1985). The incidence of Crohn's disease appears to be increasing, however, and that of ulcerative colitis remaining the same (Kirsner, 1985). Their etiology is unclear but it appears to be associated with multiple factors including diet, emotions, heredity, infections, and immunity, rather than a single cause (Kirsner, 1985). Although multiple occurrences of these diseases in the same family have been documented, evidence supporting a role for genetic factors in the pathogenesis of the diseases is incomplete (Kirsner, 1985).

In summary, urinary diversions, although rare in women of childbearing age, are indicated for such conditions as bladder cancer, neural injuries,
congenital disorders, trauma to the bladder, and inflammatory disorders. Fecal diversions requiring permanent colostomies or ileostomies are more commonly seen in women of childbearing age, with Crohn’s disease currently being the usual indication.

The Impact of Living with a Stoma

Although the research-based literature does not specifically address the psychosocial or cultural implications of a stoma for pregnant women, it does address the daily challenges of living with a stoma. A review of this literature should provide insight into how a stoma affects pregnancy.

In a study to determine how individuals cope with a permanent ileostomy, Kelly (1991) interviewed a convenience sample of 45 individuals, 30 women and 15 men, each with a permanent ileostomy due to ulcerative colitis. Twelve of these people had their operation within the twelve months prior to the interview, another 20 had surgery between 1 and 5 years before the interview, and 13 had surgery more than 5 years before the interview.

Using the psychology of coping theory developed by Lazarus as a basis, Kelly describes his findings in
terms of a technical level, an intra-subjective level, an inter-personal level, and an inter-subjective level of coping.

The first level of coping, the technical level, concerns the technical skills necessary to manage body waste. Ongoing technical problems cited by the group included the continuous need to obtain, apply, and monitor stoma appliances, and the need for constant attention to prevent surgical and medical complications, such as food blockages and peristomal skin breakdown.

The second level of coping, the intra-subjective level, concerns the emotional and affective elements with which the person with an ileostomy has to contend. Although the strongest feelings of anxiety, anger, and depression were noted among persons with recently acquired ileostomies, a consistent undertone of unhappiness was noted among the group in general. The author attributes the unhappiness to the fact that the ileostomy itself was generally considered undesirable by the subjects and, despite their best efforts to lead an ordinary life, it might at any time thwart them.

The third level of coping, the inter-personal
level, concerns social interaction with others. The key issue identified by the group was how to construct a normal identity. This issue was dealt with in a variety of ways including putting the ileostomy into perspective and not defining it as a major problem, engaging in normal activities, and concealing the stoma.

The fourth level of coping, the inter-subjective level, concerns the need to verbally make sense of what has happened. The author concludes that the subjects’ explanations of how they cope with their ileostomies is a coping method in its own right as it provides an opportunity to interpret their situation.

Although the problems identified by Kelly (1991) pertain to coping with a permanent ileostomy, similar problem areas have been identified in studies pertaining to stomas in general. Follick, Smith, and Turk (1984), assuming that individuals with stomas experience adjustment difficulties similar to individuals with other chronic conditions, used a biopsychosocial model of chronic illness to examine a range of adjustment difficulties in a sample of 131 individuals. Those with ileostomies made up 54% of the
sample, those with colostomies 39%, and those with urostomies 8%. The median time since surgery was 4.5 years.

Technical difficulty was the most prevalent problem area cited. Eighty-four percent of the sample reported having problems with one or more aspects of technical management, with skin problems being the most commonly reported. Other frequently encountered technical problems included leakage, odour, diet, clothing, and noise of the stoma. Approximately one-third of the sample reported emotional and social difficulties and almost half of the sample indicated sexual activity had become a problem since surgery. A significant proportion indicated that their families and marriages had experienced difficulties due to the stoma. Forty-six percent felt that they had received inadequate information about their stoma after surgery and 40% felt their spouse also had received inadequate information. An association was found between technical difficulties and impaired emotional, social, and marital/family functioning. In addition, an association was determined between emotional difficulties and problematic social marital/family
adjustment, and impaired sexual functioning. Finally, adequate information was associated with fewer technical problems and better emotional and social adjustment.

The authors recommend that patients be given more assistance with technical management, more information about how to cope with living with a stoma, and that the spouse or significant other be included in the pre- and post-operative teaching sessions.

Results obtained from an early study by Dyk and Sutherland (1956) also support the finding that an association exists between the ability to adapt to a stoma and a supportive spouse. To determine the physical and emotional needs of individuals with stomas and the spouses' responses to their needs, 22 men and 16 women who had a permanent colostomy constructed within the previous 5 to 14 years were interviewed. The authors concluded that the emotional reaction of the spouse to the stoma was an important influence on the individual's own ability to adapt.

Recognizing that the response of the spouse to a stoma plays a significant role in an individual's adaptation, Kobza (1983) used a semi-structured
interview tool to determine the expressed needs of 20 spouses who had partners with a stoma. The most common needs expressed were for more information and for more support. Approximately half stated they had received no information post-operatively regarding stoma care and for those who did receive information it pertained only to physical care. With regard to the need for support, all the spouses had a tendency to hide their feelings in front of their partner and only about half had any outside support. Many expressed a desire to have someone to talk with or to give them some guidance. The author concludes that health care professionals should do more to incorporate the spouses into the rehabilitation program, especially in light of the vital role they can play.

Dlin (1978), a psychiatrist, suggests that attitudes and values associated with elimination influence one’s emotional adaptation to a colostomy or ileostomy. He claims that at an early age individuals learn that control of stool or gas is rewarded with love and praise and lack of control with disapproval, punishment, threat, and rejection. An individual with a fecal diversion, who lacks control of either the
elimination of stool or gas, may therefore experience
feelings of shame, disgust, or guilt. In addition, the
individual can no longer achieve privacy when he is
passing stool, which Dlin (1978) claims is also
cherished by our society. Rather stool or gas is
uncontrollably passed from a protruding stoma on the
abdomen into a plastic pouch. Dlin (1978) concludes
that these cultural attitudes and values add to the
psychosocial challenge of adapting to newly created
stomas.

In summary, the literature reveals that although
most individuals with stomas can lead fulfilling lives,
they may be faced with numerous technical, emotional,
social, and cultural challenges which demand ongoing
adaptation for both themselves and their partners.
However, the literature does not acknowledge if similar
challenges are endured during pregnancy or, indeed, how
these challenges may affect the childbearing
experience.

**Stomas and Pregnancy: Medical Reports**

A review of the medical literature revealed six
useful studies between 1957 and 1993 pertaining to
stomas and pregnancy. The following are brief
summaries of these studies, as they appear in chronological order of publication.

The general tendency to advise against pregnancy in women with ileostomies after colectomy for ulcerative colitis prompted two American studies by Scudamore, Rogers, Bargen and Banner (1957) and Priest, Gilchrist and Chicago (1959). A colectomy in these early studies referred to either a sub-total or a proctocolectomy. The purpose of both studies was to determine if, indeed, an ileostomy interfered with pregnancy.

Scudmore et al. (1957) included 18 pregnancies in 12 women with a total of 13 live births. The non-live births were attributed to one spontaneous abortion in the first trimester following an incision and drainage of an abdominal abscess; two abortions in the first trimester for which the causes were not stated but it was reported that segments of diseased bowel remained at the time of the abortion; one stillbirth at seven months; and one hysterotomy performed for a severe exacerbation of the colitis.

Priest et al. (1959) included 13 pregnancies in 7 women with a total of 10 live births and three early
spontaneous abortions. Two of these abortions occurred in the same woman after two uneventful pregnancies following surgery for an ileostomy. The cause of the third abortion was not explained but it was reported that segments of diseased bowel remained at the time of the abortion.

In the study by Scudmore et al. (1957), all the women who delivered did so vaginally, as did all but one, in the study by Priest et al. (1959). The indication for Caesarean section was a 22 hour labour with the breech presenting. Both studies reported partial small bowel obstructions during pregnancy as a complication, occurring once in the Scudmore et al. (1957) study and three times in the Priest et al. (1959) study. The causes of these bowel obstructions were not reported. Scudmore et al. (1957) reported that the obstruction occurred in a woman two weeks before her due date. In this case labour was induced and the symptoms promptly subsided. Priest et al. (1959) reported that one of the obstructions was actually occasional cramping sensations near the stoma and the other two each occurred at seven months gestation. All of these obstructions responded to
conservative management. Other complications reported by Scudmore et al. (1957) included one incident of stomal prolapse which did not interfere with the pregnancy and appeared not to have been treated; one relapse of colitis in a section of colon that had not been removed; and two cases of compromised healing of the episiotomy in cases where the rectum had been removed and the perineum consequently scarred. Priest et al. (1959) also reported one case of an intussusception which required revision of the ileostomy. The authors of both studies concluded that, with careful supervision, women with colectomy and ileostomy may safely undergo pregnancy with the expectation of a normal delivery in most instances.

In response to a questionnaire circulated to members of the English Ileostomy Association, Hudson (1972) received information about 89 pregnancies involving 75 women. The purpose of the study was to determine the problems with pregnancy after ileostomy. An ileostomy in this study referred to either a fecal diversion or a urinary diversion when a segment of ileum is used to construct a stoma. The principle indications for ileostomy for fecal diversion were
ulcerative colitis and Crohn's disease. Urinary diversion included four cases of congenital spina bifida and meningomyelocele and one case of pelvic fracture. The 89 pregnancies comprised 84 live births, three miscarriages and two terminations. One of the terminations was due to bowel obstruction and the other was not explained. Vaginal deliveries were performed in 43 of 60 pregnancies going to term in which the methods of delivery were reported. The 17 Caesarean sections that were reported were usually performed for obstetrical indications but at least one was for a prolapsed stoma. The most noteworthy complication was bowel obstruction, with seven cases reported. The causes for these, however, were not reported but the author did suggest that, since obstructions within this population of individuals can occur even in the non-pregnant state, those reported in the study may not necessarily be due to an enlarging uterus obstructing the stoma but rather to complications from previous bowel surgery. The author also cautions that it may be difficult to diagnose a bowel obstruction in this group of individuals due to the fact that the symptoms of an obstruction are often similar to symptoms of pregnancy.
Since an undiagnosed obstruction can have serious consequences, he recommends that laparotomies be considered for any unusual pain. Other stomal problems mentioned included ileostomy prolapse and stomal enlargement. Finally, the author concludes that pregnancy is not contraindicated for individuals with ileostomies.

In another study conducted in Ireland over a span of six years, 20 primigravid patients with ileostomies were compared to a selected group of 100 primigravida in the same age group (Barwin, Harley, & Wilson, 1974). The purpose was to analyze the effect of pregnancy on the ileostomy and the effect of the ileostomy on pregnancy, labour and the puerperium. All the women in the study group had proctocolectomies, 19 cases for ulcerative colitis and one for Crohn's disease. The complications of pregnancy for both groups included pre-eclampsia, anaemia, urinary tract infection, premature labour, induction rate, perineal lacerations, and perinatal mortality. The only significant differences found in the study group compared with the control group were a higher incidence of anaemia, a higher Caesarean section rate, and a higher incidence
of perineal lacerations. The incidence of anemia was 20% in the study group compared with 13% in the control group, with the incidence in the study group decreasing as the interval between surgery and pregnancy increased. Caesarean section rate was 40% in the study group with the main indication being severe perineal scarring from previous abdominoperineal resection. In comparison, the Caesarean section rate was 10% in the control group. The authors attribute the increased incidence of perineal lacerations in the study group to previous abdominoperineal resections. Finally, the authors report that there were no cases of obstruction due to the enlarging uterus blocking off the stoma and no cases of prolapse of the ileostomy. They suggest that good antenatal care and management during labour will minimize complications and consequently be psychologically beneficial to the ileostomy patient. They conclude that ileostomy patients can have successful pregnancies without complications to the ileostomy or to the pregnancy.

To determine if individuals with stomas can become pregnant following surgery and, if so, the occurrence of unusual complications relating to the stoma or the
pregnancy, Gopal et al. (1985), sent questionnaires to 1246 members of the American Society of Colon and Rectal Surgeons, which includes membership both inside and outside the United States. The replies to the survey provided a series of 82 pregnancies in 66 women with a total of 79 live births, two spontaneous abortions at eight and 14 weeks gestation, and one stillborn at 29 weeks gestation following corrective surgery for a bowel obstruction. Sixty-four percent of the sample had ulcerative colitis before bowel surgery with stoma, 17% had Crohn's disease, 5% had bowel cancer, and a few had other indications. Seven women had colostomies, 57 women had ileostomies, one woman had a urostomy, and one was unspecified. Of the 82 pregnancies 50 resulted in vaginal deliveries and 30 in Caesarean sections. The Caesarean sections were done in 11 cases because of infant distress, in 9 cases because the physician believed that prior abdominoperineal resection would prevent a safe vaginal birth, in five cases because previous Caesarean sections had been done, in two cases for bowel obstructions, and in one case each for ileostomy prolapse and a urostomy nipple valve retraction. The
indication for one section was unspecified. Complications included six bowel obstructions, two of which occurred in the latter part of pregnancy and were due to the pressure of the enlarged uterus on the bowel. Three of the obstructions required corrective surgery during pregnancy. Prolapse of the stoma during pregnancy occurred twice in one woman and once in three women. One was corrected two months after delivery and the others were repaired during pregnancy with or without Caesarean section. No mention was made as to the cause for these prolapses. The authors conclude that women with stomas can become pregnant after surgery and successfully deliver children vaginally, but recommend that an obstetrician and a colorectal surgeon work together throughout the pregnancy.

Nicholl, Thompson, and Cocks (1993) presented case reports of three pregnant women in New Zealand, two of whom had colostomies and one of whom had an ileostomy. All of the women had Crohn’s disease. In the first case, pregnancy was complicated by a 20 cm stomal prolapse and the development of a peristomal hernia in the first trimester. The prolapse was reducible in the prone position but a restrictive binder was required
when in the upright position. To accommodate the prolapse, the woman used a two-piece pouching system with a flexible wafer which was modified with radial slits cut into the stoma opening. The authors do not suggest a cause for the prolapse but state that it was not related to hyperemesis which may be a precursor to prolapse. Both the prolapse and the hernia were repaired at term in conjunction with a Caesarean section.

