EXPLORING THE VIEWS OF RELATIVES OF FRAIL ELDERLY PATIENTS
ABOUT THE UBC GERIATRIC DENTISTRY PROGRAM

by

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Abstract

Elderly residents of long-term care facilities (LTC) have difficulty accessing dental services. Aiming to improve access for this population, the Geriatric Dental Program (GDP) was established by the UBC Faculty of Dentistry in 2002. Within the GDP, elderly LTC residents receive fee-for-service dental treatment. The objective of this research is to explore whether having access to the GDP services had an impact on the life of the patients’ relatives (family members). This research hopes to better understand how quality of health in relation to dental health extends to relatives who are responsible for the frail elderly patients who receive the dental care. Such understanding will contribute to our recognition of a more holistic and widespread impact of dental care access to all segments of our society.

Methods: Data was collected through semi-structured, face-to-face, audio-recorded interviews with family members of elderly patients from the UBC-GDP. A purposive criterion sampling method was used to select the family members to participate in this study. The final number of participants was determined according to saturation procedures. Interview transcription and data coding procedures were conducted following Saldaña. All interviews were transcribed verbatim. In a second step, NVivo software was used to code and organize the transcripts into different categories to develop themes. The analysis of the data followed a qualitative, interpretive Thematic Analysis.

Results: Final analysis shows that family members are worried about their relatives’ oral health; they believe that it is difficult to find private dentists with geriatric expertise and to make appointments for their family members outside of UBC, and that the UBC program helped them in fulfilling this task. Moreover, the UBC-GDP made their life less stressful and relieved the burden of setting up appointments for their relatives making their life easier. Thus, the UBC GD
program positively affected the life of relatives by improving access to dental care services for the growing geriatric segment of our Canadian society. Furthermore, this study shows that the UBC GD program not only improved the perceived oral health but also impacted the relatives’ life in a positive way.
Preface

The research on this thesis utilized qualitative methods. I used interpretative thematic analysis to analyze it.

I conducted all interviews, did the research analysis and wrote this thesis under the supervision of my research supervisor.

No article of this thesis has been previously published.

This thesis was approved by the UBC Behavioural Research Ethics Board, certificate number H13-01099.
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DMFT: Decayed Missed Filled Teeth
UBC: University of British Columbia
GDP: Geriatric Dental Program
LTC: Long Term Care
Glossary

In this thesis the term “patient” will be used to refer to a frail elderly person in LTC who presented for treatment at the UBC – GDP. The term “relative” will be used to refer to a family member (spouse, child, sibling or other relative) who has overall responsibility and concern for the care of the elderly person. It is the impact of the UBC – GDP on the “relative” that is the focus of the thesis and it is the relatives who were interviewed.
Acknowledgements

First of all I would like to demonstrate my special gratitude to my supervisor Dr. Christopher Wyatt, who was my mentor, my friend, my career counsel and a person who always believed in my potential. Thank you for your excellent guidance and patience with me during my journey. Thank you, my committee members Dr. Mario Brondani and Dr. Rosamund Harison for the excellent comments during our committee meetings. I am certain that those were very pertinent and helped me in the development of this thesis.

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Finally my enduring gratitude goes to God who gave me strength and to all relatives who gave their time to participate on this research. Without them this research would not be possible.
Dedication

This thesis is dedicated in memory of my mother, a school-teacher, who always believed in me and who unfortunately passed away a few days before I was accepted as a MSc student at UBC.

Mother: unfortunately you are not physically present here at this moment please know that I got accepted on that interview that you were waiting for, I went through my dental program and I am now finalizing it. Your strength and dignity were always here with me, and wherever you are rest in peace because I was able to do it. I miss you greatly and one day we will be able to meet again.
Chapter 1: Introduction

The elderly in long-term care facilities (LTC) have difficulties accessing dental care services. Aiming at improving access for this population, the Geriatric Dental Program (GDP) was established in 2002 by the UBC Faculty of Dentistry. In the GDP, residents of LTC receive fee-for-service dental treatment at the hospital facilities, or at the UBC dental clinic when the procedures involve complex care. Currently, this program provides dental services to approximately 2500 patients. In 2000, 90% of the 259 patients who consented to treatment did so by a proxy (family member/relative); thus, it is estimated that the number of relatives providing consent for participation in the program is high. Despite the high number of relatives consenting for dental treatments, there is no research investigating how the dental treatments provided to their elder family member may have impacted the life of these relatives. It is estimated that Canada will have between 9.9 to 10.9 million seniors by 2036, which constitutes more than double the numbers that existed in 2009. Hence, this growing segment of our population needs to be further investigated regarding their oral health status and needs. However, this investigation needs to use innovative perspectives to understand if providing dental care access to this population will have an impact not only on the elderly’s oral health, but also on their family relatives.

1.1 Literature Background

In this section I will synthesize the relevant literature on the topic of this thesis. A detailed explanation about the systematic way in which the review of literature was conducted is described on the methodology section of this thesis.
1.1.1 Oral Health and the Elderly Living in Long Term Care Facilities

It is well known that the elderly living in Long Term Care Facilities (LTC) have high dental care needs\textsuperscript{5} and this claim is even present in literature dating back to 1962\textsuperscript{6}. Drake\textsuperscript{6} in his 1970 study conducted epidemiological research in five nursing homes in North Carolina and found that the mean Decayed Missing Filled Teeth (DMFT) for the 279 institutionalized elderly persons was high (mean average of 29). In addition, he observed that elderly with natural dentition presented a high rate of periodontal disease and poor oral health\textsuperscript{6}.

The high dental care needs of elderly persons found by Drake are still prevalent today. For instance, in a recent study by Chen et al.\textsuperscript{7} in Minnesota, USA, it was related that nursing home residents have poor oral health, independently of their cognitive status, and many of them have untreated caries that could result in acute dental pain or infection.

Numerous other studies support the claim that the elderly living in LTC facilities have poor oral health conditions\textsuperscript{3,8-13}; and this situation seems to be similar in many parts of the world. Petelin et al.\textsuperscript{14} found that elderly living in LTC facilities in Slovenia also presented poor oral health; root caries incidence was high with a prevalence of 83.7\% in all research participants. Another concern described by Petelin et al.\textsuperscript{14} was that the majority of the elderly did not access dental services on a regular basis, a factor that may contribute even more to the deterioration of oral health.

Specifically in Canada, Matthews et al.\textsuperscript{15} found that the majority (75\%) of the elderly living in 31 different LTC facilities had no regular dental care, and presented a high prevalence of untreated root caries (44\%). In a previous study, Wyatt\textsuperscript{16} also found that poor oral health is present in the elderly living in LTC facilities. In his study with 369 elderly, 253 needed dental care treatment; the main need was related to dental caries (96.4\%). His study concluded that
there is lack of assistance with daily oral hygiene for the elderly living in LTC facilities and that overall the elderly residents experienced poor oral health. In addition, MacEntee et al.\textsuperscript{17} also reported that inadequate oral hygiene was a common finding on the elderly living in LTC facilities. The authors mentioned that this situation might be related to the lack of priority given to daily mouth care by nurses, in comparison to other tasks such as toileting, washing and dressing elderly patients\textsuperscript{18}. Failure to address daily mouth care was also mentioned in another qualitative study; and this was due to many other demands that a LTC staff member face working with elderly residents\textsuperscript{19}.

In general from all the studies, we can conclude that epidemiological surveys reveal the importance and necessity of dental service programs for the elderly LTC residents\textsuperscript{9, 12}. Research has indicated that the elderly living in LTC facilities have a greater need for oral health care in comparison to their counterparts who live independently\textsuperscript{11}. The need for denture care, dental hygiene services\textsuperscript{8, 10, 12, 20}, dental extractions, and restorative treatment\textsuperscript{9} have been identified as being a priority for this population. The increased risk of dental caries can be related to the lack of proper daily mouth care, a diet rich in refined carbohydrates, and exacerbated by xerostomia\textsuperscript{15}. Salivary dysfunction, polypharmacy, medical conditions, dysphagia, poor diets, functional dependence, a lack of daily mouthcare assistance, and poor access to dental care services are factors that may contribute to the poor oral health status of elders with dementia\textsuperscript{13}.

\subsection{1.1.2 Impact of Oral Health Problems in the Elderly}

Oral health is an integral part of general health and a disconnection between oral health and general health may cause several problems. For instance, quality of life studies demonstrate that oral health has an impact on the quality of life of the elderly. In a study with institutionalized
elderly persons in Germany\textsuperscript{21} it was found that pain and lack of denture retention were associated with low quality of life. Oral health problems are also associated with poor quality of life in institutionalized elderly persons. In another study with 641 elderly persons, Jensen et al.\textsuperscript{22} found that poor oral-health related quality of life “was associated with perceived need for dental treatment, poor self-rated health, worse mental health, having fewer than 17 natural teeth, and relatively poor cognitive status”.

In a cross-sectional survey Locker et al.\textsuperscript{23} assessed the oral-health related quality of life of medically compromised elderly living in LTC facilities. Their study suggested that oral health problems impacted the well-being and life satisfaction of the elderly. In fact, it has been reported that poor oral health is linked to other systemic diseases such as diabetes, hypertension, myocardial infarction, stroke and aspiration pneumonia\textsuperscript{24}.

