EXPLORING ORAL HEALTH AND DENTAL CARE EXPERIENCES, PERCEPTIONS AND BEHAVIOURS OF ADULTS WHOSE PARENTS WERE INCARCERATED DURING THEIR CHILDHOOD

by

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Abstract

Objectives: Parental incarceration is an Adverse Childhood Experience (ACE) that can have a negative effect on health related Quality of Life (QOL) outcomes in adulthood. It is unclear how this ACE influences oral health in childhood and in adulthood. This study explores:

1. The oral-health and dental care experiences of men and women whose parents were incarcerated during their childhood;
2. How this childhood experience influences current behaviours and perceptions of oral health and dental care in adulthood.

Methods: Semi-structured, in-depth interviews were conducted with adults who had one or both parents incarcerated during their childhood. The transcripts were analyzed using Interpretive Phenomenology to identify and describe dominant themes.

Results: The eight participants in this study (four males, four females) were found to have experienced more than one ACE. Four themes emerged: 1) Instability; 2) Poverty, stigma and shame; 3) Past dental experiences, and 4) Value of empathetic dental professionals.

Conclusion: This study aimed to provide awareness into the concepts that exist about oral health and dental care in adults that have experienced parental incarceration. We found that participants were able to receive dental care on a regular basis during childhood, (urgent and general dental care) however, preventive dental care at home was lacking. The manner in which dental care was delivered in childhood had a strong influence on dental behaviours in adulthood. Financial barriers such as inability to afford dental-care and non-financial barriers such as dental fear, stigma and shame exist for the participants in adulthood in accessing dental care. Perceived poor dental aesthetics made participants feel low self-esteem and social isolation, and restricted

their career options. Oral health of their children is given more priority than their own and dental professionals who are empathetic are preferred. The findings of this study highlight that, similar to other vulnerable groups, it is important for dental practitioners to understand and practise Trauma Informed Care universally when working with children, in particular those who may have suffered from ACE, in order to provide experiences that promote their future oral-health.

Lay Summary

In this study we investigated the dental experiences of adults who had a parent in prison during their childhood. We conducted interviews with eight individuals, and seven of them also went to prison. We found that during their childhood, while one (or both) parents were in prison, the approach of the dentist who provided them treatment influenced their dental visits in adulthood. They experienced instability due to multiple home relocations, including foster care placement. They described experiencing poverty in childhood and in adulthood and stigma and shame due to their situation. They also experienced embarrassment due to their decayed teeth, as they were not taught how to care for them in childhood. They placed high value on their children's dental care. The findings of our study indicate that dental practitioners need to be more understanding and empathetic when treating children who have had Adverse Childhood Experiences (ACE).

Preface

This thesis is an original work of the author Nida Amir with input and guidance from research committee members Dr. Leeann Donnelly, Dr. Kavita Mathu-Muju, Dr. Rosamund Harrison, Dr. Mario Brondani and Dr. Ruth Martin. My interest arose in this project when Dr. Leeann Donnelly who was my thesis supervisor introduced it to me. I have been interested in conducting research in vulnerable population groups and have a background in qualitative research. The research study was a qualitative exploratory study requested by members of the community affected by similar circumstances (parental imprisonment).

The data was collected face-to-face in the form of semi-structured interviews that were audio recorded, transcribed and analysed using Interpretive Phenomenology. The results and conclusion of the project were displayed in a poster presentation at the Canadian Association of Public Health Dentistry Conference in Edmonton, Alberta in October 2016, and at the Dentistry Research Day at the University of British Columbia, in Vancouver BC. The ethics approval for this study were granted by the Behavioural Research Ethics Board of the University of British Columbia; H15-01408.

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Abbreviations

Adverse Childhood Experiences (ACE)

American Academy of Paediatrics (AAP)

American Academy of Paediatric Dentistry (AAPD)

British Columbia Children's Hospital (BCCH)

British Columbia (BC)

Children of Prisoners, Interventions and Mitigations to Strengthen Mental Health (COPING)

Co-investigator (Co-I)

Collaborating Center for Prison Health and Education (CCPHE)

Correctional Services of Canada (CSC)

General Education Diploma (GED)

Early Childhood Caries (ECC)

Human Immunodeficiency Virus (HIV)

Interpretive Phenomenology (IP)

Intravenous (IV)

Medical Services Plan (MSP)

Ministry of Justice (MJ)

Non-Insured Health Benefits (NIHB)

Parole Board of Canada (PCB)

People Living with HIV/AIDS (PLWHA)

Principal Investigator (P-I)

Quality of Life (QOL)

The Elizabeth Fry Society of Greater Vancouver (EFry)

Trauma Informed Care (TIC)

University of British Columbia UBC

Universal Trauma Precautions (UTP)

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Dedication

This thesis is dedicated to my husband, who always stood by me, through the tough times and the best of times, my children, whose school plays and meetings went with one parent missing, but whose patience and faith in me renewed my courage to continue on, to my parents who constantly encouraged me to strive for the best and follow my dreams.