In the second case, there were no physical problems with the stoma during pregnancy and the woman went into spontaneous labour at 41 weeks gestation and had a vaginal delivery with low mid-cavity forceps for delay in the second stage. The authors noted in this case that the woman, upon learning she was pregnant, was keen to read any information available about pregnancy with a stoma and was disappointed to discover that such information was scarce. She was apparently happy to discuss and document her experience and the authors suggest that these strategies provided her with a means of interpreting the events.

In the third case, pregnancy was complicated in two instances by bowel obstructions, the first one
occurring at 13-14 weeks gestation and the second one at 15 weeks gestation. In each instance conservative management with nothing by mouth and intravenous fluids produced resolution of symptoms over 24 to 48 hours. The woman had an elective Caesarean section at 42 weeks gestation for a high unengaged cephalic presentation.

In summary, Nicholl et al. (1993) suggest that the majority of stoma patients can expect a relatively normal antenatal course and subsequent delivery. However, they indicate that bowel obstruction can be a serious potential problem in a pregnant woman with a stoma. This may result from a lateral displacement or retraction of the bowel, a volvulus, lateral space herniation, or adhesions. They state that difficulty arises when trying to differentiate the obstruction from normal pregnancy for symptoms such as vomiting, colic, distension, and constipation are frequently seen in both situations. They therefore caution that a bowel obstruction should be suspected in any patient who has undergone previous abdominal surgery and they recommend conservative treatment for the first 24 to 48 hours and followed by surgery if necessary. The authors also recommend that psychological aspects of
the care of the pregnant patient with a stoma be considered and suggest that pregnancy may be a means for these individuals to reconstruct a normal identity.

In conclusion, six studies occurring in the United States, Britain, Ireland, and New Zealand over a span of 26 years dealing with stomas and pregnancy were reviewed. They were all done by physicians and focused primarily on medical considerations of pregnancy with a stoma. The studies ranged in size, from a collection of three case reports to others involving 82 and 89 pregnancies. In each study the ileostomy was the most common diversion but the indications for it varied according to the age of the study. In the studies conducted in the 1950's the chief indication was ulcerative colitis but in later years, it has become Crohn's disease. This reflects the trend in the surgical management of ulcerative colitis away from colectomy with ileostomy to colectomy with conservation of the rectal stump and reconstruction of an internal pouch.

Research suggests that the majority of women with stomas can anticipate uncomplicated pregnancies with vaginal deliveries. In the studies reviewed, the
incidence of live births ranged from 72% and 77% in the early studies to 96% and 100% in the later studies. It is interesting to note that in the early studies all the women had ulcerative colitis and the surgical treatment was not necessarily total colectomy as it was in the later studies. In fact, segments of diseased bowel still remained in three of the five women who had abortions in the first study and one of the three women in the second. Although a flare-up of the disease was reported in only one of these cases during pregnancy, the women's health may have been compromised. It is also interesting to note that there were no reports in any of the six studies of flare-ups of Crohn's disease during pregnancy.

The incidence of vaginal deliveries varied from 100% in the earliest study to 60% in the study in Ireland in 1974, not including the most recent study in New Zealand where only one of the three cases had a vaginal delivery. The indications for Caesarean section were usually obstetrical but did infrequently include bowel obstruction, stomal prolapse, and perineal scarring following abdominoperineal resection of the rectum.
The most frequent and the most serious complication reported was bowel obstruction, occurring in 8% and 7% of the two largest studies. It appears to be difficult to determine if obstructions were a result of an enlarged uterus applying pressure on a stoma or a result of previous bowel surgery. In most cases symptoms of the obstruction subsided with conservative management. Two authors mentioned the difficulty in diagnosing an obstruction in a pregnant women as the symptoms of an obstruction are often similar to symptoms of pregnancy. The other most commonly cited complication was stomal prolapse. Of the seven reported, five were treated surgically during pregnancy with or without a Caesarean section.

Stomas and Pregnancy: Anecdotal Accounts

A review of the Ostomy Quarterly, a United Ostomy Association (UOA) publication, revealed six anecdotal reports between 1975 and 1994 about the subject (Beaton, 1994; Goldfarb, 1991; Hoppes, 1975; Laughlin, 1991; Nordgren, 1993; Van Buskirk, 1985). Four of the women had ileostomies and two had urostomies. The indications for the ileostomies included three cases of ulcerative colitis and one case of Crohn’s disease and
the indications for the urostomies included cerebral palsy and interstitial colitis. All six women reported having had uneventful vaginal deliveries, with the exception of one 7 week premature delivery.

To analyze these autobiographical accounts, data were categorized according to physical, technical, emotional, and social concerns. With regard to physical concerns three women mentioned that their stomas enlarged during their pregnancies, one woman stating her stoma had expanded from 2.8 cm in diameter to 5.1 cm. One woman complained of adhesions during the pregnancy causing only minor problems and one woman complained of varicose veins along the perineal incision causing perineal discomfort. Only one woman mentioned that she had adjusted her diet and this was merely to increase fluids.

With regard to technical issues, two women mentioned having to increase the size of the stoma openings on their skin barriers to accommodate their larger stomas and one woman said that the pregnancy interfered with her ability to see her stoma and she therefore had to resort to a mirror to assist with the application procedure.
With regard to emotional issues, of those who reported their reactions upon discovery of their pregnancy, all expressed feelings of joy and ecstasy. Two women commented that they were grateful that the surgery and ileostomy had provided them with the opportunity to become pregnant. Several women reported their concerns about their pregnancies progressing normally due to their ileostomies and one woman with Crohn’s disease worried that her children could develop Crohn’s disease.

With regard to social issues, all the women reported having very supportive husbands. Two of the women mentioned having received a great deal of support from other women with stomas who had experienced pregnancy, and two women cited their local ostomy associations as being helpful in giving them articles pertaining to stomas and pregnancy and names of other women to locate. One woman, however, said that the ostomy association only had information about pregnancies and ileostomies and since she had a urostomy, this information was of no help to her. With regard to health professionals, two women reported that their obstetricians had been very informative and
supportive and that one of them had actually arranged for the nurses in the hospital to have a refresher course in stoma management in preparation for her hospital admission. Two of the women mentioned that they felt they had provided the hospital nurses with an opportunity to learn about stoma management.

In summary, all the women had normal deliveries and produced healthy babies. Their fears that somehow their stoma might interfere with the experience were unproven. All claimed to have had very supportive husbands. None complained about the care they received and yet the only supportive group of health care professionals mentioned were obstetricians. In general, pregnancy was perceived by all to be a very positive and uncomplicated experience. However, it is possible that these experiences are not typical for pregnant women with stomas since, perhaps only those with successful pregnancies selected to publish their accounts.

Pregnancy and Chronic Illness

Although the nursing literature does not specifically address the implications of a stoma on childbearing, several articles addressing the
implications of chronicity, in general, on pregnancy do exist. A review of these articles may provide insight into the childbearing experience for women with stomas.

Shaul, Dowling, and Laden (1987), claim that until recently there has been a cultural bias that women with disabilities should not bear and raise children and consequently the needs of such women during pregnancy have been neglected. To investigate the concerns of disabled women in regard to pre-natal and obstetrical care and early childhood, they interviewed ten women with a variety of disabilities. On the basis of these interviews the authors draw several conclusions. They conclude that most women with disabilities, in deciding whether or not to become pregnant, want to speak with a woman with a similar disability who has gone through pregnancy. They want to know what to anticipate during pregnancy and after the baby is born. The authors also conclude that pregnancy for disabled women does not usually cause a tremendous inconvenience and that support systems, such as Lamaze classes, available to non-disabled pregnant women, can be helpful to disabled women as well. Finally, they conclude that experiences with labour and delivery are similar to those of non-
disabled women.

Corbin (1987) studied strategies used by chronically ill women to manage medical risk factors of pregnancy. A sample of 20 women whose pregnancies were complicated by a variety of chronic illnesses was interviewed. The results of the study suggest that the women themselves play a significant part in the management of their pregnancies. The actions they select to maximize their chances of having a healthy baby are determined by their own assessment of the risks and the options they perceive open to them. The author, therefore, concludes that health care providers and the women should cooperate to formulate a common management plan. To achieve shared management, women should be given information about a variety of strategies they might use to manage their illnesses and pregnancies and they should be helped to incorporate these strategies into their daily lives. Further, the author concludes that women should be informed about all the risks and benefits associated with a treatment in order to allow them to make the "right decision". Finally, both the health care providers and the affected women should share their respective knowledge:
the health care providers contributing medical knowledge and the women contributing knowledge about how the illness affects their bodies.

Carty (in press), in presenting an overview of current knowledge regarding childbearing with a variety of disabilities, concludes with recommendations for nursing practice that can be applied to all women with disabilities, regardless of the nature of the disability. These recommendations include: the need to provide services in both physically accessible settings and psychologically assessable settings, that is, settings which communicate respect and sensitivity; the need to provide pre-pregnancy counselling to assist the woman and her family with decision-making about becoming pregnant; the need to plan for special needs of labour and birth and review these needs with hospital staff prior to hospitalization; and the need to provide pre-natal counselling to assist the mother to prepare for the many needs of the postpartum period.

In summary, with respect to pregnancy, women with chronic conditions share common psychosocial concerns and have similar needs. An awareness of these issues will enable health care practitioners to provide more
sensitive and effective care.

Summary

A review of the literature reveals that there are a variety of conditions which indicate the need for a stoma in women of childbearing age, the most common currently being Crohn's disease; that stomas have an ongoing impact on the daily lives of individuals; that, despite specific medical considerations, women with stomas may successfully bear children; that anecdotal accounts exist which collectively describe selected physical, technical, emotional, and social issues specific to pregnancies and stomas; and that women with a variety of disabilities or chronic illnesses share similar psychosocial concerns with respect to pregnancy. However, the small body of research-based literature concerning the effect of stomas on pregnancy that does exist has been contributed by physicians and has focused primarily on physiological issues. There is no existing research-based literature about the effect of a stoma on the childbearing experience from a nursing perspective.
CHAPTER THREE
Methodology

Introduction

This study used a case study research design to explore the childbearing experience for a woman with a stoma. In this chapter an overview of the research design, selection of the participants, ethical considerations, data collection and analysis, and reliability and validity are considered.

Research Design

The distinctive need for a case study design arises from the desire to understand complex social phenomena (Yin, 1994). Its unique strength is its ability to deal with a variety of evidence, such as interviews, observations, and documents (Yin, 1994).

In this thesis case study methodology was selected to explore, in depth, a subject of which little is known: the childbearing experience for a woman with a stoma. According to Yin (1994) the case, or unit of analysis, may refer to an individual, a group of individuals, or an event. However, regardless of what the unit refers to, its specific time boundaries must be defined. If the study is concerned with one unit of analysis it is referred to as a single-case study and is considered an appropriate design when the
phenomenon or phenomena of interest is rare, or critical, or revelatory in nature. If more than one such case is included in the study, the study is referred to as a multiple-case design.

Multiple-case designs must be considered as multiple experiments and not as multiple subjects within one experiment (Yin, 1994). That is, conducting six or ten case studies is analogous to conducting six or ten separate experiments. Each individual case study is a complete study in which convergent evidence is sought regarding the facts and conclusions for the case. The case study protocol is replicated for each case and the findings compared across cases.

A multiple-case study design was selected for this study. Even though six cases were selected for the study, the phenomenon is still rare as only eight such cases were reported in the past 18 months in the Lower Mainland, Fraser Valley, and Sunshine Peninsula of British Columbia. Each case is defined as the childbearing experience for a woman with a stoma, with childbearing having a definite duration from conception to postpartum.

To ensure that a design is appropriate for a selected study, Yin (1994) suggests that the researcher should
consider the following criteria: the type of question being posed; the extent behaviours can be manipulated; and the degree of focus on contemporary events as opposed to historical ones. Case study design is preferred when the research questions are concerned with operational links rather than with frequencies or incidence and, as such, are often "how" or "why" questions rather than "who", "what", or "where" questions (Yin, 1994). Also, case study design is preferred when the relevant behaviour cannot be manipulated and when the study is concerned with examining contemporary events as opposed to historical ones (Yin, 1994). The historical method is preferred when the researcher must rely on documents and artifacts as opposed to "live" individuals to obtain evidence.

With these criteria in mind, case study design appeared to be appropriate for this study. The research question for the study satisfied the first criteria as it is a "how" question, specifically "how does a stoma affect the childbearing experience?". Further, the study was not concerned with manipulating behaviour and focused on contemporary events as opposed to historical ones.

Selection of the Participants

The selection criteria and selection procedures will be
described.

Criteria for Selection

The participants for this study included the women with stomas who had experienced childbirth, their respective partners, and the physicians who provided obstetrical care during pregnancy and delivery.

The women who participated were selected based on the criteria that they had given birth to a child within the past approximate 18 months; that they had a stoma when they gave birth; and that they were willing and able to speak about the experience.

Partners who participated in the study were selected for their availability and willingness to share their observations about the childbearing experience.

Physicians who participated in the study were selected by the women who had experienced childbirth. The criteria for their selection included their involvement in the pregnancy and delivery and their willingness and availability to discuss this experience with the researcher.