In a systematic review, Azarpazhooh and Leake\textsuperscript{25} found evidence for the association between oral health and respiratory diseases such as pneumonia; however, there is weak evidence associating chronic obstructive pulmonary disease and oral health. In another review of the literature, in 1988, Limeback\textsuperscript{26} found that “it is likely that poor oral health of institutionalized elderly directly contributes to the increased risk of lower respiratory tract bacterial infections” (p. 133). However, it is not known “whether the risk of pneumonia can actually be diminished with improved oral hygiene”. In spite of this, the author believed that an improvement in oral hygiene will reduce bacterial load levels, reducing the risk of aspiration of a large bolus of bacteria, which will consequently reduce the risk for bacterial pneumonia. Despite the evidence, however, the medical community places little importance on daily mouth care for the prevention of systemic infections\textsuperscript{26}.
Malnutrition is also another issue that the elderly living in LTC facilities face. Although teeth are not required for digestion in healthy elderly individuals, a problem in the masticatory system may lead to poor food selection resulting in an unbalanced diet\textsuperscript{5}. Mojon et al.\textsuperscript{5} examined 324 institutionalized frail older adults and found that the ones with compromised oral functional status present with nutritional deficiencies, and that the presence of fewer than six occluding pairs of teeth or the absence of dentures in edentulous persons were predictors of malnutrition or low Body Mass Index.

To further verify the association between malnutrition and oral health status in the elderly living in LTC facilities, Van Lancker et al.\textsuperscript{27} conducted a systematic review of the literature. Their review found that there was an association between oral health status and malnutrition. However, they concluded that their findings should be interpreted with caution due to the complexity of the relationship of oral health status and nutritional intake.

Although there is a need to carefully interpret the impact of oral health problems in the elderly, overall oral health has been associated with general health and quality of life\textsuperscript{28}. Periodontal disease and cariogenic pathogens are intrinsically related to systemic health in many ways, and specifically for the elderly, these oral diseases are related to heart disease, strokes and aspiration pneumonia\textsuperscript{25, 29, 30}. Poor oral health is also related to malnutrition and involuntary weight loss in the elderly, and it is also correlated with poor quality of life\textsuperscript{28, 31-34}. Hence, it can be argued that proper dental care should positively impact the life of the elderly.
1.1.3 Impact of Dental Treatment on the Elderly

It is known that the institutionalized elderly do not visit dental professionals as frequently as they should\textsuperscript{21} for a variety of reasons\textsuperscript{18}. However, dentists may improve the quality of life of elderly residents of LTC by providing dental treatment or regular aftercare dental treatment\textsuperscript{21}.

A recent review of the literature provides good evidence that improved oral hygiene and professional oral health care reduce the progression or occurrence of respiratory diseases such as pneumonia among high-risk elders living in nursing homes or in intensive care units\textsuperscript{25}, consequently improving the quality of life of the elderly.

A recent cross-sectional study\textsuperscript{35} with 189 elderly persons found that poor oral health was associated with poor oral health-related quality of life. In this study Christensen et al.\textsuperscript{35} found that oral health was influenced by past history of dental visits, and that there is a need to treat periodontal disease and to address the lack of teeth. However, rather than focusing on traditional restorative procedures (treatment of caries) dentists should focus on removing loose teeth and providing dentures to patients with very few teeth. Furthermore, they concluded that preventive oral health activities might eliminate bleeding symptoms and prevent further dental caries. This study supported the hypothesis that the provision of appropriate dental care will have a positive impact on the life of the elderly.

Other studies also support the hypothesis that the provision of dental care for the elderly may positively impact their quality of life. For instance, Naito et al.\textsuperscript{36}, demonstrated that the provision of dental care services for institutionalized elderly Japanese improved the “activities of daily living” (ADL) and “oral health-related quality of life”. According to them, their research is the first controlled study with nursing home residents demonstrating that dental treatment influences ADL and oral health-related quality of life. Furthermore, they mention that the dental
staff can facilitate the quality of life of residents when they help the elderly maintain optimum oral health, contributing to the general well being and improving the quality of life of elderly residents.

However, a study conducted in Hong Kong with institutionalized Chinese elderly residents did not find improvements on the general oral health assessment index (GOHAI) after dental treatment was provided. The provision of dental treatment improved elderly subjects’ satisfaction on oral health and the perceived oral health status, but the authors found no change in the mean GOHAI score between baseline and after treatment. Although there are contradictory studies on the impact of oral health treatment on the quality of life of elderly, it is important to know that the majority of the studies demonstrate that adequate oral health treatment positively impacts the quality of life of the elderly.

In relation to the effects of dental treatment on masticatory function, adequate prosthetic therapy can restore masticatory function as evidenced by increased muscle activity during chewing, reduced chewing time and the number of chewing strokes until swallowing. In fact, detrimental dental conditions are associated with nutritional deficiencies in the elderly and the presence of a good dentition is related to better nutrient intake that might have an indirect impact on quality of life. Thus, if we want to improve the nutritional status and quality of life of the undernourished elderly, we also should reestablish their masticatory function.

Another benefit of dental treatment is that the treatment rendered to an elderly person may positively impact the lives of their close relatives such as first-degree family members. According to Locker et al. the hypothesis that oral health may have an impact on the family was first suggested in 1981 by Sheiham & Croog. This issue has been investigated in depth in the pediatric dentistry literature; indeed according to Locker et al. the American Academy of
Paediatrics suggests that child health refers to both health of the child and health of the family. Locker et al.\textsuperscript{40} found that oral health conditions affect parent and family activities. Parent-caregivers reported that because of the child’s oral health conditions, the child required more attention. In addition parent-caregivers report financial difficulties, time off from work, feeling of guilt or worries due to their child’s oral health condition\textsuperscript{40}. Although pediatric dentistry is advanced in this field of research, to our knowledge this is not the case in the context of the elderly population. Research related to how an oral health problem or a dental care service for the elderly may influence the life of family relatives, specifically a spouse or children, is not documented in the dental literature.

However, similar research is present in the literature related to cancer patients. Edwards and Clarke\textsuperscript{42} mentioned that the diagnosis of cancer is a stressful event on the life of relatives; and relatives can suffer from depression and anxiety, providing evidence of the effects of cancer on the whole family not only on the patient. In addition, it has been documented that cancer pain creates a burden not only on the patients but also on their relatives\textsuperscript{43}. Piteathly and Maguire\textsuperscript{44} conducted a literature review to demonstrate how cancer can psychologically impact the lives of partners or relatives. They mentioned that some relatives became depressed, anxious or distressed when dealing with the cancer of their family member. From the above-cited research we can conclude that cancer can indeed affect the life of relatives, and suggestions have been made that health programs need to include not only patients but also their relatives to help them to cope with the problems associated with cancer\textsuperscript{45}.

In relation to dentistry, this systematic search of the literature, revealed only three studies that focused on the perception of relatives of the elderly in LTC facilities. Interestingly two articles\textsuperscript{19,46} are from Brazil and one\textsuperscript{47} from Canada.
Reis et al.\textsuperscript{19}, in Brazil, investigated how caregivers perceived the oral health of the institutionalized elderly. They found that caregivers perceived the elderly person’s oral health as a burden. However, in this study\textsuperscript{19} the persons considered caregivers were staff members from the LTC facility and not elderly’s family members (relatives). In a similar study in Brazil, Unfer et al.\textsuperscript{46} also investigated how staff caregivers perceived the oral health status of the elderly in their care. They found that the barriers to oral health care were beyond the control of the caregivers and involved issues of lack of time and lack of personnel to provide oral health care to the elderly.

Matear and Barbaro\textsuperscript{47}, in Canada, on the other hand, conducted interviews with family relatives to investigate which dental treatments were deemed to be more important to the elderly family member. That is, the authors investigated the importance and priorities of dental services from the family relative’s point of view. However, they did not investigate how the elderly person’s oral health affected the life of the relatives.

None of these three studies explored how the dental care service for the elderly influenced the life of family caregivers (relatives). Thus, to our knowledge, this thesis is an original study exploring the impact of dental care access for the elderly in LTC facilities on their family, i.e. their relatives.

1.2 Purpose

1.2.1 Research Problem

Epidemiological surveys point out the importance and necessity of programs offering dental health services for the elderly living in LTC\textsuperscript{9,12}. Lack of dental care services for residents of LTC facilities may negatively impact the life of their relatives; for example, children or
spouses of LTC residents may need to take time off from work to seek dental treatment for their relative. In addition, relatives may feel stressed due to the lack of dental care services for elderly family members. However, there is no research that has investigated how dental care services for the elderly influenced the life of family relatives.

1.2.2 Research Objectives

The objective of this research is to explore whether dental care provided by the UBC GDP has an impact on the elderly patient’s relatives, and if so, what was the nature of this impact.

1.2.3 Research Question

To what extent does the UBC Geriatric Dental Program (GDP) impact the lives of elderly patients relatives?
Chapter 2: Methodology

This chapter presents a description of the methods used in this research. Because the literature review is considered a quasi-systematic review of the literature, the chapter begins by reporting on how the review of the literature was conducted, followed by a description of the selection of participants for this research. Subsequently, data collection procedures are explained including a description of the pre and post interview forms and the interview environment. Further, the methods of data analysis are reported, including how transcription, coding, and themes were developed. The chapter ends describing how the results were analyzed to answer the research question.

2.1 Review of Literature

2.1.1 Purpose of review of literature

The purpose of this quasi-systematic review of literature\(^1\) was to understand the oral health situation of the elderly who live in LTC facilities. To achieve this purpose, I developed the following guiding question.

2.1.2 Guiding review of literature research question

What is the current evidence regarding the oral health of elderly residents in LTC facilities?

\(^1\) I use the term quasi-systematic in this thesis to refer to the fact that the review of literature was conducted using specific keywords and medical subject headings. Papers were selected using an inclusion criteria related to the literature review question. This is not considered a systematic literature review because only the student was involved in all phases of the review process, that is, developing the search strategy, and excluding and selecting papers.
2.1.3 Literature review exclusion and inclusion criteria

After the definition of the guiding research question, the inclusion and exclusion criteria were established. To be included, an article should comply with the following criteria: (a) empirical or review articles, (b1) related to oral health condition of elderly in LTC facilities, or (b2) related to the negative impact of oral health on life of the elderly life, or (b3) related to the impact of dental treatment on the elderly who lived in a LTC facility. Articles were excluded if they: (a) were written in a language other than English, (b) were editorials or letters to the editors, (c) were not specifically related to the topic of oral health for the elderly living in LTC facilities.

2.1.4 Literature review methods

The review of the literature was conducted using the Ovid database. This specific database was selected because of its relevance to dentistry. The initial search included the “Ovid MEDLINE 1946 to Present”² (last search run on March 18, 2014), it was not limited by language or date of publication. Based on the guiding research question, keywords and medical headings were developed to be used in the search strategy. Table 2.1 presents the detailed search strategy used on Ovid Medline and the number of articles retrieved according to each keyword, heading and combination of headings/keywords (search run on March 18, 2014). In total, 224 entries were retrieved.

² Official name: Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) 1946 to Present
Table 2.1 Search strategy with subject headings and keywords used on Ovid MEDLINE and the number of retrieved articles correspondent to each strategy used

<table>
<thead>
<tr>
<th>Strategy</th>
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<tbody>
<tr>
<td>exp Oral Health/</td>
<td>10075</td>
</tr>
<tr>
<td>elderly.mp. or exp Aged/</td>
<td>2328678</td>
</tr>
<tr>
<td>exp Homes for the Aged/</td>
<td>10893</td>
</tr>
<tr>
<td>exp Nursing Homes/</td>
<td>31488</td>
</tr>
<tr>
<td>exp Long-Term Care/</td>
<td>21416</td>
</tr>
<tr>
<td>1 and 2</td>
<td>2445</td>
</tr>
<tr>
<td>3 or 4 or 5</td>
<td>53098</td>
</tr>
<tr>
<td>6 and 7</td>
<td>224</td>
</tr>
</tbody>
</table>

After merging the 224 entries on EndNote® X7, 7 duplicated articles and 35 others that were written in a language other than English were excluded, yielding 182 articles for the initial screening. The initial screening was conducted by reading the titles and abstracts of all 182 articles; through this process, 105 articles were deemed not intimately related to the research question and were thus excluded. Therefore, 77 articles remained to be read in full (Appendix A).

These 77 articles were further classified according to their main topics: Oral health condition of the institutionalized elderly (46 articles); negative impact of the oral health on the elderly (18 articles); and positive impact of dental treatment on the elderly (14 articles).

These 77 articles constituted the base bibliography to consult for writing the literature review. Further articles were pre-selected using cross-reference techniques in which new articles were selected according to the citations found in the previous articles or by looking further into literature from other disciplines, such as psychology or sociology. Figure 2.1 represents the procedures employed in the review of literature.

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3 One article appeared in two categories at the same time
Figure 2.1 Strategy used and number of papers selected for the review of literature
2.2 Data Collection Methods

This section presents a description of the selection of research participants and the procedures used to collect data, explaining each part in sufficient details for research reproducibility.

2.2.1 Population Inclusion and Exclusion Criteria

Immediate family members of elderly patients who had one or more appointments in the GDP program for dental treatment in 2013, and who had signed the consent form for the dental treatment were included in this study.

The included subjects were selected based on: (a) relationship to the patient (immediate family member, not power of attorney; for example, children, spouse or sibling), (b) place of residency (only family members of elderly residents from greater Vancouver), and (c) ability to understand English. Thus, to select the participants for this research, a purposive sampling method was used, more specifically, a criterion sampling based on inclusion and exclusion criteria\(^48\). The final number of participants was determined according to saturation procedures\(^48\). Twelve interviews were necessary to confirm saturation (to be explained in a subsequent section). Table 2.2 describes the demographics of the research participants and their relationship to the elderly patient.
I interviewed seven women and 5 men. From those interviewed, five were sons; four were daughters, one niece, one sister and one wife (Table 2.2). More specifically, the family members were bringing their mother, father, aunt, sister and husband to the program.

Participants were recruited through GDP administrative staff who had a previous contact with the prospective participant. A UBC staff employee (gatekeeper), other than the student researcher, contacted possible research participants by telephone. The gatekeeper followed a script (Appendix B – Pre-Screening: telephone script and pre-interview form) to explain the research project and to ask if the family member had interest in participating in the research. If the family member accepted, the gatekeeper then checked the inclusion criteria, and if family member was eligible, she or he was asked for permission to be contacted by the student researcher.

The student researcher then contacted the family member to explain the project in more details, confirm the inclusion criteria, and schedule a time and appropriate place for the interview (or to secure a landline phone number to conduct the interview over the phone if the participant preferred).

<table>
<thead>
<tr>
<th>Relatives’ Sex</th>
<th>N</th>
<th>Relationship with elderly patient</th>
<th>N</th>
<th>Status of elderly patient</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>7</td>
<td>Son</td>
<td>5</td>
<td>Mother</td>
<td>6</td>
</tr>
<tr>
<td>Male</td>
<td>5</td>
<td>Daughter</td>
<td>4</td>
<td>Father</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Niece</td>
<td>1</td>
<td>Aunt</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Sibling</td>
<td>1</td>
<td>Sister</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Wife</td>
<td>1</td>
<td>Husband</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 2.2 Participants demographics and their familial relationship with the elderly patient
2.2.2 Interview environment

All interviews were conducted at UBC at a time when the family member brought their elderly family member for a dental appointment. From the contacted participants only two declined to be interviewed, without explaining the reasons to do so (one person declined during the phone conversation with the gatekeeper and the other one declined a few minutes before the scheduled interview at UBC). No further information can be mentioned about these two participants because I do not have their consent to access their demographic information.

During the interview process, after an introduction between the student researcher and the relative, the project and the consent form (Appendix C – Consent Form) were read and explained to the interviewee (elderly family member). The research participant received a copy of the consent form and the suggested financial compensation of $100, $25 to pay for parking, time spent outside of work/house, meals and $75 to apply to the elderly patient’s comfort fund. The research participant signed a receipt to confirm that she or he received this compensation (Appendix D – Receipt). Although one may think that $100 would bias and favor the relatives to participate in this research, I found relatives who did not want to participate in this research, and ones that mentioned that they did not want any financial compensation. However, the ones who did not want the financial compensation received it, and they mentioned that they would apply the full value towards their elderly family member’s comfort funds.

2.2.3 Interview Process

Each interview was approximately 35 minutes long. However, the length of the interview varied depending on the availability of the interviewees and the amount of information needed.
Interviews were conducted at UBC in a consultation room where the participant was able to answer sensitive questions with his or her privacy guaranteed. The interviews were done individually and face-to-face with the relative family member, and were audio recorded using a password-protected personal computer (Apple MacBook Pro – Software used: Audacity).

A semi-structured interview guide was developed specifically for this research. The questions asked during the interview encompassed different topics aimed at understanding whether having access to dental treatment within the UBC GDP may or may not have had an impact on the daily life activities of the elderly and of the relative or family member.

As the objective of this research was to understand how the UBC geriatric dental program affected the life of the patients’ relatives, the questions were asked only to the family members who signed the consent form for the dental treatment of the elderly person at the UBC GD Program. No elderly person who received dental treatment at the UBC GD Program was interviewed as part of this research.

The questions asked were open-ended and specific follow-up questions asked to clarify the interviewee’s answers or to further understand an episode being narrated by the interviewee. The semi-structured interview guide (Appendix E – Interview Protocol) presented guiding questions only, organized in themes, and the specific phrasing of the questions and order into which they were asked slightly varied to follow the flow of the conversation (interview process). Moreover, the interviewer (student researcher) strived to use neutral (non-leading) questions, also using the participants’ own terms whenever possible.
2.2.4 Post-Interview Form

At the end of the interviews, the interviewer completed a post-interview form (Appendix F – Post Interview Form) to: (a) critically analyze the interview process, (b) suggest new themes to be investigated, and (c) make recommendations for the next interviews. These post-interview forms were also included in the database for interview analysis.

The post-interview form was important because it was the first step of data analysis, functioning as a logbook and also helping to find deficiencies on the interview process, which allowed for further modifications to be made on the next interviews.

2.3 Analytical Process

All interviews were analyzed following thematic analysis as described by Braun and Clarke49. This method identifies, analyzes and reports patterns in the data producing insightful analysis with a thematic description of the predominant themes of the full data corpus49. Specifically, in this research, an inductive semantic thematic analysis was conducted, in which the transcripts were coded without trying to fit the codes to preexisting coding frames. The semantic approach means that themes were identified from explicit meanings of the data. According to Braun and Clarke49, thematic analysis is an adequate method for qualitative descriptive studies, such as this one, which aims at describing the surface of events and to be close to the data at the same time50, 51.

The thematic analyses of the interviews consisted of five steps as described by Braun and Clarke49: (a) familiarization with the data, (b) generating codes, (c) searching for themes, (d) refining themes, and (e) defining and naming themes.
2.3.1 Familiarization with the data

This first phase of thematic analysis consisted of (a) verbatim transcription, including non-verbal utterances when necessary, (b) checking of the transcripts against the original audio recording to verify accuracy, and (c) active reading of the data; that is, repeated reading of transcripts, searching for data patterns.

The researcher listened to and manually transcribed the audiotapes. After the transcripts were completed, they were read and checked to confirm their accuracy. Necessary utterances such as pauses and comments related to voice intonation and other sounds used to communicate (such as “laughs”, for example) were marked on the transcripts using commas or the word inside a parenthesis (for example, (laughs)). The repeated reading of the transcripts was done to search for data patterns; this led to the next phase of data analysis called “generating initial codes”.

2.4 Generating initial codes

The second phase of thematic analysis is developing codes from the database. Coding is a process used to analyze the data; it is the first analytical step to move further from concrete statements of data by making analytical interpretations of the available data. The entire data corpus minus the post-interview forms was coded (i.e. full transcripts were coded), remaining as open as possible for potential themes. This phase was done using a computer assisted qualitative data analysis software, NVivo 10, and consisted of the following steps: (a) first cycle coding, (b) second cycle coding, and (c) categorization of codes.