Since multiple-case designs follow replication logic rather than sampling logic, the data collected will only be compared between cases in support of the conceptual framework rather than making direct inferences to a larger
Selection Procedures

The President of the Vancouver Chapter of the United Ostomy Association (UOA) and four enterostomal therapy (ET) nurses practising in the Lower Mainland and Fraser Valley of British Columbia were sent introductory letters (Appendix A) describing the purpose of the study and asking for their participation in sending an information letter (Appendix B) to any client with a stoma who had experienced childbirth within the past approximate 18 months. Information letters were sent to eight clients in the Lower Mainland, Fraser Valley, and Sunshine Peninsula who were known to fit the criteria. The letter included a description of the purpose of the study and the researcher's desire to interview them, their partner, and the physician involved in their childbirth experience. Women interested in participating were then asked to contact the researcher. The researcher would have been satisfied with a single case study but, as is often the case with areas about which little is understood, individuals wanted an opportunity to talk and consequently six women volunteered to participate. The partners of all but one also volunteered to participate in the study. All the women granted permission to the
researcher to interview the physician involved in their childbearing experience and provided the researcher with their names. An information letter was then sent to the physicians, describing the purpose of the study and requesting their participation in describing the childbirth experience (Appendix C).

**Characteristics of the Participants**

Six women, five partners, and five physicians participated in the study. One partner refused to participate and two women had the same physician. At the time of childbirth, the women ranged in age from 24 to 39 years of age. All the women had ileostomies, one a consequence of ulcerative colitis and the others, consequences of Crohn's disease. At the time of their participation in the study all had experienced childbirth within the past 28 months. For two women it was their second pregnancy with an ileostomy and for four, their first. However, two of these four had been pregnant prior to bowel surgery with ileostomy.

**Ethical Considerations**

The researcher ensured protection of the rights of the informants by:

1. Obtaining approval from and adhering to the
standards set by The University of British Columbia

Behavioural Sciences Screening Committee For Research and Other Studies Involving Human Subjects.

2. Explaining to the participants in writing the purpose of the study and the expectations the researcher has for their involvement.

3. Obtaining written consent from each woman (Appendix D) and her respective partner (Appendix E) prior to conducting the initial interview. The consents addressed the audio-taping of interviews and the participants’ right to refuse to comment or to withdraw from the study at any time without consequence.

4. Obtaining written consent from each woman to interview the physician involved in her childbearing experience (Appendix F).

5. Assuring the participants that any information they shared would be held in the strictest confidence and that they would never be identified in any published or unpublished materials. In addition, they were told that the audio-tapes would be erased following completion of the study.

Data Collection

Each individual case of a multiple-case study design is
a complete study within itself. This multiple-case study design included six cases and the data collection procedures were replicated for each case.

Data collected for case studies may come from a variety of sources of evidence including documents, archival records, interviews, observations, and physical artifacts (Yin, 1994). Despite the sources of evidence selected, Yin (1994) suggests that the benefits derived from the data can be maximized by adhering to three principles of data collection.

The first principle is that multiple sources of evidence, as opposed to single sources, are used to collect data about the same phenomenon. This process, referred to as triangulation, leads to converging lines of inquiry and ultimately strengthens the findings or conclusions of the study. Each case in the study relied on interviews with the woman who experienced childbirth as well as her partner and physician.

To collect data from the women and their partners an informal interview guide, consisting of open and closed-ended questions was used (Appendix G). Each interview was audio-taped and lasted approximately one hour. It was conducted in a setting of the participant’s choice. All the
women selected to be interviewed in their own homes. Three women agreed to have their partners interviewed during the same visit and two requested that their partners be interviewed on the telephone at a later date. Each woman was contacted following the interview to seek clarification of data. On completion of the interviews, the audio-tapes were transcribed and analyzed.

Physicians selected by the women to be informants for the study were interviewed on the telephone. Open and closed-ended questions were used to solicit their impressions of how the stoma affected the childbearing experience (Appendix H). The researcher made notes during these telephone interviews and relevant quotations were used in the case report.

The second principle of data collection described by Yin (1994) pertains to the organization and documentation of the data. Yin (1994) recommends that the researcher using case study methodology establish a presentable database of evidence so that other researchers can review the evidence directly and not be limited to written case reports. Due to ethical considerations, a database was maintained only until the study was completed and was made accessible only to members of the research committee.
The third principle of data collection is concerned with maintaining a chain of evidence so that the reader can follow the derivation of evidence from the research question to the conclusions and vice versa. One method to maintain a chain of evidence is to incorporate sufficient citation of the relevant portions of the case study database into the report (Yin, 1994). In this study direct quotations from the transcripts were included in the written case reports. A chain of evidence can also be achieved by maintaining a link between the content of the protocol and the initial study questions. To achieve this link, questions about the effect of the stoma on pregnancy were organized around major concepts selected from Snyder’s (1979) childbearing framework: the physiological system, the self system, the family system, the social system, and the cultural system. Major areas of concern identified from the literature review also contributed to the content of the interview guide.

Data Analysis

In a multiple-case study research design the data for each case are analyzed separately and then a comparison is made across cases.

Data from all sources were thoroughly examined for each case: the transcriptions of the interviews with the women
and their partners; and the notes taken during the telephone interviews with the physicians and partners. Yin (1994) suggests that the analysis can be facilitated by making a matrix of categories and placing the data within the categories.

In keeping with this recommendation, the data for each case were grouped according to the major concepts of Snyder's (1979) childbearing framework (Appendix I) and analyzed separately to determine how the stoma affects each system and how the systems interact to create a unique and holistic experience for each individual woman. Findings were then compared across cases and presented in a cross-case report.

Yin (1994) suggests that the quality of the analysis is enhanced when the researcher brings expert knowledge to the case study. The researcher for this case study is a certified ET nurse and is cognizant of current issues about stomas. My expert knowledge and experience with individuals with stomas was most useful in the analysis of the data.

Reliability and Validity

Case study methodology can employ a variety of tactics to achieve reliability and validity. Yin (1994) suggests that reliability can be achieved by following a case study
protocol and including sufficient citation to the relevant portions of the database within the case study report. Both tactics would enable a later researcher to repeat the case study and arrive at similar findings and conclusions.

The case study protocol is intended to guide the researcher in carrying out the study. Yin (1994) recommends that the protocol should include an overview of the case study project detailing the purpose of and the setting for the study; an account of the data collection procedures utilized; an interview guide outlining specific questions to be asked and probable sources of evidence to be used; and a plan for reporting the findings. These recommendations were adhered to.

The second method recommended by Yin (1994) to achieve reliability, namely the inclusion of sufficient evidence in the case report, enables other researchers or readers of the case reports to review the evidence and draw independent conclusions.

Yin (1994) suggests that the validity of a case study design can be enhanced by ensuring the presence of both construct and external validity. To achieve construct validity, a chain of evidence and multiple sources of data were used. Both tactics helped to ensure that data
collection procedures did indeed reflect the research question and both were described earlier in the discussion of data collection. Another tactic to achieve construct validity is to have the draft case study report reviewed by key participants and other researchers. In this study the draft report was reviewed by members of the research committee and by the women involved with the childbearing experiences. These reviews greatly reduced the likelihood of reporting false findings.

The external validity of a case study is concerned with whether the study's findings can be generalized beyond the scope of the study. Case studies rely on analytical generalization as opposed to statistical generalization (Yin, 1994). That is, in case study methodology, the researcher tries to generalize a particular set of results to a broader theory rather than to a larger population. A theory must be tested through replication of findings before it can be used to identify other cases to which the results are generalizable. A multiple-case study can facilitate this process for it subjects a theory to repeated testing. In this multiple-case study, the findings from each case were generalized to the conceptual framework underlying the study. The replication of findings increased the likelihood
that the framework might be acceptable for a larger population.

**Summary**

This chapter outlined the research design used in this study. The selection of the participants, ethical considerations, data collection and analysis, and reliability and validity were described.

A multiple-case study research design enabled the researcher to explore, in depth, a subject of which little is known. Major concepts selected from Snyder's (1979) childbearing framework were used to organize the collection and the analysis of the data. Data for each case were collected and analyzed separately and the findings compared across cases.
CHAPTER FOUR

Findings of the Study

Introduction

This multiple-case study is a collection of six individual case studies, each exploring the childbearing experience for a woman with a stoma. The data for each case were analyzed separately to determine how the stoma affects each system and how the systems interacted to create a unique and holistic experience for each woman. The findings are summarized in six individual case reports and a comparison of findings is presented in a cross-case report. Quotations are integrated throughout the chapter to illustrate and substantiate the researcher's interpretations.

Individual Case Reports

Case 1

Ms. A. developed ulcerative colitis when she was 21 years old. At the age of 25 she had a total proctocolectomy with ileostomy. She became pregnant with her first and second children at the ages of 34 and 39 respectively. Although the second pregnancy is the case under consideration, references are also made
to the first one.

With her first pregnancy Ms. A developed a stomal prolapse at 20 weeks gestation which was surgically revised during pregnancy. At term she had a vaginal delivery for a healthy newborn but four days postpartum again experienced a stomal prolapse requiring surgical revision.

She was concerned about having a second pregnancy in case her stoma should again prolapse and therefore sought pre-pregnancy counselling from her general surgeon. Despite being told she would face the same risks a second time, she and her partner decided to take the risk. Her second pregnancy also progressed normally until at 20 weeks she again had a stomal prolapse. She was less anxious this time as she knew what to expect but nevertheless found the prolapse inconvenient and uncomfortable. After tolerating it for several weeks she had a laparotomy and surgical revision. This procedure placed an added strain on the family. She and her partner worried about the effects of surgery, anaesthetics, and medications on the fetus, plus had to make alternate child care arrangements for their toddler during the 10 day hospital stay.
Unfortunately the stoma prolapsed again at 36 weeks gestation. To expedite a surgical revision in the non-pregnant state, she was referred to an obstetrician and an attempt was made to induce labour at 37 weeks. Following two further attempts at induction her membranes were ruptured at 40 weeks and, using one hand to reduce the stoma during a five hour labour and delivery, she gave birth to a healthy newborn. One week postpartum she again had a laparotomy and surgical revision of prolapse.

Her stoma also enlarged in diameter during pregnancy which she attributed to her expanding abdomen. Prior to pregnancy she required a 38 mm flange and during pregnancy, a 57 mm flange. She returned to a 38 mm flange after pregnancy. She also commented that she had greater difficulty concealing her stoma during pregnancy as "It's a lot harder to disguise a bump on a round tummy." Finally, she noted, "The baby always sat really low [during the pregnancy]" and attributed this to the absence of her colon and rectum.

Towards the end of her first pregnancy she developed a partial bowel obstruction which presented
with cramping and liquid output. It lasted three weeks, during which time she "lived on Ensure". She had no bowel obstructions, however, with the second pregnancy.

She did not know any other women with stomas who had experienced childbirth and aside from reading a few articles about stomas and pregnancy published by the United Ostomy Association, had little knowledge about the experience when she entered her first pregnancy. She attended pre-natal classes but the impact of the stoma on pregnancy or hospitalization was never addressed. Of all the health care providers she had contact with, her family physician was the one who gave her the most support during pregnancy. He kept her informed about her progress, included her in decision-making, and provided her with information she needed regarding management of the prolapse and bowel obstruction. He also was able to allay her and her partner's concerns about surgery during pregnancy.

Her physician described being concerned about a recurrent prolapse with the second pregnancy and the issue of the most appropriate mode of delivery. He thought a vaginal delivery would increase pressure on
the stoma but a Cesarean section might be complicated by adhesions.

Despite being concerned that the nurses on the obstetrical ward would not be capable of providing stomal care following surgery, she found she did not need their assistance aside from the occasional emptying of her pouch. An ET nurse in the hospital was available to change her stomal barrier as necessary.

Ms. A. felt that, aside from the stomal prolapse, having a stoma did not affect her pregnancy. She said, "Except for the prolapse the fact that I had a stoma and got pregnant didn’t make any difference." She also thought that the joy of having her children was worth any discomfort she experienced during pregnancy.

Conclusion.

Ms. A.'s pregnancy was interrupted by two incidents of stomal prolapse, one requiring a laparotomy and surgical revision during pregnancy, the other requiring her to manually reduce her stoma as she gave birth to her child. In addition, Ms. A. had to modify her pouching system to accommodate a larger stoma. These physiological effects of the stoma on pregnancy gave rise to discomfort and caused concern
and inconvenience for both Ms. A. and her family. Despite these concerns, Ms. A. perceived her pregnancy to be a positive experience as she believed the joy of having a child was worth any discomfort or worry she had endured.

Case 2

Ms. B. developed Crohn’s Disease at the age of 34 and at 38 became pregnant with her first child. Her pregnancy progressed normally until 20 weeks gestation at which time she had a flare-up of Crohn’s disease. She was admitted to hospital where her condition deteriorated, finally necessitating an emergency subtotal colectomy with ileostomy for a bowel perforation. The following passage depicted her reaction to surgery.

I think part of the problem is that it was emergency surgery ... I woke up and this was the furthest thing from my mind ... to losing everything and waking up with an ileostomy. I didn’t even know what [an ileostomy was].

In addition to being anxious about how to cope with a new ileostomy she and her partner were also concerned about the effect of surgery, anaesthetics, and medications on the fetus.

Despite receiving follow-up care by an ET nurse and attending a local ostomy association support group
meeting, she did not feel prepared to cope with her ileostomy after discharge from hospital. This viewpoint is illustrated in the following quotation.

Your day to day life really changes and no-one has a lot of answers ... I always felt that when I came home with the ostomy they just sent me home and there was nothing after that, there was nothing.

Fortunately, her husband provided tremendous emotional support and even took responsibility for the technical aspects of stomal care, such as fitting and applying appropriate pouching systems.

She had some concerns about the effect of the ileostomy on pregnancy but felt that she could not address these with her obstetrician as she sensed he did not think it was a relevant issue. She said she would have "loved" to have talked to another woman with a stoma who had experienced pregnancy but never had the opportunity. She attended pre-natal classes and was too embarrassed to mention the stoma.

At 26 weeks gestation she experienced abdominal pain and nausea and went to the Emergency Department at her community hospital. Suspecting an obstetrical complication, she was admitted to an obstetrical ward. This proved to be a disturbing experience, for on
admission, she was told by a nurse that her stoma made her a "dirty patient" and she should not be there. She was then transferred to a tertiary care centre, where she stayed for several days. She was treated with analgesics but the cause of the pain was never diagnosed.