First cycle coding is a straightforward way to break the transcripts in little pieces of information; it is simple and direct, and is open to any theoretical direction the data may bring, allowing the emergence of new ideas. During this phase segments from all 191 pages of
transcripts4 (1.5 line space, Times New Roman 12) were coded, using words that summarized the incident reported by the participant, a process also called incident-by-incident coding52. In the end of the first cycle coding 79 different codes were generated.

After coding all data from each interview, codes were re-evaluated and the necessary modifications were made, i.e., renaming them and merging similar codes to a unique code/category that would better reflect the participants’ original meanings. This further analytical step is called second cycle coding, and requires some analytical skills to integrate, in a concise way, the codes developed during the first cycle coding, allowing the student researcher to develop a coherent data analysis synthesis from all interviews1. According to Saldaña1 the primary goal of second cycle coding is to “develop a sense of categorical, thematic, conceptual, and/or theoretical organization” of first cycle coding (pg. 149); that is, the codes were reorganized into a smaller list and/or to create categories that were merged to develop themes that would answer this thesis research question.

In this phase (second cycle coding) steps used in axial coding were employed to develop categories. Axial coding is a way to analyze the codes integrating them into categories in an axial way creating a vertical hierarchical relationship; that is, a code is analyzed and compared to different codes from other interviews; those might be merged in a group called category that is further analyzed and transformed in themes (Figure 2.2). After doing this analysis an additional analysis is conducted grouping different categories, if appropriate, to a more general level (themes). Themes are considered a general level analysis that will answer the research question (Figure 2.1).

4 The transcripts composed the entire data corpus (minus the Post-interview form)
Figure 2.2 Development from coding to category (specific to general level). Figure adapted from Saldaña¹.

During the analytical process, first cycle coding generated 79 codes; second cycle coding resulted in 12 categories and 6 themes (Table 2.3).

<table>
<thead>
<tr>
<th>Coding Phase</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of interviews</td>
<td>12</td>
</tr>
<tr>
<td>Episodes analyzed</td>
<td>660</td>
</tr>
<tr>
<td>First cycle coding</td>
<td>79 codes</td>
</tr>
<tr>
<td>Second cycle coding</td>
<td>12 categories</td>
</tr>
<tr>
<td>Second cycle coding</td>
<td>06 themes</td>
</tr>
</tbody>
</table>

Table 2.3 Coding phase
2.5 Searching for, refining and naming themes

The last three phases of thematic analysis consisted of: (a) searching for themes, (b) refining themes, and (c) defining and naming themes. These analytical phases were performed concurrently with the second cycle coding, that is, categories were refined and themes were created as the categories emerging from the second cycle coding were created. The themes were refined and compared among different interviews to understand their data pattern distribution.

The final phase of the thematic analysis was defining and naming themes for analysis. During this phase each theme was defined and quotes were selected from the transcripts to illustrate the main focus of each theme.

According to Braun and Clarke\textsuperscript{49} a theme “captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set” (pg. 82). Thus, the themes represent how the geriatric dental program affected the life of the relatives.

In the next chapter I will describe the themes, discussing how each theme contributes to answer the research question. The reason for combining results and discussion in a single chapter is to create a better flow to understand the results without breaking them into the traditional quantitative report format where results and discussion are presented in separated chapters. Qualitative reports that combine results and discussion in a single section have been previously published (e.g.\textsuperscript{53}).
Chapter 3: Results and Discussion

In this chapter, the six themes that emerged from the thematic analysis are described. These themes are also explained in terms of how they were developed from codes to categories and then to themes. Finally, each theme is described through illustrative quotations derived directly from the data. In addition, at length, and in the context of the research question, a discussion of each theme and the correspondent illustrative quotations is also provided. Ultimately, these themes help to understand how the dental treatment performed for the elderly patient of the UBC Geriatric Dental Program had an impact on the life of the relative. Therefore, through the themes I answer the research question: “To what extent does the UBC Geriatric Dental Program (GDP) impact the lives of elderly patients’ relatives?” The themes found in this research are:

(a) Relatives are concerned about their elderly family member’s oral health;

(b) The Geriatric Dental Program provides good access to dental care services for elderly patients;

(c) The Geriatric Dental Program provides a “dental home” for the elderly patients;

(d) Relatives perceived better oral health for their elderly family members after the dental treatment;

(e) The reputation of UBC gives peace of mind in relation to quality of care; and

(f) The Geriatric Dental Program alleviates stress in the life of the relatives.

5 Twelve quotations are used to illustrate the six themes found on this research. However, this does not mean that only twelve quotations fit the themes
3.1 Theme 1: Relatives are Concerned About Their Elderly Family Member’s Oral Health

A theme that emerged from the analysis was related to family members’ concern about their elderly relatives’ (spouse, siblings, parents) oral health. The evidence for this theme was prevalent when analyzing the interviews as all interviewees indicated this concern; indeed, “concern” was the main motivation for them to search for dental treatment for their relative.

Several instances (i.e., episodes discussed by the interviewees) demonstrated this concern, as exemplified by the following codes:

(a) The caregiver wanted the best for the family member;
(b) The caregiver was concerned about the elderly’s general health; and
(c) The caregiver was concerned about the elderly’s oral health condition.

In addition to those codes, two categories fit under this theme, for a total of 12 codes within them. Table 3.1 presents these categories and the respective codes.

<table>
<thead>
<tr>
<th>Categories</th>
<th>“Oral health of the elderly affecting the caregiver’s life”</th>
<th>“Reasons to look for dental appointments”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Codes</td>
<td>• Feeling guilty;</td>
<td>• Oral issues noticed by the caregiver;</td>
</tr>
<tr>
<td></td>
<td>• Frustration;</td>
<td>• Elderly mentioning about an oral health need;</td>
</tr>
<tr>
<td></td>
<td>• Feeling better;</td>
<td>• The importance of oral health.</td>
</tr>
<tr>
<td></td>
<td>• Need for traveling;</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Effects on working conditions;</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Family disagreements,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Night sleep being affected;</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Responsibility;</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Family gatherings being affected by the elderly’s oral health condition.</td>
<td></td>
</tr>
</tbody>
</table>

Table 3.1 Categories and their respective codes

Figure 3.1 demonstrate the axial relationship of all codes and categories generating this theme.
All codes and the two categories were analyzed and merged into a single theme. This theme represents a more general level in which an assertion about evidence found in the data is made. That is, the theme provides evidence that the family members were indeed concerned about the oral health of their elderly relative based on quotes coded in the transcripts.

The concern for the oral health of family member has been investigated in the pediatric dental literature. Abanto et al. 54 observed that poor oral health conditions in the child resulted in concerns to the parents affecting their quality of life.

A similar concern appeared in our research. In the following quotation Gary, (pseudonym) who is 65 years old, talks about his concern regarding the oral health situation of his 86 year old mother who lives in a long-term care facility.
3.1.1 Quotation 1

Gary: “I have been worried about the oral condition for quite a while, but trying to get her to see a dentist and setting up an appointment was hum, it was difficult to, I guess also for myself just knowing how much the cost would be, and how much time would be required and that stuff, so it was nice to know that UBC was available for my mother, for the work for her to be done”

In this quotation Gary, who accompanies his mother to the GDP, expressed a feeling of concern about his mother’s oral health. He describes that it had been “a while” since he had tried to schedule an appointment for his mother with a private dentist. However, this was not an easy task for him. Although he does not explain why the task of taking his mother to a dentist was difficult, he perceives that after being enrolled in the geriatric dental program the task to find a dentist for his mother became easier. He mentions that with this program (UBC - GDP) he knows beforehand the costs and the number of dental visits that would be necessary to complete his mother’s dental treatment. Other participants also mentioned that after the initial consultation the UBC Geriatric Dental Program would send them a letter describing the oral health findings, treatment options and the estimated costs with the number of necessary dental visits to complete the dental treatment, helping them to make a decision regarding the oral health care of the elderly family member in their care. Furthermore, Gary goes on and explains that just knowing that “UBC was available” for his mother already helped him to deal with his concern for his mother’s oral health.
Some of the caregivers interviewed were so concerned about the oral health situation of their family member that one of them mentions the notions of morality and legality when dealing with the situation of her mother.

3.1.2 Quotation 2

Lisa: “it is so constant that it really infuses itself, you know into your life, and, you know, legally and morally, you know, personally that's what you have to do, but it just becomes infused into your life”

In this quote Lisa (pseudonym), the 66 year old daughter of an 87 year old woman patient from the UBC GD program, states that her concern and feelings of responsibility about her mother’s oral health is so intense that it “infuses” into her life. Lisa mentions that the oral health of her mother is not just a concern, but a moral and legal obligation that she has for her mother. Indeed, good oral health is a person’s right and Lisa mentions it as a personal legal and moral obligation that she has towards her mother.

Oral health as a human right was recently discussed in the “Nairobi Declaration on Oral Health” in Africa, which stated that oral health is an integral part of general health and both are subject to the same determinants of health. On ethical and humanistic grounds, oral health is a human right rather than an entitlement, and a person should be able to have adequate access to dental care services to be able to maintain good oral health status.

Our interviews demonstrated that family members reported various levels of concern regarding the oral health situation of their elderly relatives. This concern is evidence of the impact that the dental needs of elderly family members have on caregivers’ lives. The preoccupation with their relatives’ oral health and especially the difficulties that caregivers may
encounter when seeking appropriate oral health care for their elderly relative is an indication of not only their concern but also how this concern impacts the caregivers’ lives. Thus, even though the caregivers perceived a dental need that required professional care, and even though they were concerned about it, sometimes it was difficult for them to take the relatives to a dental professional to receive the appropriate dental care. However, the existence of the UBC GD Program provided good access to dental care services for this population and worked as a “safety net” for them. The next theme found in this research exactly describes this situation.

3.2 Theme 2: The Geriatric Dental Program Provides Good Access to Dental Care Services for Elderly Patients

The difficulty in finding dentists who accept or that were knowledgeable about treating frail elderly patients was a concern that arose from the interviews. All interviewees mentioned this issue, also pointing out that the geriatric dental program provided good access to dental care services for their elderly family members.