She carried the baby to term and, following a trial of labour, had a Caesarean section of a healthy newborn. She described the Caesarean section as a "piece of cake" compared to her previous surgery. She was overwhelmed with emotion when the baby was born and made the following comment.

As soon as I heard that first cry ... my heart just broke and I thought "what have I put you through?". It just made it very real.

Her partner continued to assist with stomal care postpartum.

Her obstetrician reported that Ms. B had a smooth pre-natal course following her bowel surgery with ileostomy and he had no concerns about the effect of the stoma on the pregnancy or delivery.

Ms. B. concluded that she did not feel her pregnancy had been a normal experience. She said, "The
whole pregnancy was just not normal, because its not normal to have [either surgery during pregnancy or an ileostomy]."

Conclusion.

Ms. B.’s pregnancy was dramatically interrupted by a bowel perforation as a consequence of Crohn’s disease. Following surgery with ileostomy she was faced with having to adapt to a new stoma while nurturing a pregnancy. These challenges were stressful for both Ms. B and her partner. She perceived her pregnancy to be abnormal and continues to feel upset about the trauma she and her child endured.

Case 3

Ms. C. developed Crohn’s disease at the age of 26. She became pregnant with her first child at the age of 30 and had an uneventful pregnancy. However, postpartum she had a flare-up of Crohn’s disease and an eventual proctocolectomy with ileostomy. Approximately one year later, at the age of 32, she became pregnant with her second child.

She had an uneventful pregnancy and did not need to modify any aspects of her stomal care. She did not think the stoma noticeably changed in size during
pregnancy but commented that it retracted postpartum and became difficult to pouch. It remains retracted and a source of concern. Although she did not think her thirst increased during pregnancy, she explained that, regardless of pregnancy, she must drink at least eight glasses of water a day to maintain adequate stomal function. She described this as being the most difficult aspect of having a stoma.

I don’t have any problems with food, I know what I can’t eat and its very few things ... but the hardest thing for me to do is sit down and take time to drink water.

She was under the care of an obstetrician during pregnancy and consequently said she had no concerns. Aside from her mother, who had a newly constructed stoma due to ulcerative colitis, she did not know another person with a stoma and consequently never talked to a woman with a stoma who had experienced pregnancy. She did not belong to an ostomy association and never attended pre-natal classes.

She described her bowel surgery with ileostomy as a very positive experience for it allowed her "to get [her] life back" after having been so sick with Crohn’s disease. She thought her husband had helped her to adapt to having a stoma because he readily accepted it,
whereas she thought "some guys might think [the stoma is] too weird or yucky" and would not be able to cope with it. She thought it also would be more difficult to acquire a stoma as a single person and subsequently have to explain it to a new partner.

At term Ms. C. had a Caesarean section for a healthy newborn. She did not require assistance with stomal care during hospitalization and concluded that the stoma did not have an effect on her pregnancy because "... its just part of me now." She and her partner both considered her second pregnancy to be far better than her first because she was able to care for her baby postpartum. With her first pregnancy she had been too ill with Crohn's disease to do so.

Her obstetrician, also, was not concerned about the effect of the stoma on pregnancy or delivery but was concerned that perineal scarring, as a result of bowel surgery, would interfere with healing following vaginal delivery. He consequently elected to do a Caesarean section.

Conclusion.

Ms. C. did not suffer any physiological implications of having a stoma during pregnancy
although postpartum had to contend with a retracted stoma. She and her partner were both grateful that she remained healthy throughout pregnancy and postpartum and consequently perceived the pregnancy to be a very positive experience.

Case 4

Ms. D. was diagnosed with ulcerative colitis at the age of 25 and gave birth to her first child at 34. Following delivery she had a flare-up of colitis and at the age of 35 underwent a sub-total colectomy with ileostomy. At surgery it was determined that she had Crohn’s disease rather than ulcerative colitis. At 37 she became pregnant with her second child.

She felt well during pregnancy and was still exercising at least three times weekly until 28 weeks gestation. She said, "I had a really good pregnancy as far as I felt very good through my whole pregnancy ... and I wasn’t sick." She reported two episodes of watery stool which she attributed to food blockages but did not know whether these were a result of pregnancy or if they would have occurred anyway. Both times drinking grape juice seemed to relieve the symptoms and she did not require medical treatment or
hospitalization.

She had to make some modifications to her pouching procedure. She needed to adjust the stomal opening on her skin barrier to accommodate a larger stoma as its diameter expanded from 25mm to 32mm during pregnancy. It resumed its original size postpartum. She also had to change the brand of skin barrier she was using because the adhesive backing caused skin irritation.

With respect to pre-natal care she made the following comment.

The obstetrician was very important in the care of the fetus and the pregnancy itself but as far as the pregnancy with the ileostomy the ET nurse was my best resource.

ET nurses gave her anecdotal accounts published by the Ostomy Quarterly about stomas and pregnancy and they arranged for her to talk to a woman with a stoma who had experienced pregnancy. Although she appreciated this opportunity it also alarmed her because the woman had experienced two incidents of stomal prolapse during pregnancy. Although she attended pre-natal classes with her first pregnancy, she did not feel the need to do so with the second. She was not interested in joining an ostomy association, but did belong to the Society for Intestinal Research, an association for
individuals with inflammatory bowel disease.

Her main concerns about the effect of the stoma on pregnancy were whether stomal output would increase during labour and whether the stoma would prolapse during delivery. She also was concerned that the hospital nurses would not have the expertise necessary to assist with stomal care if she required it.

[I didn’t know] how familiar every nurse on the floor is [with stomal care] because I know [nurses] get some training in it but I found [when I had my bowel surgery] the two [ET nurses] took care of these sorts of issues, but the regular nurses were not that familiar with the products ... and some of them were not helpful.

She also mentioned, that although the ET nurses have expertise with stomal care, they are only available eight hours a day.

Her partner reported being concerned about whether the stoma would interfere with his wife’s progress during labour and delivery and whether she might suffer a flare-up of Crohn’s disease. He suggested, however, that he always worried about a possible recurrence of Crohn’s disease regardless of pregnancy.

None of their fears materialized, however, and at term she had an uncomplicated spontaneous vaginal delivery of a healthy newborn. In response to the
delivery, her partner said it was "like a cake walk" compared to the pain she had endured with Crohn's disease and bowel surgery. She did not need nursing assistance with stomal care and even emptied her own pouch during labour.

Her obstetrician did not have any concerns about the effect of the stoma on pregnancy and considered both the pregnancy and delivery to be unremarkable.

She implied that her stoma had little effect on her pregnancy because she felt she had adapted to having a stoma. The following quotation illustrated this viewpoint.

I'd had my stoma for ... over a year and I was quite comfortable, after a year, a year seemed to be the turning point for me ... when I really started to feel like I could live with it.

Conclusion.

Ms. D. felt well during pregnancy and aside from two episodes of watery stool which she attributed to food blockages and some modifications to her pouching procedure for an enlarged stoma and a peristomal skin irritation, had an uneventful pregnancy. Although she and her partner had some concerns regarding the effect of the stoma on pregnancy and hospitalization these fears never materialized. Her positive attitude to the
stoma appeared to contribute to her perception that the stoma had little effect on pregnancy.

Case 5

Ms. E. developed Crohn's disease at the age of 20. At 24 years of age she had a sub-total colectomy with ileostomy and two years later, following a recurrence of Crohn's disease, had the remaining colon, apart from the rectum, excised. She was 27 years old when she became pregnant with her first child and 30 when she became pregnant with her second. The second pregnancy is the one considered here.

Her main concerns during pregnancy were whether she would experience a flare-up of Crohn's disease, whether she and the fetus would receive adequate nourishment as a consequence of her colectomy, and whether her baby would be born with Crohn's disease or some other bowel disease.

She consulted with The United Ostomy Association for information about the effect of Crohn's disease and the stoma on pregnancy. They sent her some anecdotal accounts published by the Ostomy Quarterly and put her in contact with a woman with an ileostomy who had experienced childbirth. Although she appreciated these
efforts, she still felt she lacked information. To deal with her concern regarding nourishment, she consulted with a dietitian and supplemented her diet with vitamins and iron. Due to an increase in thirst she raised her fluids beyond her usual intake of two litres per day.

Her stoma enlarged during pregnancy and she needed to increase the size of the stomal opening on her skin barrier. She also needed to increase the frequency of changing the skin barrier because she felt the seal on the skin barrier weakened more readily since her protruding abdomen could not support the weight of the pouch.

At 32 weeks gestation she experienced a "really bad" bowel obstruction. She was hospitalized and after three days of bowel rest the obstruction spontaneously resolved. Her obstetrician could not say whether her enlarged uterus contributed to the obstruction or if it would have occurred regardless of the pregnancy. To prevent further problems she altered her diet to include smaller more frequent meals and a further increase in fluids.

Her obstetrician’s main concerns during pregnancy
were whether a flare-up of Crohn's disease would occur and whether the presence of a rectovaginal fistula would interfere with delivery. She thought the fistula might be traumatized by a vaginal delivery and that it also might interfere with the healing of the perineal floor. Therefore at term Ms. E. had an elective Caesarean section for a healthy newborn.

Compared to the ostomy surgery, she said the Caesarean section "was so easy". During hospitalization she did her own stomal care except for one occasion when a nurse emptied her pouch while she was in the recovery room. In response to this assistance she laughingly observed, "[the nurse] didn't have a clue of what she was doing". On a more serious note, however, she commented that a nurse, unaware that laxatives are contra-indicated for individuals with ileostomies, tried to administer to her a routine laxative suppository in preparation for her Caesarean section.

She thought her partner and her obstetrician were very supportive throughout the pregnancy. Regarding the obstetrician she said, "she included me in everything ... she made me feel part of it."
She stated that she gained a "sense of pride" from her childbearing experiences. The following statement reflects this sentiment.

After having been sick for so long and going through all that surgery and pain and agony and drugs and everything and being able to look at [my children] ... I mean a lot of people figured I'd never have kids ... and being able to have them and say I know I did this.

She claimed she was glad she had bowel surgery and the ileostomy because without them she would never have been able to fulfil her lifelong ambition to have children. She said, "I've got two healthy kids and that's, that was all that mattered, that was my justification for everything I went through."

Conclusion.

Ms. E.'s pregnancy was interrupted by one episode of bowel obstruction requiring hospitalization and medical management. She subsequently had to modify her fluid intake and eating patterns and as a result of an enlarged stoma and a protruding abdomen had to modify her pouching procedure. As a consequence of Crohn's disease she had a Caesarean section. Despite discomforts she endured, modifications she had to make, or concerns she had about the effect of the stoma on pregnancy, she was grateful that her ileostomy had
provided her with an opportunity to have children.

Case 6

Ms. F. developed Crohn’s disease when she was six years old. At the age of 10 she had a total proctocolectomy with ileostomy. She became pregnant with her first child at the age of 24.

Aside from periodic episodes of nausea and general discomfort, her pregnancy progressed normally until 16 weeks gestation, at which time her stoma suddenly prolapsed about six inches. She recalled being at work as a cashier when this occurred and feeling both shocked and terrified. Initially conservative measures, such as wearing a tensor around the stoma when up or remaining supine, were taken to reduce it, but at 28 weeks she was hospitalized for a local revision. She and her partner were both concerned about the effect the medications, the anaesthetic, and the surgery would have on the fetus but the attending physicians were able to allay their fears. She did her own stomal care during hospitalization and implied she preferred to do so. She said, "[Nurses] rarely ever bother me when I’m in [the hospital]."

Her stoma also enlarged in diameter and
necessitated a larger stomal opening in the skin barrier. Due to an increase in thirst she also modified her diet to increase fluid intake.

She attended one pre-natal class pertaining to Caesarean sections when she thought she may have this mode of delivery. She did not belong to an ostomy association and never did any reading on the subject of stomas and pregnancy. She said she did not feel she needed any information because "I’ve had it so long, ... like you know its nothing to me really." She did, however, talk to another woman with a stoma who had experienced pregnancy. This woman had also experienced a prolapsed stoma during pregnancy.

Her obstetrician’s main concern was the possible recurrence of a stomal prolapse during delivery. She wanted to avoid pressure on the stoma during the second stage of labour and she also wanted to avoid a Caesarean section due to the risk of bowel adhesions. She therefore elected to do a vaginal delivery and two weeks before her due date Ms. F. was admitted to hospital to have induction of labour. She was given an epidural anaesthetic and following a 26 hour labour, had an episiotomy and a forceps delivery. Immediately
postpartum the baby developed a fever and was taken to an intensive care nursery, where he stayed for several days. She felt "really, really bad" about this and responsible for his condition. She described the episiotomy as being "very painful" and said she felt like she had been "kicked by a boot". She did her own stomal care during hospitalization.

She described being amazed that she had given birth to "this really healthy great guy" after having been ill with Crohn’s disease for so much of her life. She admitted, though, that she and her husband continue to worry that their son may someday get Crohn’s disease.

Conclusion.

Ms. F.’s pregnancy was interrupted by one episode of stomal prolapse which required her to be hospitalized and undergo surgery during pregnancy. This created concern for both her and her partner and altered her delivery. Other physiological effects of the stoma on pregnancy which required modifications to be made included an enlarged stoma and an increased thirst. Despite any inconveniences and concerns, Ms. F. was grateful her stoma had provided her with an
opportunity to have a healthy child.

Summary of Individual Reports.

Data collection procedures were replicated for each case and the findings reviewed and summarized into six individual case reports. Although the participants often implied the stoma had little effect on pregnancy, a review of the data in relation to Snyder’s (1979) conceptual framework, suggested that the stoma did, in fact, affect each childbearing experience. Physiological implications of having a stoma during pregnancy constantly interacted with the woman’s self system and family system and with her social and cultural environment to create a unique experience for each woman. For some, the presence of a stoma produced unpleasant physiological complications and psychosocial concerns, but for all, it provided an opportunity to have and care for children, an experience they may otherwise not have had. Issues identified in each study will be expanded and compared in a cross-case report.