This theme emerged from the following codes:

(a) Going to the dentist before the GDP;
(b) Wheelchair accessibility;
(c) Close location to home;
(d) Specialized care;
(e) There are physical resources at UBC;
(f) Handy dart availability;
(g) Onsite visits done by GDP; and
(h) Easy in making appointments at GDP.
The codes b to h led to the development of a category named “Easy access”.

Further, the following codes led to the development of a category named “Difficulties related to dental care services before the UBC GDP”, which was also included within this theme:

(a) Losing hope in the system;
(b) Difficult to find a dentist outside the UBC GDP; and
(c) Taking time off work.

All of the codes and the category were merged into a more general statement that created the second theme presented in this thesis: “The geriatric dental program provides good access to dental care services for elderly patients”. Figure 3.2 exemplifies the codes and categories under this theme.

Figure 3.2 codes and their relationships

The use of the word “access” in this thesis follows the definition of access by Penchansky and Thomas\textsuperscript{56} who define access as a degree of fit between the client and the system. This fit
encompasses five dimensions: (a) availability, (b) accessibility, (c) accommodation (d) affordability and (e) acceptability\(^5\). These dimensions are also called the 5 A’s of access.

A simplified way to describe these components is that *availability* is related to the number of available dentists, that is, the supply of dentists. *Accessibility* is the location of dentists (supply) relative to the location of patients, that is, distance/transportation to dentists. *Accommodation* refers to how easy it is to get an appointment and is influenced by working hours, walking services, and telephone services. *Affordability* includes methods of payment, acceptance of dental insurance and the possibility of making payments in installments. *Acceptability* is related to the “provider attitudes about acceptable personal characteristics” of patients (pg. 129).

The next quote is an example of how the UBC GDP provided adequate *availability* and *accessibility* for its patients. Mary (pseudonym) (54 years old) talks about her experience of bringing her 88 years old mother to the UBC GD program.

### 3.2.1 Quotation 3

Mary: “in having somebody to go to do the basic checkup just to check her teeth at her geriatric house, then that means that I do not have to take four hours off (work)”

Mary is concerned with the oral health of her mother, however, she works many hours per day, as she told us later on the interview. She tell us that taking her mother to the dentist affects her work schedule and she would need to take four hours off work. In this quote, Mary explains to us that just “having somebody” to check the teeth of her mother at the LTC helps her, because she does not need to stop working to take her mother to the dentist. In fact, later on during the interview, Mary mentions that because she had taken her mother to UBC on that day
she would need to work until late that night to compensate for the time spent away from work. Although, she knows that eventually she will need to bring her mother to the UBC dental clinic, she is thankful that the UBC GDP personnel do site visits at the geriatric home. Those visits will act as a triage and then she will decide when she needs to take her mother to the dental clinic. In this sense, the UBC GDP provided adequate availability and accessibility for her mother because she had available dentists to look for her mother’s oral health at a convenient location – her mother’s geriatric house.

Other aspects of access to dental care services were also mentioned during the interviews. Accommodation was one of them, exemplified by the quote from Margaret (pseudonym), a 71 years old woman who brings her blind sister (73 years old) to the program.

### 3.2.2 Quotation 4

Margaret: “it takes care of me having to be the initiator of appointments for my sister”

In this quote Margaret (pseudonym) mentions that the program helps her find dental care for her sister. She tells us that the program is the initiator in making the appropriate arrangements for her sister’s dental appointment. This quote is an example of accommodation because the program deals with the issues of scheduling appointments for patients. As a matter of fact, many other participants mentioned that making appointments at the UBC GDP was very easy, and that the staff members were always willing to accommodate changes in the schedule according to the caregiver’s needs.

Acceptability was reported as excellent by the caregivers and all of the interviewees mentioned that the UBC GDP staff members treated them very well.
Nevertheless, few caregivers mentioned that the cost of dental treatment was higher than private dentists. However, all of them were able to afford the costs of the program. The majority of them were not concerned with the higher fees because they were looking for quality of care. Although the program’s higher fees were mentioned and could be considered a barrier to services for this elderly population, because this topic was not frequently discussed during the interviews and because the aim of this research was not related to financial issues, a hypothesis related to cost of treatment was not further explored.

In general it can be concluded that the UBC GDP provided good access to dental care services for elderly patients, and is one model for improving access to dental care for this geriatric population. Therefore, another way in which the program positively affected the lives of caregivers was by providing access to dental services to their relatives, saving precious time the caregivers would have otherwise spent searching for private dentists and taking their family members to consultations outside of the long term care facility. However, providing access to dental care services is not the only need of this population. In addition to providing access, the program should provide a sense of safety and security for the caregivers, especially when they need to take their relatives to a dentist. This issue is exactly what the next theme describes.

3.3 Theme 3: The Geriatric Dental Program Provides a “Dental Home” for Elderly Patients

Dental safety net clinics are clinics that provide dental care services for an underserved population. These clinics might be viewed as a strategy to improve access to dental care services for that specific population. Usually these clinics are affiliated with a social service agency or a dental school.
Through the analysis of the interviews, it became evident the UBC GDP program might act as a safety net or “dental home” for the caregivers. This conclusion came after analyzing the following codes:

(a) Good dentist-patient relationship;

(b) Caregivers know where to go if a dental issue happens;

(c) Peace of mind;

(d) Caregivers are satisfied with the UBC GDP;

(e) It is easy to make appointments at UBC GDP; and

(f) Caregiver is gaining hope in the system again.

Three other codes were separated and resulted in the emergence of the category “Difficulties faced by the caregivers before the UBC GDP”:

(a) It is difficult to find a dentist “outside”;

(b) Losing hope in the dental care system; and

(c) Need to take time off work.

After analyzing these codes and merging them, the theme “The Geriatric Dental Program Provides a “Dental Home” for the Elderly Patients” emerged. Figure 3.3 demonstrates the codes and categories developed under this theme.
The next quote describes how Mary, already cited on the previous section, feels about the UBC GD program. What she says exemplifies how the program could be seen as a dental home (safety net) program for a caregiver.

### 3.3.1 Quotation 5

Mary: “it takes away the guilt, now I know, because teeth is a credible part of her health and I know that if they are not being taking care of it will affect the whole body system so the guilt about where do I take her, and not having looked to it, the fact that I know now, it will allow me to bring her around here if there is a problem again”

In this quote Mary mentions how the dental program takes away her guilt of not knowing where to take her mother if a dental problem happens. She understands now that oral health is an integral part of general health.
For Mary an oral health problem needs to be addressed as she recognizes the relationship between oral health and general health: “if they are not being taking care of it will affect the whole body system”. Thus, as soon as Mary is aware of an oral health problem (“now I know, because teeth is a credible part of her health”) she believes that it needs to be addressed, and in her case, just knowing where she can take her mother removes her feelings of guilt (“it takes away the guilt”).

Mary’s quote, specifically at the end, illustrates that the dental program could be considered a dental home for the persons who participate in it because it takes away the burden of the caregiver by providing a sense of security about where to take their relative if a problem arises again. As a consequence, this program might not only be improving the oral health of the patients but it also may be alleviating the stress in the life of the caregivers, two themes that will be described later in this thesis.

In the next quote Gary is again talking about his mother’s oral health; he also suggests that the UBC GDP is a safety net for him.

3.3.2 Quotation 6

Gary: “it is just good knowing that you’re going to a place that seems to be caring, that seems to care about a mother who has been, who is a senior, who is struggling, has fears, and for some reason, I have a good feeling that you received, that the facility will do well in dealing with her concerns”

In this episode Gary (pseudonym) confirms that the program transmits some sense of security to him. He believes that the program will treat his mother well and in the correct manner. In this sense, the clinic is acting as a safety net for him or dental home for his mother.
He also mentions that the clinic “seems to be caring”, which is a recurrent statement for all interviewees, who perceived that the program was “caring” and improving the oral health of their elderly relatives. Thus, the emergence of the next theme, “caregivers perceived a better oral health for their elderly family member’s after the dental treatment”.

3.4 Theme 4: Relatives Perceived Better Oral Health for their Elderly Family Member’s After the Dental Treatment

The interviewees mentioned that the program improved the oral health situation of their elderly family members. Because I did not analyze the dental charts of the patients, and I did not have objective measurements regarding oral health before and after dental treatment, I can only refer to oral health of the elderly as perceived by the relatives (caregivers) as having improved.

The following codes were included in this theme:

(a) Better eating habits after the dental treatment done at UBC GDP;

(b) Better oral health after dental treatment done at UBC GDP;

(c) Treatment received at UBC GDP

A unique code “good experience with the UBC GDP” led to the development of a category named “caregivers are happy with the UBC GDP”. Another category named “bad oral health experience before dental treatment” was also developed from the following codes:

(a) Elderly mentioning about oral health issues;

(b) Elderly changing eating habits;

(c) Elderly not complaining about oral health;

(d) Oral health situation before dental treatment.
Merging all codes and categories led to the development of a general idea (theme) named “Relatives perceived better oral health for their elderly family member’s after the dental treatment”. Figure 3.4 demonstrates the codes and categories developed under this theme.

Figure 3.4 Codes and their relationships

In the next quote, Lisa (pseudonym) describes how UBC GDP improved the oral health situation of her mother.

3.4.1 Quotation 7

Lisa: “because she got, you know, a full set [of dentures], and she is smiling, and she looks like a little bit more back to her standards”

In this quote Lisa describes how the dental treatment changed the way her mother behaved. Lisa described previously during the interview that her mother’s dentition started to
deteriorate and completely changed her appearance, but she was not sure how this dental problem affected her mother. However, after her mother received her dentures at the UBC GDP she started to notice that her mother started to smile again and she was looking “more back to her standards”.

The World Health Organization (WHO) defines health as a state of complete physical, mental and social wellbeing, that is, oral health is not necessarily the absence of disease or infirmity, but a physical or mental state that a person feels well\textsuperscript{58}. Although there are many definitions of oral health\textsuperscript{59, 60} Locker\textsuperscript{61} mentions that oral health is mainly defined by the reductionist view that oral health is the absence of disease in the mouth rather than focusing on the social aspects that an oral health problem may bring to a person, such as the ability to eat, smile, and socialize with others in their community. If we follow a more sociological view of oral health it can be argued that the new “full set” of dentures that Lisa’s mother received improved her social and psychological condition because now she is smiling and looking “a little bit more back to her standards”, that is, her dental treatment improved her oral health and now she is socializing better than before.

Other caregivers discussed better physical wellbeing of their relatives after the dental treatment done at the UBC GDP. For example, Hannah (pseudonym) (52 years old) describes how the dental treatment took away the pain that her father (86 years old) was experiencing.

3.4.2 Quotation 8

Hannah: “as soon as, he was already being treated for the abscess so he obviously, he did not feel the pain, but his health was improved after the first time that we were here”
This quotation gives a classic example of how dental treatment affects and improves the oral health of a person. Here Hannah mentions that after her father received appropriate care his pain disappeared and his health improved.

The episodes described by the relatives demonstrate how they perceived an improvement in the oral health of their elderly family members after the dental treatment. Inasmuch as the oral health situation of their elderly family member is a concern to the relatives (as evidenced in the first theme presented earlier), having the perception of improvement in their elderly family member’s oral health is a positive impact that the UBC GDP program has on the relatives’ lives. Furthermore, this perception of improvement in the oral health of the elderly family members is linked to a sense of security that UBC GDP program transmits to the relatives. This sense of security led to the development of a new theme that will be described next: “The reputation of UBC gives peace of mind in relation to quality of care”.

### 3.5 Theme 5: The Reputation of UBC Gives Peace of Mind in Relation to Quality of Care

This theme relates to the sense of security that the dental program gives to the relatives (caregivers). This sense of security happens because of the good reputation UBC has in the community. The emergence of this theme unfolded through the analysis and combination of the following codes:

(a) Caregivers are impressed by the UBC facilities; and

(b) Caregivers in general are not concerned with costs.

Other codes were combined into a more general category “caregivers trust UBC”:

(a) Teaching facility;

(b) Specialized care;
(c) There are resources at UBC;
(d) There is a plan;
(e) There is good quality of care;
(f) There is communication with medical staff.

Furthermore, two other codes were merged to create a category that explains the motives the relative had in taking their elderly family member to the UBC GDP: “Reasons to go to GDP”. These codes were:

(a) Specialized care;
(b) UBC reputation.

When I analyzed and combined all of these codes and category I developed the theme “The reputation of UBC gives peace of mind in relation to quality of care”.

Figure 3.5 illustrates the codes and themes in a vertical relationship giving the emergence of a theme.

Figure 3.5 Theme UBC reputation gives peace of mind in relation to quality of care and its categories and codes
The next two quotes exemplify how UBC’s reputation gives peace of mind to the relatives. In the quotes, Bob (pseudonym), 56 years-old brings his 81 year-old mother to the program and explains that because this “specialized program” is connected to an educational institution it gives him peace of mind in relation to the standard of care.

3.5.1 Quotation 9

Bob: “Now just knowing that it is a geriatric specialist program makes me feel that I am giving my parents the best that I could, that I have found something, you know, that is the best fitting to the age group and needs (...) absolutely, being a teaching facility”

3.5.2 Quotation 10

Bob: “you know, probably into the degree that I suppose if there is any doubt that, you know, that I made the right or wrong choice for dentist, again, citing that this is a specialist for geriatrics we save a lot of debate about whether we should go to this person or not or that person, it is kind of my insurance, my mental insurance, that I do not have to justify having secured a good doctor or bad dentist, but this is a reputable specialist, what else can you want? (laughs)”

As evident in these quotes, Bob tells that he believes he is providing the best that he can to his mother to care for her oral health, mainly because the program is affiliated with a teaching facility and the dentists are specialists “for dental geriatrics”. Although there are no specialists in
dental geriatrics in Canada, he and many other interviewees think that the dentists in this program are specialists in geriatric dentistry.

In his second quote (quotation 10) he mentions that other persons can argue or make judgments about his decision of bringing his mother to the program (“if there is any doubt that, you know, that I made the right or wrong choice for dentist”). However, he assures himself that he is doing the correct thing as soon as he recalls UBC reputation and its specialized care (“citing that this is a specialist for geriatrics we save a lot of debate (…) it is kind of (…) my mental insurance, that I do not have to justify (…) this is a reputable specialist”).

Indeed, all interviewees related some aspect of the quality of the dental treatment with UBC’s reputation which provided a sense of security to the relatives. Many of them were impressed by the UBC dental clinic facility and the resources that were available. They were also impressed by the ease that existed in the communication between dental and medical specialists from different fields.

In some aspects, this sense of security or “peace of mind” also contributed to alleviating the stress that the relatives had in relation to the oral care of their relatives. Their decision to enroll their family members into the program was justified not only by the convenience related to making appointments and consultations (already discussed in previous themes) but it was also justified in terms of the excellence of the program. The dentists participating, who the relatives see as specialists in elderly care, and the infrastructure and resources available to their elderly family member were examples of excellence. The next theme further expands how this recognition of the UBC GDP as a reputable program positively impacts the lives of the relatives.
3.6 Theme 6: The Geriatric Dental Program Alleviates Stress in the Life of the Relatives

All relatives (caregivers) had a sense of responsibility for their elderly family member. This sense of responsibility together with personal issues and daily activities created some level of anxiety and stress in the life of the relative. Analyzing the interviews, it became evident that, to some extent, the UBC GDP helped to alleviate the stress in the life of the relative.

The codes that were merged to create the theme “the geriatric dental program alleviates stress in the life of the relatives” were the following:

(a) Feeling of security;
(b) Peace of mind;
(c) Less burden;
(d) They know where to go;
(e) Predictability;
(f) Feeling better;
(g) GDP reduces the stress.

Figure 3.6 illustrates the codes and themes in an axial relationship giving the emergence of a theme.
Figure 3.6 Codes and their relationships

In the next quote, Hannah (pseudonym) details how a better oral health situation for her father alleviates one of the concerns that she has in her life. As theme 1 demonstrates, the relatives are concerned about the oral health situation of their elderly family members, and, as the next quote will demonstrate, the program alleviates this concern by reducing the stress in the life of the relatives.

3.6.1 Quotation 11

Hannah: “I don’t have to worry about him having an abscess, I don’t have to worry about having anything going septic, I don’t have to worry that his nutrition is a big thing instead of trying to find substitutes like boost, he can eat food that he previously enjoyed, I know that he can eat and now he will be able to chew”

In this quote Hannah describes how her father’s oral health problem brings stress to her life; she worries about her father having an infection due to a dental problem or that her father
will not be able to eat properly. In this sense, because now she has the help of the UBC GDP she can be less concerned about those issues, that is, the dental program alleviated the stress she was experiencing.

The next quote is from a 61 year-old woman, Judith (pseudonym), who brings her 91 years old father to the program. In this example, Judith tells how the program acts as an “assistant” in her life.

### 3.6.2 Quotation 12

Judith: “it is like having an assistant, you know, somebody helping you, it is someone lending you a hand, giving you a hand to, helping you, because when you take care of an older person there is always something going on, you know, they have back pain, or they are not eating well (…) so the fact that here, this part of it is seen, it is so easy compared to everything else, it is a helping hand, and the people are very friendly”

In this episode Judith describes that when a person takes care of an elderly person there are so many issues that need to be looked after in addition to their dental care (“there is always something going on, you know, they have back pain, or they are not eating well”) that the concern for the elderly’s wellbeing can be related to many other things such as food intake and pain. However, the dental program is providing some help for her as she mentions “it is like having an assistant you know, somebody helping you, it is someone lending you a hand, giving you a hand to, helping you”. With the assistance that she receives from the dental program her concern and stress is relieved at least in relation to dental care “so the fact that here, this part of it is seen, it is so easy compared to everything else, it is a helping hand”.

46
As described previously, a dental problem affects the life of the relatives, because they are concerned with the oral health situation of their elderly family members. When the program provides what the relative seeks for their elderly family member the stress that they have regarding the oral health component in their life is reduced. This reduction in stress will consequently affect the life of the relative in a positive way. In fact, many relatives introduce the notion of happiness to the interview. They mention that because their elderly family members are happier with the dental treatment, they (relatives) also become happy.

The theme “the geriatric dental program alleviates stress in the life of the relatives” demonstrated a powerful function that the UBC GD program provides to relatives’ lives. As demonstrated in the previous quotation, a person who is a relative has many responsibilities, and any support from a reputable source, such as UBC, can help alleviate the difficulties that a relative encounters.
Chapter 4: Conclusions, Limitations and Implications

4.1 Conclusions

This research investigated how having access to dental treatment by the UBC GDP for the elderly affected the lives of their relatives. Using a semi-structured interview questionnaire, I interviewed relatives who signed the consent forms for dental treatment of the elderly in the UBC GD program. The interviews were audio recorded and analyzed using qualitative research methods aiming at answering the following research question:

“To what extent does the UBC Geriatric Dental Program (GDP) impact the lives of elderly patients’ relatives?”

After coding and analyzing all interviews using thematic analysis I concluded that the UBC GD program indeed has a positive impact on the life of the caregivers.

There were many ways in which the program had a positive impact on the life of the caregivers. This positive impact was mainly because the relative was worried about the elderly family members’ oral health situation, which brings a level of stress to relatives’ lives. However, knowing that they have a place to take their elderly family members if a dental problem arises alleviates this concern. Relatives then focus on other aspects of their life or on other aspects of the life of their elderly family member. As Judith mentioned (Quotation 12), “there is always something going on (...) they have back pain, or they are not eating well”.