Cross-Case Report

The findings from the six individual case studies are expanded and grouped according to Snyder’s (1979)
childbearing framework into the physiological, the self, the family, the social, and the cultural systems and a comparison made across the cases. Although each system is addressed separately it will be considered in light of how it interacts with the others.

**Physiological System**

The physiological system represents the physiological adaptations to pregnancy. An analysis of the case studies revealed that all the women had ileostomies, with one being the consequence of ulcerative colitis and the others, consequences of Crohn's disease. There were no reports of recurrences of Crohn's disease, however, after ileostomy. Despite all delivering healthy babies, the women all experienced physiological implications of having a stoma during pregnancy.

**Stomal prolapses.**

Two women experienced stomal prolapses during pregnancy. In one case the prolapse occurred at 20 weeks gestation and, after a surgical revision, recurred at 36 weeks. The same woman had experienced two stomal prolapses with her first pregnancy. In the other case, the stoma also prolapsed at 20 weeks
gestation. The prolapses caused discomfort, inconvenience, and alarm for both the women and their partners. In addition, they required the women to undergo surgery during pregnancy.

In both cases the women were unprepared for such a complication and terrified when it first occurred. The two narratives below illustrated this experience.

With the first one I remember my overwhelming sense was nobody warned me of any complications of becoming pregnant, ... that I could have any problems whatsoever with a stoma. I mean I found out what a prolapse was after I prolapsed. I was terror struck, it was just a horrifying experience. That's the feeling that won't go away.

I went in the washroom and I just like freaked right out ... like I've had my ileostomy for fourteen years before that and never seen anything like that.

One partner implied that his fear was enhanced by the fact that very little is known about the implications of stomal prolapse during pregnancy. He said, "Even the doctors were not familiar with it happening during pregnancy".

In attempts to avoid revision surgery, conservative measures were initially taken in both instances to reduce the prolapses. Lying down or strapping a wide tensor around the stoma when up,
helped to reduce it but the women found the measures inconvenient and uncomfortable. As one woman said, "you don't want anything tight on [when you're pregnant]" and the tensor needed to be frequently released in order for the stoma to function. The citation below depicted the discomfort and inconvenience the women endured.

It was like being semi-blocked.... I would just sit down and relax ... or lay back in sort of more of a reclining position and let it just flow and then I'd strap up again in order to be mobile.

Both women eventually needed to be hospitalized for surgical revision. This placed an added strain on the families.

Obstructions.

Three women reported partial or complete bowel obstructions. These gave rise to feelings of confusion, discomfort, a need to modify diets, and in two instances, hospitalization during pregnancy.

In all cases the obstructions presented with abdominal discomfort and altered stomal output. One woman described how a modification to her diet helped to resolve the obstruction.

I possibly had two episodes where there was somewhat of a blockage meaning that my stool was really watery so that I knew that something wasn't
quite right but they both cleared on their own, actually I drink grape juice and it helps usually.

Two women required hospitalization and in both cases difficulty occurred with differentiating the pain from labour pain. One woman described how the pain was initially a generalized discomfort occurring in conjunction with abdominal pressure. It eventually localized proximal to the stoma and she therefore concluded she had developed a bowel obstruction. In the other case the hospital staff also appeared uncertain about the diagnosis and admitted the woman to an obstetrical ward. In both cases the obstructions were managed conservatively with analgesics, and in one case intravenous fluids.

Also, in both cases the physicians were uncertain whether the enlarged uterus contributed to the obstruction or whether the obstructions would have occurred regardless of pregnancy. In one case the woman related the obstruction to eating an excessive amount of bread stuffing and drinking inadequate fluids. To prevent further problems she modified her diet to include smaller and more frequent meals and more fluids.
Alterations in stomal size and peristomal skin irritation.

Four women reported that the base of their stomas enlarged in diameter during pregnancy requiring modifications to pouching procedures. One woman described the frustration that was associated with this change.

Other than [the obstructions] the most frustrating thing was changing my stoma [size]. After my fifth month of gestation I started to change, like the actual shape of the stoma on the skin, the size ... it enlarged slightly.

All the stomas, however, returned to their original size following delivery. One woman reported that she never noticed any changes to her stoma during pregnancy but that it retracted following delivery and has remained that way. She attributed this to a weight gain of fifty pounds during pregnancy and its eventual loss postpartum.

One woman had to change her brand of ostomy products during pregnancy for she observed that the adhesive tape on the skin barrier was irritating her skin.

Diet.

Although most women noted a need to increase fluid
consumption since bowel surgery with ileostomy in order to satisfy thirst and to prevent food blockages, only two recalled a further increase in thirst during pregnancy with a need to drink more fluids. The following quotation illustrated how thirsty one woman was.

When I’m pregnant I drink like mass quantities of fluid, I drink lots anyways but when I was pregnant I found that I was just like a bottomless pit for water.

Unfortunately this women experienced a food blockage and to prevent further problems she again adjusted her diet to include more fluids and smaller, more frequent meals.

Mode of delivery.

Three women had vaginal deliveries and three had Caesarean sections. With respect to the women who had vaginal deliveries, one who had required a surgical revision of a stomal prolapse during pregnancy, had an epidural and forceps delivery to prevent a repeat prolapse and another, whose stoma was prolapsed at the time of delivery, had to use her hand to reduce the stoma during delivery. The following quotation described how she coped with childbirth.

One hand was on the nitrous mask and the
other hand was on the stoma holding it down basically is how I delivered.

Three other women had Caesarean sections, one for an obstetrical reason (failure to progress), one due to perineal scarring as a consequence of a proctocolectomy, and the other due to the presence of a rectovaginal fistula as a consequence of Crohn’s disease.

All three women who experienced Caesarean section viewed it in relation to previous bowel surgery and considered it to be a "piece of cake" in comparison.

Conclusion.

All the women experienced physiological consequences of having a stoma during pregnancy, necessitating adaptation. Two women suffered stomal prolapses, three experienced some degree of bowel obstruction, five reported altered stomal sizes and shapes, one complained of a peristomal skin irritation, and two acknowledged increased thirst. Despite these physiological implications, all had healthy babies.

The findings reveal that complications such as stomal prolapse and bowel obstruction can cause discomfort, hospitalization, surgery, complicated deliveries, and fear and inconvenience for both the
woman and her family. The findings also reveal that pregnant women may need to modify their pouching procedures to accommodate larger stomas and may need to raise fluid intake to satisfy an increased thirst.

**Self System**

The woman's self system is concerned with her emotional adaptation to pregnancy. The ability to emotionally adapt to pregnancy will be influenced by a multitude of factors specific to each individual experience. An analysis of the case studies revealed that factors affecting the women's ability to adapt to pregnancy with a stoma were her perceptions of having a stoma and the concerns it generated. These concerns related to personal concerns and concerns about the health of the fetus and of the child postpartum.

**Perceptions of having a stoma.**

It appeared that the women's perceptions of the effect of the stoma on pregnancy were influenced by whether they perceived the stoma as improving their health status and quality of life. Five women had been ill for a considerable length of time prior to bowel surgery with ileostomy and had subsequently experienced an improvement in health. Two of these women suggested
that the stoma had provided them with an opportunity to have children or to care for their child. The following narratives illustrated this viewpoint.

I wouldn't have had [children] if I hadn't had surgery ... because I was on so many drugs like there was no way that I would put a [fetus] through that.

One woman, prior to her surgery with ileostomy, had been too sick with Crohn's disease to care for her first baby. However, after bowel surgery with ileostomy she was able to care for her second baby. She said:

With the first [baby] I couldn't take care of her because I was too sick ... so I wanted to make sure I got in the time with the second one that I missed with the first.

In one case, however, a woman, who had required emergency bowel surgery with ileostomy during pregnancy and had not recently been ill with Crohn's disease, felt that the stoma had interfered with her childbearing experience.

Personal concerns.

Concerns were expressed about whether the stoma would interfere with pregnancy; whether adequate assistance with stomal care would be provided during hospitalization; and whether a flare-up of Crohn's
disease would occur during pregnancy.

Three women expressed concerns that the stoma, itself, would interfere with pregnancy. Two were concerned that it might prolapse either during pregnancy or labour. One woman had experienced stomal prolapse with a previous pregnancy and the other had talked to someone else who had experienced this during pregnancy. In both cases, their anxiety was increased due to lack of knowledge about the subject. The following statement illustrated this concern.

[Stomal prolapse] was one of the things I was worried about because no-one seemed to know that much and I thought boy am I going to prolapse while I'm delivering? I was really concerned about the contractions and that it might [prolapse], but it didn't do anything.

The concern that the bowel would become "spastic" and yield a high output of stool during labour was another concern expressed. Finally one woman implied that "not knowing" about the impact of the stoma on pregnancy was a concern in itself.

I mean I had these missing pieces and even though they're not the pieces that have to do with having kids, is my body still going to be able to [work]?

In addition to worrying about the stoma interfering with the progress of labour three women also worried that the nursing staff would not have the
expertise or the necessary products to assist them with technical aspects of stomal care when they were hospitalized. One woman who needed to have a laparotomy and revision of a stomal prolapse had worried that the nursing staff on the obstetrical ward would not be able to assist her post-operatively. As it turned out, she was able to explain to the nurses how and when to empty her pouch and to arrange for an ET nurse who worked in the hospital to change her skin barrier. Another had worried that the nurses would not know how to empty her pouch during labour. In this situation, the woman proved not to need any assistance with stomal care during labour. Finally, one woman worried that she would not have access to appropriate ostomy products and wanted to caution other women with stomas to take an ample supply of their own products to the hospital.

The concern that pregnancy might incite Crohn's disease was expressed by one woman. She stated:

Even though its still in remission its still there, its not like its gone so ... is [the pregnancy] going to cause the Crohn's to come up?

Despite this fear, she never did experience a relapse. In fact, a relapse occurred in only one case,
and here the woman had not had previous bowel surgery. When it occurred, at 20 weeks gestation, she required a sub-total colectomy with ileostomy. Following the surgery she did not have any further relapses for the balance of her pregnancy.

**Concerns about the fetus.**

Concerns were expressed about whether the fetus would be affected by the absence of the colon or by surgery during pregnancy.

The first concern was expressed by one woman and the following statement illustrated her concern.

Because I'm missing all this bowel, am I still going to be able to nourish the baby properly and am I going to be nourished properly and is he going to get everything he needs?

All three women who required surgery and one who required hospitalization and medical management during pregnancy described being concerned about how the medications, or the anaesthetic, or the surgery would affect the fetus. For instance one woman said:

I used to have nightmares that he had giraffe size legs or green horns because I just thought of everything that I had gone through.

This same woman said that she began to feel that perhaps her purpose in life was "to have some baby with a disability." She never verbalized this concern
at the time, however, due to the fear that if she did, it would come true.

Another woman who had also required surgery during pregnancy expressed the following reaction to her baby being born with a high fever, necessitating admission to an intensive care nursery: "I felt really, really bad, I thought it was something I did." This comment moved the woman to tears as it reminded her of the sorrow she had experienced at the time of delivery.

**Concerns about their children.**

Three women expressed concern at the time of their interviews about whether their children may have inherited Crohn's disease. This concern is expressed in the following quotations.

The only thing you worry about now though with having kids is passing [Crohn's disease] down onto them. Because my mother's mother had the diverticulitis, my mother had the colitis and I got the worst out of them, Crohn's.

There's always going to be that little spot in my head where [my husband] and I both ever wonder if he's ever going to get Crohn's.

... and is he going to be born with Crohn's or some other bowel disease or the unknown, like not knowing.

Although the concern that the children may develop Crohn's disease is not directly related to having a
stoma, it is indirectly related, as Crohn's disease is the usual indication for stomas in women of childbearing age.

Conclusion.

An analysis of the findings reveal that two women expressed gratitude that the stoma had provided them with an opportunity to either have children or to care for them. Concerns raised by the women were physiological, psychosocial, or cultural in nature and had implications for both themselves and their family. They expressed concerns regarding whether the stoma would interfere with pregnancy; whether adequate assistance would be provided during hospitalization; and whether flare-ups of Crohn's disease would occur. They also expressed concerns about the effect surgery and the absence of colon could have on the fetus. In addition, they worried that their children may develop Crohn's disease. A common theme in these self-reported causes of anxiety were a lack of knowledge and a fear of the unknown.

Family System

The family system is concerned with the network of significant family members involved with the
childbearing experience. The structure and dynamics of these interpersonal relationships will affect the childbearing experience and conversely the childbearing experience will affect the relationships. An analysis of the case studies revealed that the five partners who participated in the study all had concerns about their wives' pregnancies. It also implied that hospitalization during pregnancy placed an added strain on both the women and their families. Finally, it disclosed that all the women considered their partners to be important sources of emotional support.

Partners' concerns.

Four of the five partners interviewed in the study stated they had been concerned about their wives' health during pregnancy. There were several sources for concern and these included stomal complications, relapses of Crohn's disease, and surgery during pregnancy.

Two partners whose wives developed stomal prolapses worried about the physiological and the psychosocial implications these would have. They did not understand the cause of the prolapses nor their effect on their wives' health, plus they worried about
the discomfort and inconvenience they caused.

Another partner claimed he worried that his wife would have a relapse of Crohn's disease during pregnancy. He reported:

But I still worry about [Crohn's disease], I mean I'm always going to worry about it, it's not something that just because she's pregnant, or whatever, it's every time she gets tired or she gets ... sick or anything, you know I worry about it happening because she spent so much time in the hospital since we've been married.

This same partner intimated that his anxieties were heightened by his lack of information. He asserted that he had been more concerned at the beginning of the pregnancy because he "didn't know anything" about stomas and pregnancy and he had worried that the stoma might not "stand up" to the pregnancy and delivery. His wife, however, had been able to provide him with enough information to alleviate most of his fears.