Taking care of an elderly person is not an easy task, and the presence of the UBC GDP provides the relatives a sense of security, a sense that somebody is also looking after their elderly family members. Thus, the sense of responsibility of taking care of somebody becomes shared between the relatives and the UBC GD Program. Sharing responsibility in dentistry is something that happens daily, and Cultural Historical Activity Theory has already been used to demonstrate
how the sharing of responsibility of dental treatment is divided between the student, patient and clinical supervisor in the dental school practice. That is, Cultural Historical Activity Theory demonstrates how the legal and moral responsibility towards the dental treatment of a patient in the dental school is shared among the dental student, clinical professor, and patient, and how this responsibility changes after the dental student graduates, in which it becomes shared more toward the dentist and the patient. In this research we observed the responsibility for oral health being shared by the UBC GDP and the relative rather than only UBC GDP and elderly patient, or relative and elderly patient. Thus, providing a sense of security for the relatives.

All the themes are connected and one led to the other. However, it is interesting to note, that although the themes seem to follow a linear progression they are all intertwined and are similar in many aspects, figure 4.1 explains the relationship among the different themes.
Figure 4.1 Relationship among different themes

Figure 4.1 demonstrates that a relative is concerned about the oral health situation of the patient (elderly person). The UBC – GDP provides good access to dental services for the elderly acting as a “safety net” for the relative, i.e. “dental home” for the elderly person. The program is perceived as a “dental home” providing “peace of mind” for the relative. When the elderly patient accesses the program, i.e. receives dental treatment, relatives perceive an improvement on the oral health of the elderly. This improvement in the oral health was influenced by the “peace of mind” effect and by the UBC’s good reputation. As a consequence, relatives might become less stressed about the oral health of the elderly family members creating a loop that will affect the perception that the program provides a safety net for the relative if a future visit is necessary.
4.2 Study Limitations

In terms of recruitment of participants, this research has the potential following limitations: (a) the interviewees may not have disclosed any problems they encountered with the UBC GDP; consequently the results from the research are skewed and may be overwhelmingly positive; (b) the caregivers who participated in the interviews might be only those who are satisfied with the program; and (c) there is no interview with caregivers who did not accept to have treatment in the program. In the next paragraphs I will address each of these potential limitations and elaborate on the study merits despite these potential limitations.

4.2.1 No disclosure of problems by the caregivers: consequently the results are too positive

The argument that this research describes only positive results about the UBC GD Program is true but it might be refutable for two reasons. First, the findings reported here are based on data exactly as it was reported during the interviews with participants. Although in qualitative studies the aim is not generalization to a larger population, the rigorous methods employed to code and analyze the data ensured that these themes reflected the contributions of the participants. In the interview questionnaire, the questions provided opportunity for participants to either report problems and to report absence of problems; the fact that all participants referred to similar ways in which the program enhanced their lives is a strong indication of the positive impact of the program.
4.2.2 The caregivers who participated in the interviews might be only those who are satisfied with the program

The recruitment of participants followed purposive sampling but all participants invited to participate in this research were those whose family members were scheduled for a dental appointment on a specific day, according to the researcher’s availability. Thus, insofar as the available days were dictated by the researcher’s schedule, and that all patients’ caregivers for each specific available day were contacted, the selection of participants was not biased towards any particular characteristic of the participants. From all the contacted persons, only two declined to participate in this research; one declined right before the beginning of the interview because she decided not to spend time doing the interview, and the other one declined for unknown reasons during the telephone conversation. Therefore, participants could be satisfied or dissatisfied with the program and there was no pre-selection of satisfied caregivers only. Thus, there might be no evidence to support the claim that only satisfied caregivers would participate on this research.

4.2.3 No interviews with caregivers who did not have treatment at the program

Certainly, interviewing caregivers who did not participate in the UBC GD program is an interesting suggestion for future research. However, my research question is related to caregivers who attended this program and not to the ones who did not attend. Thus, interviewing the caregivers who did not accept dental treatment as part of this program would not be consistent with the research question.
4.3 Validity of the results

Validation for this research was done following some points of Guba and Lincoln’s Trustworthiness Criteria\textsuperscript{63}. This approach to judge the validity of qualitative research makes a parallel with quantitative research validity methods. For example, \textit{credibility} is the qualitative equivalent of internal validity, \textit{transferability} is the qualitative equivalent of external validity, \textit{dependability} is the qualitative equivalent of reliability check, \textit{confirmability} is the qualitative equivalent of objectivity.

To achieve \textit{credibility} (the qualitative equivalent of internal validity)\textsuperscript{63}, I strived to keep my interpretations as close as possible to the participant’s original views and meanings. I used quotations with their own words to analyze the data and to create themes that reflected these words. In addition, I used \textit{progressive subjectivity} creating an \textit{audit trail} of the progress of the data analysis, interpretation, and conclusions using a \textit{logbook}; in this research the post-interview forms worked as my logbook. That is, right after each interview I recorded the interpretations of the data using the post interview form to compare the interpretations of one interview with the subsequent interview. This creates a logbook demonstrating the evolution of data interpretation throughout the data analysis process. I did not use member check to achieve credibility because research participants may not be the best ones to confirm or deny the interpretations of the results. Member check may lead to conflicts between the interpretations of a researcher and a layperson. However, any time that I had a doubt about something discussed during the interview I asked the respondent to clarify. As a matter of fact, problems with member check technique have been described on the literature by Morse et. al.\textsuperscript{64} “The problem of member checks is that, with the exception of case study research and some narrative inquiry, study results have been synthesized, decontextualized, and abstracted from (and across) individual participants, so there
is no reason for individuals to be able to recognize themselves or their particular experiences” (pg.7).

*Transferability* (the qualitative equivalent of external validity) was achieved because I provide detailed information about the research using *thick descriptions* of the themes\(^{65}\), using illustrative quotes from the transcripts, including information from the dental program context and its participants. In this sense, readers can decide if my results can be transferred or not to other contexts or settings.

The *dependability* (the qualitative equivalent of reliability) was achieved through verifications of the raw data (audio) comparing to its orthographic transcriptions to ensure accuracy of the data sources. Furthermore, the use of quotes was used to illustrate all findings of this study.

The *confirmability* (the qualitative equivalent of objectivity) was assured through the documented rigorousness of the interpretive and analytical process, that is, the coding. To achieve integrity of the findings, the findings were rooted in the data itself, and excerpts from the dataset substantiated all conclusions and assertions in this study. In this manner, a reader is able to follow the study interpretations confirming or disconfirming them.

### 4.4 Implications

Many implications can be drawn from this study. These implications can be related to future research, or research agencies, or more specifically to dental care professionals. For example, this research addressed many points of the Canadian Institutes of Health Research (CIHR) Knowledge Translation initiative.
According to the Canadian Institutes of Health Research, knowledge translation is a “dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge”66. To some extent this research project addressed some of the sectors that the Knowledge Translation Module targets: a) synthesis was made by a narrative synthesis (review of the literature) of the impact of dental care services on the caregiver’s life; b) dissemination was achieved by exposing the research findings to the scientific community during my participation in local and international conferences; c) exchange was achieved by the interaction between the researcher and the knowledge user (administrators of the program) aiming at exchanging knowledge for mutual learning; d) ethically-sound application of knowledge was done following strict ethical guidelines and always taking the research participants’ needs first.

In addition to the knowledge translation implication this research has further implications for: (a) health professionals, (b) dental schools/students, (c) LTC administrators, (d) dental program administrators, and (e) future research.

Health professionals may benefit from the findings, which provide evidence of the impact of oral health related issues on the life of caregivers of elderly persons in long term care facilities. As a direct application of this knowledge, health care professionals may advocate for better access to dental services for this elderly population, by demonstrating that dental treatment will directly affect not only the life of the elderly but that of his her entire family, particularly the caregiver.

Similarly, dental schools and curriculum designers may use the results of this research to aid in the development of dental curricula that address issues of dental care services for the elderly in Canada, thus preparing future dentists to be aware of these phenomena. LTC
administrators benefit from the findings of this research because it demonstrates the importance of dental care services for their clients. And finally, dental program administrators may take advantage of the results of this research to develop mass-scale quantitative surveys to verify the importance (or satisfaction) of the program. In this sense, this research creates topic/themes that can be used to develop structured questionnaire questions in quantitative research; these questionnaires can be applied in a representative study population using statistical methods.

4.5 Final Thoughts

As a result, this study concludes that relatives are concerned with their elderly family members’ oral health, and the UBC Geriatric Dentistry Program provided good access to care becoming a “dental home”. The relatives perceived that the oral health of the elderly family member was improved. UBC’s reputation gives peace of mind in relation to quality of care and alleviated the stress on the life of the relatives. Therefore, this study shows that the UBC GDP not only improved the perceived oral health and provided access to dental care services for the elderly, but also impacted the relatives’ life in a positive way.
References


Appendices

Appendix A  Papers Selected From the Literature Review

This bibliographic section represents the 77 papers included on the literature review. Not all of them were cited on the thesis due to the length of this thesis. The cited papers cited on this thesis are cited as “references”.

These are not the references used in the thesis:

<table>
<thead>
<tr>
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<th>Journal/Journal Details</th>
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<tr>
<td>Assessment of oral health status and treatment needs of elders associated with elders' homes of Ambala division, Haryana, India.</td>
<td>Indian Journal of Dental Research 2010;21(2):244-7.</td>
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<td>Gerritsen PFM, Cune MS, van der Bilt A, de Putter C.</td>
<td>Dental treatment needs in Dutch nursing homes offering integrated dental care. Special Care in Dentistry 2011;31(3):95-101.</td>
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<td>Martin KU, Martin JO.</td>
<td>Meeting the oral health needs of institutionalized elderly. Dysphagia 1992;7(2):73-80.</td>
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<td>Sheiham A, Steele J.</td>
<td>Does the condition of the mouth and teeth affect the ability to eat certain foods, nutrient and dietary intake and nutritional status amongst older people? Public Health Nutrition 2001;4(3):797-803.</td>
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<td>Soh G, Chong YH, Ong G.</td>
<td>Dental state and needs for episodic care of institutionalized elderly in</td>
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Appendix B  Pre-Screening: telephone script and pre-interview form

1- Introduce you as a UBC Staff. “Hello Ms/Mrs Y. Here is X (the caller already knows the family member), from the UBC geriatric program in the Faculty of Dentistry.”