The partner whose wife needed to have an emergency sub-total colectomy at 20 weeks gestation had initially worried whether his wife would survive surgery and continued to worry throughout the pregnancy about her compromised state of health.

Two partners implied they had fewer concerns about their wives' health status with the pregnancy under
consideration than they had with the previous one because with the previous pregnancy their wives had been very ill with Crohn's disease. One said:

She did a lot better with [this] one than she did before so it was actually less of a worry for me because she didn't spend any time in the hospital this time.

All the partners who expressed concerns implied that their concerns were reduced when they were provided with information about the issue.

Hospitalization.

Hospitalization, and in three cases subsequent surgery, placed an added strain on the women and their families. All of the women who had to have surgery during pregnancy and their partners professed to have worried about the health of the fetus. They had fretted about the effect that the medications, anaesthetics, and surgery would have on the fetus.

One of the women also alluded to the fact that hospitalization and not the stoma had interfered with her role as a mother because it meant she had to make alternate arrangements for the care of another child at home. The following narrative demonstrated this.

It makes absolutely no difference whether I have a stoma or no stoma in how I care for little ones, what interfered for me was the surgery ... that
would interfere with anybody.

**Partners' support.**

All of the women reported that their partners had been very supportive throughout pregnancy and delivery. One woman reported:

Another important thing is a supportive partner because he was in there through the whole thing ... he was there for both deliveries and my ultrasound.

Another woman noted that her partner had assisted her with stomal care throughout pregnancy. The following account described his involvement.

When I started to get bigger because of the pregnancy I couldn't see what I was doing, ... so I couldn't [put on my own pouch]... he would have to do everything, I would just go and lie on the bed and he'd ... just do it all.

**Conclusion.**

Concerns expressed by the partners were mainly physiological in origin and related to incidents of stomal complications, possible flare-ups of Crohn's disease, and the effect of surgery, anaesthetics, and medications on the fetus. There seemed to be a direct relationship between the degree of the partner's concern and his wife's health status. That is, if the woman felt well, her partner would have fewer concerns. However, as one partner suggested, because Crohn's
disease is chronic in nature there is always the potential for worry. Lack of knowledge and fear of the unknown intensified these concerns. All the women considered their partners to be important sources of emotional support.

Social System

The childbearing experience takes place within a social system which includes such groups as the community where the woman lives and the organizations where she receives care. All such social groups will affect the childbearing experience. A review of the case studies revealed that women and their partners sought support during pregnancy from physicians, nurses, ET nurses, a dietician, pre-natal classes, and the United Ostomy Association (UOA).

Physicians.

All the physicians were considered helpful with respect to obstetrical issues and some were also very supportive with respect to stomal concerns. Three women implied that, of all the health care providers they had contact with, physicians were the ones who had provided them with the most support during pregnancy. Their knowledge and their ability and interest to share
this knowledge helped to reduce anxiety. The following narratives illustrated this viewpoint.

I guess I wasn't too concerned because I knew I was closely being watched by the obstetrician. I had all my faith in him and I really liked him, I felt very comfortable with him.

I had every confidence in her and that alone was, I mean the biggest, the biggest plus because as soon as something came up she would say to me I'm not sure about this, I'm going to find out ... anything that I wasn't sure of I would ask her and she would either give me the answer or say I don't know but I'll find out ... so I mean she was, she was the best thing of a scary situation.

The third woman implied that her physician, in addition to providing information about stomal management, also included her in all decision-making.

Both partners whose wives had undergone surgery during pregnancy for stomal prolapses, also reported that physicians substantially reduced their fears. The following quotation demonstrated how physicians were able to relieve one partner's fears.

They didn't rush, they talked it over a lot, they went over all the options ... they kept the family doctor informed. The [anaesthetist] sat down and explained to us about the drugs.

Two other women, however, felt that although their physicians had closely monitored the fetus, they had not been able to provide the support they needed regarding their ileostomy. One woman lamented:
Everybody knew [the stoma] was there but even when I went for my checkups . . . nobody ever asked me, how I was doing with the ileostomy. If I went for a checkup for my pregnancy I was definitely there for the pregnancy.... I would sometimes like to talk about a couple of things but that wasn't really in their [area].

Another recommended that individuals with stomas should seek alternate forms of support if they feel their physicians are unable to help them. She made the following comment.

If you're not getting the answer from your doctor don't think that that's your final resource. Find someone who can help you, find the right person to help you with the problem.

The physicians' main concerns regarding the effect of stoma on pregnancy were related to physiological issues. Concerns were expressed about the management of stomal prolapse and the most appropriate mode of delivery. Only one physician recalled being concerned about the possible recurrence of Crohn's disease.

Hospital nurses.

All the women had the impression that obstetrical nurses were concerned solely with obstetrical issues. The following remark illustrated this viewpoint.

The nurses stayed right away from me... [they] didn't have a clue.... They dealt with what they knew about which was the baby.

Another woman maintained, "The baby stuff is more
important, more concern than I [am]." However, she implied she was comfortable with this notion.

One woman who had a laparotomy one week postpartum, complained that the nurses on the obstetrical ward were not aware of her surgical needs. She contended:

That's where the OB ward falls apart because they're not used to ... the kind of surgery I had ... it is much easier to be a surgical patient on a surgical ward.

Only three women required nursing assistance with stomal care during hospitalization for childbirth, and all three implied that the nurses did not have adequate skills to assist them. One woman said, "One of the nurses in recovery had to empty [my pouch]...and she didn't have a clue what she was doing."

In addition to not knowing how to do technical aspects of stomal care, one implied that nurses lacked knowledge about the physiological implications of an ileostomy. She described becoming alarmed when a nurse wanted to administer a routine laxative suppository in preparation for a Caesarean section and another wanted to administer one post-operatively. It disturbed her that neither nurses were aware that she had an ileostomy and that laxatives are contraindicated for
individuals with ileostomies.

Further, two implied that nurses found stomas disagreeable. One remarked, "There are some nurses who are totally afraid of it and won't come near you with a ten foot pole." She went on to relate how she could usually sense their reluctance to provide assistance. She said, "The body language gives it away, they don't want to do it."

On another occasion a woman was admitted to an obstetrical ward at 26 weeks gestation with undiagnosed pain and was told she should not be there. She described the following scene.

[The nurse] proceeded to tell me that I wasn't welcome there, I was considered to be a dirty patient and they're going to have to get me out of maternity right away. I just felt absolutely terrible, I felt like the dirtiest person.

However, this lack of expertise with respect to stomal care seemed to extend beyond the obstetrical ward. All the woman had experienced numerous hospitalizations prior to childbirth and some implied that nurses in general lacked adequate skills. The following statement exemplified this impression.

There are very few nurses who know, there are very few doctors, anybody who knows anything about it ... each time I've gone in I've gone in having to educate anybody who has come near me because
they're just not familiar with it.

Another woman still appeared upset three years following bowel surgery with ileostomy because nurses on a general surgical ward had not been able to tend to her stomal needs. She attributed their lack of skills to their lack of experience. She remarked:

I found that because they had two [ET nurses] who came around and took care of these sort of issues, the regular nurses were not that familiar with the products ... and some of them were not helpful.

ET nurses.

Although nurses, in general, were not considered to be sensitive or knowledgeable about stomal management, two women claimed that ET nurses had been helpful. As one woman asserted:

The obstetrician was very important in the care of the fetus and the pregnancy itself but as far as the pregnancy with the ileostomy the ET nurse was my best resource.

Another woman said, "The ET nurse is basically the knowledgeable person and that's it." Enterostomal therapy nurses provided information about all aspects of stomal care; assisted with technical aspects of stomal care during hospitalization, such as changing pouches and barriers; supplied published anecdotal accounts on stomas and pregnancy; and arranged visits
with women with stomas who had experienced pregnancy.

**Dietician.**

Only one woman sought advice from a dietician during pregnancy. In this case the woman had been alarmed that the absence of colon might interfere with her nutritional requirements and wanted advice regarding the need for additional nutrients. She consequently supplemented her diet with vitamins and iron.

**Pre-natal classes.**

Although three women attended pre-natal classes in preparation for childbirth, none raised the issue of having a stoma. One woman suggested she had been too embarrassed to discuss the issue. She remarked, "How can you explain especially to young people the ostomy and I still feel I have a really, almost a negative connotation."

**United Ostomy Association.**

All the women, with the exception of one, received assistance from the UOA during pregnancy, despite the fact that only two were members. The UOA issued four women with anecdotal accounts about stomas and pregnancy and also arranged for three to have a visit
from a woman with a stoma who had experienced pregnancy.

Although most of the women appreciated reading the articles, two complained that they only described personal accounts of selected aspects of pregnancy. The following narrative suggested one woman's dissatisfaction.

They sent me an article, a few articles ... but they weren't really much help. I mean there was a lady that had a baby so she wrote herself, her own experiences but I mean ... all it talked about was her own [experience] like it [did not] answer questions.... There [were no] references where I could go [to find out ] what can I expect with [pregnancy] ... there was nothing.

The three who talked with a visitor expressed gratitude as they felt the visitor was able to understand their concerns. One woman said, "It was kind of neat [to talk to her because] she understood the prolapse part and not being able to get up". Two women, however, suggested that although they appreciated talking to the visitor, they would have appreciated an opportunity to talk to several women, rather than only one, to gain a broader perspective. The women who did not have an opportunity to speak to a visitor, conveyed their regret.

One woman in the study was already a UOA visitor
for women with stomas who were either pregnant or contemplating pregnancy and three reported they would like to do the same. They felt they could provide others, like themselves, with support during pregnancy.

Although all the woman were keen to talk to another woman with a stoma who had experienced pregnancy most also expressed an interest to talk to another individual with a stoma about their bowel surgery or daily implications of living with a stoma. One woman said, "I would have loved to [have talked to a woman with a stoma during my pregnancy], I would still [like to talk to another woman with a stoma]."

Another woman made the following comment.

Anything I can do for the next person to help them to you know, get through [the surgery], I'm more than willing to be there and say ... I've done it and you can do it.

All the woman appeared eager to share their experiences with the researcher.

Conclusion.

Health care professionals such as physicians, nurses, and dieticians, and support groups provided care for these women during pregnancy. All had an effect on the childbearing experience. Some were able to provide information and expert care and consequently
help to reduce fears. However, sometimes the information was inadequate or the care less than desirable and in these situations fears were intensified.

In most situations the women had to seek their own support and assistance and devise ways to facilitate a positive childbearing experience.

Cultural System

The cultural system is the structure within which the physiological, self, family, and social systems operate. In this study, culture includes the attitudes and values held by society in relation to childbearing and stomas. These values provided the framework for the woman and her partner to define and evaluate their particular childbearing experience.

Although several women suggested their stomas had little effect on their pregnancies, others suggested it set them apart from others. This sentiment was revealed by one woman when she said she had been planning to work during pregnancy "up until [when] normal people [work]". Another described feeling too self-conscious to disclose her stoma to her pre-natal instructor. One woman described her perceptions of how
others reacted to her stoma.

I don't think [the nurses] thought I was normal or that [the stoma] was normal and probably because of ignorance [nurses] don't know about it.

All the women expressed joy at being able to give birth to a healthy baby, but one woman also suggested that childbearing provided her with an opportunity to feel like other women. The following narrative illuminated this emotion.

After each delivery I thought I'm just like every other woman at this moment...and I still am as far as the kids are concerned.

Conclusion.

Attitudes about stomas and childbearing influenced the women's perceptions about their childbearing experiences. The analysis of the case studies suggested that the stoma made some women feel unique whereas childbearing provided an opportunity to feel like others.

Summary of Cross-Case Report.

The findings from the six individual case studies were expanded and then grouped according to Snyder's (1979) childbearing framework into the physiological, the self, the family, the social, and the cultural systems and a comparison made across cases. Although
each system was addressed separately it was considered in light of how it interacted with the others.

The most serious complications noted in the study included three cases of bowel obstruction and two cases of stomal prolapse. Altered stomal shapes, peristomal skin irritation, increased thirst, and complicated deliveries were also noted. Concerns were expressed about whether a flare-up of Crohn's disease would occur during pregnancy or whether the stoma would interfere with pregnancy or the health of the fetus. Four women required hospitalization during pregnancy which placed an added strain on both the women and their partners. Both sought support from each other and from physicians, nurses, and support groups. The knowledge, skills, and attitudes of these groups in turn affected the childbearing experience.

Summary of Findings

This study was undertaken to explore how a stoma affects the experience of childbearing. To answer this research question six case studies were reviewed, their findings analyzed according to the major concepts of Snyder's (1979) childbearing framework, and presented in six individual case reports. Finally, the findings
were expanded and compared across cases and presented in a cross-case report.
CHAPTER FIVE
Discussion, Conclusions, Implications, and Summary

Introduction
This chapter will begin with a discussion of the findings in relation to the literature. Conclusions about how a stoma affects the experience of childbearing will then be drawn and implications for nursing practice, education, and research identified. Finally, a summary of the study will be presented.

Discussion
Five of the six women in the study had ileostomies as a result of Crohn's disease and one as a result of ulcerative colitis. This is consistent with the literature which reports that Crohn's disease is currently the most common indication for ileostomy (McGarity, 1992) and that Crohn's disease has a peak prevalence prior to age 35 (Mendeloff, 1985). Crohn's disease was also the indication for ileostomy in the most recently published study about stomas and pregnancy by Nicholl, Thompson, and Cocks (1993).

Physiological System
Complications of pregnancy, altered stomal sizes and peristomal skin, diet, and modes of delivery will
be addressed in relation to the literature.

Complications of pregnancy.

The most serious complications noted in the study included three cases of bowel obstruction and two cases of stomal prolapse. These findings are consistent with medical studies reviewed on stomas and pregnancy in which the most frequent and serious complication reported was bowel obstruction, (Gopal et al., 1985; Hudson, 1972; Nicholl et al., 1993; Priest et al., 1959; Scudamore et al., 1957) and the second, stomal prolapse (Gopal et al., 1985; Hudson, 1972; Nicholl et al., 1993; Scudamore et al., 1957). Similar to reports in the medical literature, the symptoms of bowel obstruction subsided with conservative management (Nicholl et al., 1993; Priest et al., 1959) and were difficult to differentiate from symptoms of pregnancy (Hudson, 1972; Nicholl et al., 1993). In two cases of bowel obstruction women were admitted to hospital with suspected obstetrical complications. With regard to stomal prolapse, both cases were revised surgically during pregnancy which is consistent with the treatment described in the literature (Gopal et al., 1985; Nicholl et al., 1993; Scudamore et al., 1957).
However, the medical studies reviewed do not address other concerns related to either of these complications, such as the women's concerns about the health of the fetus, the partners' concerns, and altered life-styles.

**Altered stomal sizes and peristomal skin.**

The study's findings revealed four cases of enlarged stomas during pregnancy, one case of stomal retraction postpartum, and one case of peristomal skin irritation as a consequence of a reaction to adhesive tape. However, all of these alterations can occur regardless of pregnancy. One study in the research-based literature revealed the occurrence of stomal enlargement during pregnancy (Hudson, 1972) but stomal retraction or peristomal skin irritation were not mentioned. Three women in the six anecdotal reports reviewed, however, referred to alterations in stomal size during pregnancy.

All of the above changes required modifications to pouching systems. Aside from a pouching modification for stomal prolapse described by Nicholl et al. (1993), the research-based literature concerning pregnancy and stomas does not address technical difficulties.
However, the literature pertaining to coping with a stoma in general does suggest that individuals with stomas have ongoing technical problems including the continuous need to obtain, apply, and monitor stoma appliances to deal with stomal and peristomal changes (Follick et al., 1984; Kelly, 1991).

Diet.

The study's findings revealed that two women needed to increase their fluid intake as a consequence of increased thirst. After an incident of food blockage, one decided to further increase her fluids and eat smaller more frequent meals to prevent further problems. Increased thirst during pregnancy is addressed in obstetrical literature, but not specifically addressed in the research-based literature pertaining to stomas and pregnancy. Kelly (1991), however, asserted that individuals with stomas need to give constant attention to diet to prevent surgical and medical complications, such as food blockages.

Mode of delivery.

In contrast to the the medical literature, which revealed the majority of women with stomas experienced uncomplicated pregnancies with vaginal deliveries
(Barwin et al., 1974; Gopal et al., 1985; Hudson, 1972; Priest et al., 1959; Scudamore et al., 1957), the findings suggest that women with stomas may experience complicated deliveries. In three cases, Caesarean sections were performed and in one, a vaginal delivery was assisted with forceps. This contrast to the literature can perhaps be explained by this study's small sample size.

A review of anecdotal reports also revealed a majority of uneventful vaginal deliveries, with the exception of one 7 week premature delivery. It is possible, however, that only women with uncomplicated deliveries selected to publish their accounts.

The study's findings also differ from findings by Shaul et al. (1987) who imply that the experiences of disabled women with labour and delivery were similar to those of non-disabled women. Women with stomas, however, were not included in their sample.

The selection of the most appropriate mode of delivery was the chief concern expressed by the physicians in the study. Factors such as perineal scarring resulting from proctocolectomy, stomal prolapses, a rectovaginal fistula, and adhesions from
previous bowel surgery influenced their decisions, and consequently the mode of delivery selected. The rarity of the situation and the scarcity of literature about the subject seemed to compound the decision process.

In summary, although the research-based literature adequately describes the physiological factors associated with complications of pregnancy and modes of delivery, it fails to address the psychosocial and cultural issues these may create for both the women and her family. It also fails to address the issue of pregnant women acquiring altered stomal sizes, possible peristomal skin irritation, or increased thirst. However, the literature does suggest that non-pregnant individuals with stomas may have ongoing technical difficulties with stomal management and a need to constantly monitor their diet. It appears that these tasks and their accompanying frustrations and inconveniences apply to pregnancy as well.

**Self System**

The findings revealed that three women mentioned being grateful for bowel surgery with ileostomy for improving their quality of life and providing them with an opportunity to either have or care for children.
The notion that pregnancy was perceived as an opportunity for individuals with stomas to lead ordinary lives was also expressed by Nicholl et al. (1993).

The findings from the study also disclosed that women had concerns regarding whether their stoma would interfere with pregnancy; whether adequate assistance would be provided during hospitalization; whether a flare-up of Crohn's disease would occur; and whether surgery or the absence of colon would effect the fetus. In addition, they worried that their children may develop Crohn's disease. The underlying theme for all these concerns was lack of knowledge and fear of the unknown. Aside from brief suggestions that women with stomas may need psychological support during pregnancy (Barwin et al., 1974; Nicholl et al., 1993) the research-based literature on stomas and pregnancy fails to address the emotional issues experienced by this group of women during pregnancy. However, literature related to chronic illness and pregnancy does address the issue that women with chronic illnesses, in general, have special concerns which can be reduced by the provision of information (Carty, (in press));
However, a review of published anecdotal accounts on stomas and pregnancy also revealed that several women worried that the stoma may interfere with pregnancy and one worried that her children may develop Crohn's disease.

**Family System**

The main concerns expressed by the partners were the health of their wife and that of the fetus. Hospitalization along with a lack of information intensified these concerns. Finally, the findings disclosed that all the women considered their partners to be important sources of emotional support. These findings have not been addressed in the research-based literature pertaining to stomas and pregnancy.

However, the literature does acknowledge that emotional support from a partner facilitates an individual's adaptation to a stoma (Dyk & Sutherland, 1956; Kobza, 1983) and that a partner's concerns can often be relieved by the provision of information (Kobza (1983). Family support is also a key issue in the childbearing literature.

A review of the anecdotal accounts published on
stomases and pregnancy also recognized the significant role that a partner can play in providing emotional support during pregnancy.

Social System

Three notable findings worthy of discussion are the fact that all the women wanted information about their pregnancies, all found they had to take some initiative in finding the information, and all wanted to talk about their experiences of pregnancy and about coping with a stoma in general.

Information about pregnancy and the effect of the stoma on pregnancy was sought from resources persons, such as physicians, ET nurses, and a dietician, and from support groups such as pre-natal classes and the UOA. In effect most women were trying to learn more about the experience of childbearing to reduce their fears and in some cases to empower themselves to make the right choices. The desire for pregnant women with stomases or other chronic conditions to learn about their situation is also documented in the literature (Nicholl et al, 1993; Corbin, 1987). All the physicians were considered knowledgeable with respect to obstetrical issues and most were considered helpful with respect to
stomal issues. Some physicians recognized the importance of providing information and including the women and their partners in decision-making. These strategies proved very effective in reducing fears and fostering a positive perspective of pregnancy. This finding supports Corbin's (1987) claim that women with chronic illnesses should be provided with ample information so that they can make the right decisions and learn to manage risk factors of pregnancy.

Obstetrical nurses, although perceived as competent care givers with respect to obstetrical issues, lacked the cognitive, psychomotor, and affective skills necessary to provide effective care for individuals with stomas. This observation was also noted in the nursing literature (Joachim, 1990; Keirstead, 1989) and Joachim (1990) further suggests that nurses would benefit from stomal instruction in the cognitive, psychomotor, and affective domains. ET nurses, on the other hand, were perceived by several of the women to be valuable sources of knowledge and support with regard to stomal care. Keirstead (1989) also compared the skills of these two professional nurses and, in her thesis to determine the learning
needs of individuals with newly created colostomies, reported that hospital nurses were perceived as having limited knowledge about stomal care and ET nurses as having expert knowledge. However, the very fact that ET nurses are considered to be the experts might be the reason why general duty nurses lack adequate skills. Rather than acting as resource persons for other nurses, ET nurses usually take on the sole responsibility of providing stomal care and actually spend little time advancing these skills in other nurses.

Pre-natal classes, while considered by some to be useful with respect to obstetrical issues, were not perceived by any of the woman as a support service regarding their concerns about the effect of the stoma on pregnancy, delivery, or hospitalization. Although the literature does not specifically address the need for women with stomas to have access to pre-natal counselling, Carty (in press) recommends that all women with disabilities, regardless of the nature of the disability, review their special needs for labour and birth with hospital staff prior to hospitalization. Perhaps pre-natal classes would have been perceived by
the women in the study as more helpful if the instructors had provided an opportunity for women to express their concerns and had helped to formulate plans of care to address these concerns during hospitalization. However, individuals with stomas must also be prepared to take the initiative of informing care givers of their special needs.

The UOA, although recognized as a source of support for many individuals with stomas, had little literature about stomas and pregnancy and a limited number of volunteer visitors. Both these factors were unavoidable as little knowledge exists about stomas and pregnancy aside from a few medical studies and anecdotal accounts, and few women who have stomas are available to discuss childbirth, as few have experienced it.

Due to a paucity of literature and resource persons, the women often had to use their own initiative in acquiring information and appropriate assistance. As Corbin (1987) noted, women with chronic illnesses often play a significant part in the management of their pregnancies. The findings from this study suggest that the women themselves became the
experts at recognizing their needs and at finding appropriate assistance.

Similar to findings by Shaul et al. (1987) and by several anecdotal reports reviewed, all the women reported that, during pregnancy, they would have liked to have talked to another woman with a stoma who had experienced pregnancy. As Shaul et al. (1987) observed, most women with disabilities want to speak with a woman with a similar disability who has gone through pregnancy to gain insight into what to anticipate during pregnancy and postpartum. Also, similar to findings by Nicholl et al. (1993), all seemed keen to share their experiences of childbearing with the researcher and recounting the events of the pregnancy possibly helped them come to terms with it.

Further, most women were interested in discussing with the researcher their surgery with ileostomy and, or, their daily implications of living with a stoma. These observations also correspond to findings by Kelly (1991), who suggests that individuals' explanations of how they cope with their ileostomies are a coping method in their own right as they provide them with an opportunity to interpret their situations.
In summary, the findings from the study suggest that health care professionals and support groups can be instrumental in reducing fears and facilitating positive perceptions of childbearing.

Cultural System

The findings suggest that the stoma made most women feel unique and sometimes even shameful or embarrassed. These findings were also noted in the literature (Dlin, 1978; Kelly, 1991). Also, similar to findings in the literature, the study suggests that individuals with stomas strive to construct a normal identity and that pregnancy may help to achieve this (Kelly, 1991; Nicholl et al., 1993). The success at being able to give birth to healthy newborns perhaps contributed to the perceptions by all the women in the study that their childbearing experiences had overall been positive experiences.

Despite the fact that women with stomas have experienced childbirth since the mid-1900's, little has been published in scholarly health care literature about their psychosocial needs. Shaul et al. (1987) have suggested that a cultural bias has existed that women with disabilities should not bear or raise
children and that consequently the needs of these women have been neglected. Perhaps this bias has extended to women with stomas as well.

Summary of Discussion

The research findings have been discussed in relation to the literature. The two most serious complications noted in the study were bowel obstruction and stomal prolapse and these and their respective methods of treatment have been previously identified in the literature. However, the psychosocial issues related to these complications have not been addressed in the health care literature. The study's findings with respect to altered stomal sizes, peristomal skin, and fluid intake have received only brief mention in the literature related to stomas and pregnancy but the health care literature does address the need for individuals with stomas to continually monitor their stomas, peristomal skin, and diet. In contrast to the literature, four of the six women in the study required operative deliveries or obstetrical intervention as either a direct or indirect consequence of having a stoma. However, similar to the findings in the literature, they all gave birth to healthy babies.
The emotional concerns that a woman with a stoma and her partner may have during pregnancy have not been addressed in the scholarly health care literature. However, the significance of the partner's support for individuals with stomas has been discussed.

The study's findings that the women wanted more information about their pregnancies, that they needed to take some initiative in finding the information, and that they wanted to talk about their experiences of pregnancy and about coping with a stoma in general are all consistent with the literature pertaining to chronic illness and pregnancy. Also perceptions about the ET nurses' expertise and the general nurses' lack of expertise with respect to stomal care are congruent with findings in the literature related to the non-pregnant individual with a stoma.

Finally, the embarrassment associated with having a stoma has been documented in the literature as has a brief suggestion that pregnancy perhaps provides an opportunity for individuals with stomas to construct a normal identity.

In summary, the study's findings substantially add to the body of knowledge pertaining to the childbearing
experience for a woman with a stoma and they also provide further insight into the ongoing challenges faced by individuals with stomas.

**Conclusions**

Although each case study presented with different findings, in each case the stoma affected the woman's physiological, self, family, social, and cultural systems and these interacted to create six unique childbearing experiences. These findings suggest that Snyder's (1979) childbearing framework is applicable to this population and possibly to others. The following conclusions are drawn.

1. Physiological implications of having a stoma during pregnancy include: bowel obstruction, stomal prolapses, altered stomal sizes and shapes, peristomal skin irritation, increased thirst, and operative deliveries.

2. Complications of pregnancy cause fear and inconvenience for both the woman and her family.

3. Women with stomas need pre-natal counselling to learn what they can anticipate with pregnancy, labour delivery, and postpartum; to share their concerns and their knowledge; and to participate in formulating a
management plan for their pregnancy and hospitalization.

4. Basic and continuing nursing education programs need to address the affective, cognitive, and psychomotor skills necessary to care for individuals with stomas.

6. Factors that contribute to a positive childbearing experience include: a healthy pregnancy and postpartum; a supportive partner; knowledgeable and caring physicians and nurses; available research-based literature regarding the effect of stomas on pregnancy; and someone to talk to with similar needs.

7. The technical, psychosocial, and cultural challenges faced by women with stomas during pregnancy are not unlike those experienced on a daily basis by any individual with stoma.

8. Bowel surgery with ileostomy may provide an opportunity for women who are ill with inflammatory bowel disease to have children.