2- There is a research project that is looking to talk to immediate family members of elders who live in LTC facilities and who have received dental treatment from the program in the last year. The aim of the project is to understand how the dental care treatment offered through the program may have influenced the life and health of your (family member – husband/wife – father/mother) and to some extent how this influenced your life.

3- They would like to meet people and discuss this topic face-to-face with them. These discussions are audio-recorded and very informal. This could be held at any place that you want; however, if you cannot meet them they could call to your landline and talk over the phone. There is no dental examination, it is only an interview. That takes approximately 45 minutes.

4- You can withdraw from the research at anytime and you do not need to answer all the questions, and this will not affect the ability of the participation of your family member in the GDP dental program. If you decide to participate on the interview they will provide you a compensation of $100, a part of this should be allocated to the patient’s comfort funds and the other part is to cover the costs of your time spent doing the interview.

5- Would you be willing to participate?

If yes. Good! But to participate we only need to check if you are eligible for the research and we would need to see if you fit some criteria (Explains the criteria).

If the person meets the criteria the staff will ask permission to the family member to share the contact information with the student researcher; thus, the student researcher can contact the
person to schedule the interview at a time and location that is more appropriate for the participant.

Pre—interview form (next page)

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<td>At least 1 dental appointment in the last year: ☑ YLS</td>
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<td>Place of residency (Greater Vancouver): ☑ YLS</td>
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<td>Location:</td>
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</table>
Appendix C  Consent Form

Title of the Study: Exploring the views of elderly patients’ family members on the impact of the UBC Geriatric Dentistry Program on the Family Life and Health.

I. STUDY TEAM

Principal Investigator: Dr. Christopher Wyatt, Department of Oral Health Sciences, Faculty of Dentistry. Telephone: 604-822-1778.

Co-Investigator: Diego Machado Ardenghi, MSc/Diploma in Prosthodontics Graduate Student, Faculty of Dentistry and Graduate Studies, UBC. Telephone: 604-827-0577.

This research is for a Master of Science degree and it will be part of a thesis.

II. SPONSOR

The study is being funded by internal funds from the UBC Faculty of Dentistry.

III. INVITATION AND STUDY PURPOSE

You have been invited to take part in this study because you have a family member who is a patient on the UBC Geriatric Dentistry Program (GDP). We want to learn more about how the UBC GDP positively influences the life of patients’ family members.

IV. STUDY PROCEDURES

If you say “Yes, I want to be in the study”, here is how we will do the study: we will invite you to participate in an interview, in which you and a researcher will meet or talk over the phone during a time convenient for you and previously agreed upon. The interview should take approximately 1 hour. If you find that this period is too long, we will offer to shorten the interview and to continue it on another day, at your convenience. Since it is impossible for the researcher to take notes of everything you say during the interview, the interview will be audio
taped for transcription. During the interview, the researcher will ask questions related to your family member health, past and present experiences with health care, and how the UBC GDP specifically influenced the life of your family. You may decline answering any particular question, as you wish.

V. STUDY RESULTS

The results of this study will be reported in a graduate thesis and may also be published in journal articles and books.

POTENTIAL RISKS OF THE STUDY

We do not think there is anything in this study that could harm you or be bad for you. Some of the questions we ask may seem sensitive or personal. You do not have to answer any question if you do not want to.

VII. POTENTIAL BENEFITS OF THE STUDY

Although you may not perceive an immediate benefit from participating in this research, we ultimately aim to improve the UBC GDP for its patients and family members. Thus, you may be indirectly helped by this study.

__________________________________________________________________________

Subjects’ initials               Date
VIII. CONFIDENTIALITY

Your confidentiality will be respected. Any reference to information collected during the interviews will be made in a manner that guarantees your anonymity. The transcripts of the interview will not contain any names, not yours or that of the people or places you mention during the interview, to avoid recognition. Subjects will not be identified by name in any reports of the completed study. Data records will be kept on a password protected computer hard disk. Information that discloses your identity will not be released without your consent unless required by law. At any point in the study, if you reveal that there has been an incident that involves abuse and/or neglect of a child or an elderly person (or that there is a risk of such occurring) please be advised that the researcher must, by law, report this information to the appropriated authorities.

IX. PAYMENT

A compensation of $100 Canadian dollars will be offered to you to cover costs, such as transportation and food. You will receive this compensation at the end of the interview.

X. CONTACT FOR INFORMATION ABOUT THE STUDY

If you have any questions or concerns, please contact the principal investigator of the study listed at the top of the first page of this form.

XI. CONTACT FOR COMPLAINTS

If you have any concerns about your right as a research subject and/or experiences while participating in this study, you may contact the Research Information Line in the UBC Office of Research Services at 604-822-8598 or if long distance e-mail RSIL@ors.ubc.ca or call toll free 1-877-822-8598.

XII. PARTICIPANT CONSENT AND SIGNATURE PAGE
Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to withdraw from the study at any time without giving a reason and without any negative impact on the participation of your family member on the UBC GDP.

- Your signature below indicates that you have received a copy of this consent form for your own records.
- Your signature indicates that you consent to participate in this study.

________________________________________________________
Participant Signature                                                        Date

________________________________________________________
Printed Name of the Participant signing above
## Appendix D  Receipts

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Christopher Wyatt, Diego Ardenghi  
Faculty of Dentistry  
UBC |

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<th>DATE:</th>
<th>DESCRIPTION</th>
<th>AMOUNT</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Interview participation</td>
<td>$100.00</td>
</tr>
<tr>
<td></td>
<td>“I have received $100 as compensation for my time in taking part in this interview”</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Signature: ____________________</td>
<td></td>
</tr>
<tr>
<td></td>
<td>TOTAL</td>
<td>$100.00</td>
</tr>
</tbody>
</table>
Appendix E  Interview Protocol

Semi-Structured Interview Protocol:

Oral Health condition
1- Could you please describe how was the oral health condition of your spouse/partner/parent [“the patient”] immediately before s/he started the oral health program? [Probe: functioning, food intake, speaking, pain, discomfort, use of medication, worries about teeth/oral health]

2- What dental treatment did your relative undergo on the program?

Access to dental care services
3- How did the patient accessed dental services before?

Program related questions
4- Why did you choose to have your relative participating in the program rather than visiting an outside dentist?

Impact of the dental care service on the patient and family
5- How was your and yours (father/mother/husband’s) experience before/during/after the dental treatment?

6- If there was no dental treatment from UBC would you have to take time off work to deal with the dental condition of your (husband/father)? (Adapted from Family Impact Scale)

7- Does that oral condition required more attention from you? (Adapted from Family Impact Scale)
8 – Has your sleep been disrupted because of your (husband/father) oral health condition?  
(Adapted from Family Impact Scale)

9- Have your family activities been interrupted because of the dental conditions of your  
(husband/father)? (Adapted from Family Impact Scale)

10- Have you been upset or worried because of the dental conditions of your (husband/father)?  
(Adapted from Family Impact Scale)

11- Has your father/husband’s dental problems caused disagreement or conflict in the family?  
(Adapted from Family Impact Scale)

12- Did you notice any changes in the life or health of the patient after the dental treatment?  
Could you please describe these to me?

13- Do you think these changes have an impact in any way on your life and/or health? How?  
Why? Please, give examples. [Probe: family activities, time, emotions and feelings, finances]

Program related questions:  

14- How would you and/or the patient evaluate this program? Why? Could you please give me  
examples?

15- Is there any aspect of the program that you would like to be different? Why?

Note: These questions are guiding questions only; the specific words used and the order in which  
the questions are asked may vary slightly depending on the interviewees’ answers to previous  
questions. Moreover, these questions work to introduce topics during the interview, but other  
questions will probably be asked, to clarify the respondents’ answers and to ask for specific  
examples or elaborations on a particular answer. These follow-up questions are expected but
cannot be anticipated, as they are dependent on the interviewees’ answers, and therefore are absent from this interview protocol.
## Appendix F  Post Interview Form

### Post interview form

<table>
<thead>
<tr>
<th>Interview #:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Name of interviewee:</td>
<td></td>
</tr>
<tr>
<td>Gender:</td>
<td>M / F</td>
</tr>
<tr>
<td>Relationship with patient:</td>
<td></td>
</tr>
<tr>
<td>OK for follow-up?</td>
<td>Y / N</td>
</tr>
<tr>
<td>(ie. via phone, email, interview)</td>
<td></td>
</tr>
<tr>
<td>If no, reason:</td>
<td></td>
</tr>
</tbody>
</table>

### Interview coordinates

<p>| Location:            |                                           |
| Date:                |                                           |
| Time of interview:   | From: to:                                 |</p>
<table>
<thead>
<tr>
<th>Interview Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>General mood of interview: (calm / nervous, hostile / friendly)</td>
</tr>
<tr>
<td>Were there any interruptions? (ie. via phone, email, interview)</td>
</tr>
<tr>
<td>Y / N</td>
</tr>
<tr>
<td>If yes, what happened?</td>
</tr>
<tr>
<td>How did this affect the interview?</td>
</tr>
<tr>
<td>Was there anything important that was not recorded?</td>
</tr>
<tr>
<td>Problems encountered with methodology:</td>
</tr>
<tr>
<td>----------------------------------------</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Summary of information relevant to identified themes:</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>New themes to be explored:</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Recommendations for next interview:</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>