Implications for Nursing Practice

The findings suggest a number of implications for nursing practice.
1. Nurses involved in pre-natal classes need to be sensitive to the special needs of women with stomas and provide them with an opportunity to express their concerns. In addition the following interventions should be implemented: women with stomas should be referred when possible to an ET nurse for continued support; the women should be informed about possible physiological implications of having a stoma during pregnancy; and the women's special needs during labour, delivery, and postpartum should be reviewed with hospital staff prior to hospitalization.

2. Partners should be included in pre-natal counselling and the childbirth experience as they are considered important sources of support.

3. Nurses must support the woman's efforts to practice independent stoma management and decision-making.

4. ET nurses need to work closely with the UOA to assist with training women with stomas who have experienced childbirth to become visitors for other women contemplating or experiencing pregnancy.

Implications for Nursing Education

The findings suggest the following implications
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for nursing education.

1. All nurses need basic and continuing education with regard to the affective, psychomotor, and cognitive domains of stomal care.

2. ET nurses should be actively involved in basic and continuing nursing education programs regarding the affective, psychomotor, and cognitive aspects of stomal care.

Implications for Nursing Research

The study's findings suggest the following areas of research would enhance understanding of the childbearing experience for women with stomas.

1. Nurses' attitudes towards caring for patients with stomas.

2. How ET nurses can be more effective in raising the public's and health care professionals' awareness about the needs of individuals with stomas.

3. The impact of Crohn's disease on pregnancy prior to, or following bowel surgery with ileostomy.

Summary

Individuals with stomas face ongoing challenges that can be physiological, psychosocial, and cultural in nature. Although research exists that describes how
a stoma affects the daily lives of individuals, only a few medical studies have been done to determine how a stoma affects childbearing. The findings from these studies, while replete with physiological considerations, do not address psychosocial or cultural implications. The research question put forth therefore was: how does a stoma affect the childbearing experience?

Case study methodology was the research design selected to explore this question. This was an appropriate design for it allowed the researcher to use a variety of evidence to explore in depth a subject about which little is known. Only eight women with stomas living in the Lower Mainland, Sunshine Peninsula, and Fraser Valley of British Columbia were noted to have experienced childbirth in the past 18 months and six participated in the study.

To strengthen the conclusions of the study, data were collected from each woman, her partner, in all but one case, and her physician. An informal interview guide consisting of open and closed-ended questions was used to solicit their impressions of how the stoma affected the childbearing experience. The interviews
with the women and their partners took place in their homes and were audio-taped and transcribed. Partners who could not be present for the interview were interviewed on the telephone. All the physicians were also interviewed on the telephone and the researcher made notes during the telephone interviews. In each case study the data obtained from the interviews with the partners and the physicians supported the women's own stories.

Snyder's (1979) holistic model of the childbearing experience was used to guide the observations and the analysis for the study. Data were collected and analyzed according to the major concepts of the model: the physiological system, the self system, the family system, the social system, and the cultural system and conclusions drawn about how the stoma affects each system and how the systems interacted to create unique childbearing experiences for each individual woman. The findings were presented in six individual case reports and common issues were then identified, expanded, and compared in a cross-case report. These findings were then discussed in relation to the literature.
Finally conclusions were drawn about the effect of the stoma on the childbearing experience and implications for practice, education and research suggested.
References


Quarterly, 28 (3), 6-9.


Kirsner, J.B. (1985) Chronic inflammatory bowel


Snyder, D.J. (1979). The high risk mother viewed in relation to a holistic model of the childbearing


Appendix A

School of Nursing
The University of British Columbia
Vancouver, B.C.

Introductory Letter to Individuals Recruiting Participants

Dear __________________:

My name is Margery Hawkins. I am an Enterostomal Therapy Nurse and currently a student in the Master of Science in Nursing program at the University of British Columbia. I am doing a research study to explore the childbearing experience for women with stomas. Very little is known about this experience and consequently a lack of theory exists on which to base effective care planning.

The findings of the study will assist health care professionals to plan effective strategies to care for pregnant women with stomas and will provide women with stomas, contemplating or experiencing pregnancy, with insight into their condition.

If you know of any women with stomas who have experienced pregnancy in the past 18 months, would you please send them this letter along with the "Letter of Information" in the stamped envelope provided.

Thank you for your assistance.

Yours truly,

Margery Hawkins, R.N.
MSN Student, UBC School of Nursing
Appendix B
School of Nursing
The University of British Columbia
Vancouver, B.C.

Information Letter to Prospective Participants

My name is Margery Hawkins. I am an Enterostomal Therapy Nurse and currently a student in the Master of Science in Nursing program at the University of British Columbia. I am doing a research study to explore the childbearing experience for women with stomas. Very little is known about this experience and hopefully the findings of the study will assist health care professionals to plan effective strategies to care for pregnant women with stomas and will provide women with stomas, contemplating or experiencing pregnancy, with insight into their condition.

If you agree to participate in the study I would like to: interview you; interview your partner, if you both agree; review your hospital health records to obtain background information about the birth of your child; and interview your physician involved with your obstetrical care. A summary of the findings of the study will be made available for you on completion of the study.

The interview with you will last approximately one hour and will be conducted at a time that is mutually convenient and in a setting of your choice. The interview will be audio-taped and transcribed and the tapes and transcriptions destroyed following completion of the study. Your privacy will be protected at all times. Any information that you share will be held in the strictest confidence and you will never be identified in any published or unpublished materials. You may refuse to comment or you may withdraw from the study at any time without jeopardy or prejudice to your health care.

If you have any questions regarding this study or if you are interested in participating in the study you may telephone me at 224-4121, or my thesis supervisor, Professor Elaine Carty at 822-7444.

Yours truly,

Margery Hawkins, R.N.
MSN Student, UBC School of Nursing
Appendix C

School of Nursing
The University of British Columbia
Vancouver, B.C.

Information Letter to Participating Physicians

Dear:

RE: ________________________________

I am an Enterostomal Therapy Nurse and currently a student in the Master of Science in Nursing program at the University of British Columbia. I am doing a research study to explore the childbearing experience for women with stomas. The title of my study is "The Childbearing Experience for Women with Stomas: A Multiple Case Study".

The findings of the study will assist nurses to plan effective strategies to care for pregnant women with stomas and will provide women with stomas, contemplating or experiencing pregnancy, with insight into their condition.

Women with stomas who have experienced childbirth in the past 18 months are being asked to participate in the study. The above patient has consented to be a participant and has agreed that I may contact you to discuss the following issues:

1. Concerns you may have had about the effect of the stoma on her pregnancy/delivery.
2. Any precautions taken regarding the above concerns.
3. Any complications that occurred that were related to the stoma during pregnancy/delivery/postpartum and the management of these complications.
4. The involvement of other physicians in the
patient's care during the pregnancy/delivery.

A "Release of Information Form" is enclosed. I will soon be contacting you by telephone to determine if you agree to participate in the study and if so, to arrange for a convenient time to briefly discuss these issues with you. The findings of the study will be made available for you.

If you have any questions about the study you may telephone me at 224-4121, or my thesis supervisor, Professor Elaine Carty at 822-7444.

Yours truly,

Margery Hawkins, R.N.
MSN Student, UBC School of Nursing
Appendix D

School of Nursing
The University of British Columbia
Vancouver, B.C.

Page 1 of 2

Woman's Consent Form

I agree to participate in the nursing research study, "The Childbearing Experience for Women with Stomas: A Multiple Case Study" to be conducted by Margery Hawkins, a graduate student in the Master's of Science in Nursing program at the University of British Columbia.

The purpose, the demands, and the benefits of the study have been explained to me. I understand that my participation includes a one hour interview with Margery Hawkins at a location of my choice. I understand that this interview will be audio-taped and transcribed and the tapes and transcriptions destroyed following completion of the study.

I understand that my privacy will be protected at all times, that any information I share with you will be held in the strictest confidence, and that I will never be identified in any published or unpublished materials.

I have read the letter that Margery Hawkins will send to the physicians involved with my pre-natal and obstetrical care and agree that she may send it. I also give permission to Margery Hawkins to read the hospital records pertaining to my childbearing experience.

I understand that my participation is voluntary and that I may withdraw from the study at any time without jeopardizing my health care.

I understand that I may clarify any further questions by contacting Margery Hawkins at 224-4121 or
Professor Elaine Carty at 822-7444.

My signature on this form verifies my intention to participate in this study. I have retained a copy of this consent form for my records.

____________________________  ___________________
Woman's Signature             Date

____________________________  ___________________
Investigator's Signature       Date
Appendix E

School of Nursing
The University of British Columbia
Vancouver, B.C.

Partner's Consent Form

I agree to participate in the nursing research study, "The Childbearing Experience for Women with Stomas: A Multiple Case Study" to be conducted by Margery Hawkins, a graduate student in the Master's of Science in Nursing program at the University of British Columbia.

The purpose, the demands, and the benefits of the study have been explained to me. I understand that my participation includes a one hour interview with Margery Hawkins at a location of my choice. I understand that this interview will be audio-taped and transcribed and the tapes and transcriptions destroyed following completion of the study.

I understand that my privacy will be protected at all times, that any information I share with you will be held in the strictest confidence, and that I will never be identified in any published or unpublished materials.

I understand that my participation is voluntary and that I may withdraw from the study at any time without jeopardizing my health care or that of my partner.

I understand that I may clarify any further questions by contacting Margery Hawkins at 224-4121 or Professor Elaine Carty at 822-7444.

My signature on this form verifies my intention to participate in this study. I have retained a copy of this consent form for my records.

Partner's Signature Date

Investigator's Signature Date
Appendix F

School of Nursing
The University of British Columbia
Vancouver, B.C.

Release of Information Form

Re:

I understand that Margery Hawkins, a graduate student in the Master's of Science of Nursing Program at the University of British Columbia will be asking you for information about the following issues:

1. concerns you may have had about the effect of the stoma on the pregnancy/delivery.

2. any precautions taken regarding the above concerns.

3. any complications that occurred that were related to the stoma during pregnancy/delivery/postpartum and the management of these complications.

4. the involvement of other physicians in the patient's care during the pregnancy/delivery.

I give you permission to discuss the above issues with Margery Hawkins.

Signed: ________________________________

Witness: ________________________________

Date: ________________________________
Appendix G
Interview Guide
Sample Questions

Research Question: How does having a stoma affect the experience of childbearing?

W = Woman; P = Partner

<table>
<thead>
<tr>
<th>Concepts from Snyder’s Model</th>
<th>Areas to be Addressed</th>
<th>Examples of Specific Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physiological Pregnancy</td>
<td>-level of health during pregnancy</td>
<td>W - How did you feel during pregnancy? W - Did you experience any complications related to your stoma during pregnancy/delivery/postpartum? What were they? (prolapse, stoma enlargement, hernia, obstruction, healing of perineum)</td>
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<tr>
<td></td>
<td>-effect of stoma on the physiology of pregnancy</td>
<td>W - Type of delivery/length of labour? W - What effect did your pregnancy have on your daily activities? W - Did your stoma function during labour/delivery? W - Did your stoma require more attention than usual during pregnancy? In what regard?</td>
</tr>
</tbody>
</table>
| Self System                        | -emotional reactions to pregnancy/parenting | **W** - Did you have any concerns about the effect of the stoma on the pregnancy/labour/delivery/parenting?  
|                                 | -level of knowledge about impact of stoma on pregnancy/delivery/postpartum | **W** - Did you receive any pre-pregnancy counselling to assist you with decision-making about becoming pregnant?  
|                                 | -emotional support                          | **W** - How did you feel upon discovery of pregnancy?  
|                                 |                                           | **W** - Were you kept informed about your progress during your pregnancy? Did you understand the explanations?  
|                                 |                                           | **W** - Did you know what to anticipate with pregnancy/delivery/postpartum?  
|                                 |                                           | **W** - Did you feel you needed emotional support during pregnancy? Who provided you with emotional support? |
| Family System                   | -effect of family system on pregnancy       | **W, P** - Was your relationship with your partner affected by the pregnancy/stoma? How?  
|                                 | -effect pregnancy on family system          | **P** - What concerns did you have about your wife's health during the pregnancy/labour/delivery/postpartum?  
|                                 | -partner's level of knowledge about impact of stoma on pregnancy/delivery/postpartum | **P** - Were you able to discuss your concerns with anybody?  
|                                 |                                           | **P** - Did you receive adequate information about the impact of stoma on pregnancy?  
|                                 |                                           | **P** - Were you included in the management planning of pregnancy? |
| Social/Cultural System | -role of health care providers  
|                       | -stoma management during pregnancy/hospitalization  
|                       | -preparations for stoma management during hospitalization/ postpartum  
|                       | -support systems  
|                       |  
|                       | W - Were the health care providers familiar with your special needs concerning stoma management during hospitalization? Were you included in the management planning?  
|                       | W - What health care providers were involved in your prenatal and postpartum care?  
|                       | W - Did you prepare for stoma management during hospitalization prior to admission?  
|                       | W - Did previous hospitalizations prepare you for your hospitalization? How?  
|                       | W,P - Were you involved with the management of the stoma during hospitalization? How?  
|                       | W,P - Did you attend prenatal classes, ostomy support groups?  
|                       | W - Did other women with stomas who had experienced childbirth provide you with any assistance?  |
Appendix H

Questionnaire for Physician
Sample Questions

1. Can you tell me what concerns you had about the effect the stoma might have on the pregnancy/delivery?

2. Were any precautions taken regarding the above concerns?

3. Did the patient experience any complications related to the stoma during pregnancy/delivery/postpartum? If so, how were they managed?

4. Were other physicians involved with the patient’s care during the pregnancy/delivery that you are aware of? If so, what were their roles?
## Appendix I

Data Analysis Matrix

<table>
<thead>
<tr>
<th></th>
<th>Physiological Pregnancy</th>
<th>Self System</th>
<th>Family System</th>
<th>Social/Cultural System</th>
</tr>
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<td>Case 1</td>
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