Chapter One: Introduction

Research provides evidence that the incarceration of a parent may pose a significant threat to child development (Johnson & Easterling, 2012). Despite rising rates of incarceration in North America in the past few decades (Raphael, 2014), this area of inquiry faces conceptual and methodological challenges. Children of incarcerated parents differ from other children in various dimensions, including family socioeconomic status, parental substance use, parental mental health, parental criminality and exposure to violence (Johnson & Easterling, 2012). Parental incarceration has now been recognized as an 'Adverse Childhood Experience' (ACE), distinguished from other types of ACE due to the unique combination of shame, trauma and stigma that children experience (Hairston, 2007). Children living with adverse childhood stressors, such as parental incarceration, tend to have worse overall health as compared to those who are not exposed to childhood adverse events (Murray et al., 2012). Children of incarcerated parents also have neglected health care needs including dental health (Bethell et al., 2014). Many parents and caregivers do not seek services for their child due to fear they will be identified by welfare agencies or because of the shame and stigma associated with their situation (Shlafer & Poehlmann, 2010).

Previous research has shown that imprisonment can transform the life course of the incarcerated person (Kulkarni et al., 2010). However less is known about how the criminal justice system affects the lives of dependents and family members. There is evidence that children of incarcerated persons are more likely themselves to become prisoners (Aaron & Dallaire, 2010). In this regard, parenting is an important factor predicting future criminality. The typical incarcerated individual provides the same kind of deprived and disrupted family life for his or her own children that he or she experienced. Thus social conditions and experiences that

produce delinquency are transmitted from one generation to the next over the life span (Farrington, 2003). The support services for families and especially for children of parents who are incarcerated usually prove to be inadequate (Chipungu & Bent-Goodley, 2004). Such services include support for the child through the arrest, trial and sentencing of their parent/s, living arrangements, health care, education and economic circumstances.

In this exploratory study, we explored the childhood dental care experiences of adults whose parents had been affected by the criminal justice system. Some of these individuals have themselves also been incarcerated and have children of their own. These individuals come from different security levels of correctional institutions in Canada. These are, minimum-security community supervision, provincial and federal institutions and maximum-security prisons. In this way we aimed to gain a broad insight into how parental incarceration during childhood impacts an individual's oral health in adulthood and how these experiences inform their current perceptions of oral health and dental care for themselves (Poulton et al., 2002).

Literature Review:

1.1 The Corrections System in Canada

In Canada, the federal and provincial governments divide the responsibility for corrections. Once a sentence has been imposed on an individual, an intake assessment takes place, which determines the risk level and needs of the person (CSC, 2015). This ensures that the incarcerated individual's initial placement is done at the appropriate level of security. The assessment takes into consideration all the factors that drove the individual to commit the offence, the level of risk to the public that he or she poses and the needs of the individual in terms of correctional services. A correctional plan is developed by the Correctional Services of

Canada that works out rehabilitation plans and activities for the incarcerated individual (CSC, 2015).

1.1.1 Correctional Services of Canada:

Sentences of two years or longer are the responsibility of the Correctional Services of Canada, who have facilities all over Canada. These include those who are serving life sentences in federal correctional Institutions and also those in community supervision.

1.1.2 Provincial Corrections:

Provincial corrections are responsible for individuals who have been sentenced for two years less a day.

1.1.3 Parole Board of Canada:

The Parole Board of Canada (PCB) makes conditional release decisions for federally incarcerated individuals as well as provincially incarcerated individuals in the provinces and the territories that do not have their own parole board. The parole board also plays a role in clemency cases, and for making decisions to refuse or revoke record suspensions and decides upon whether a person is eligible for parole (CSC, 2015).

1.2 Security Levels at Corrections Institutions:

There are three security levels in institutions in Canada:

1.2.1 Maximum-Security Institutions:

These are for individuals who pose the greatest risk of escape and danger to society, and thus these institutions are the most restrictive. Barbed-wire fences surround these buildings, and

armed correction officers are posted in towers at strategic surveillance locations. The individuals who reside in these facilities have a very strict day-to-day routine (CSC, 2015).

1.2.2 Medium Security Institutions:

These sites are also fenced and guarded well, however the individuals at these facilities have less restrictive routines. Officers who guard the posts are not armed, however weapons are available to them in specific locations, under lock and key (CSC, 2015).

1.2.3 Minimum Security Institutions:

These play a role in the process of returning incarcerated individuals to the community. These are penitentiaries that resemble small communities where incarcerated individuals live in small units in groups of seven or eight. Barbed wire fences do not surround these units and they do not have armed (or unarmed) guards. Incarcerated individuals in these institutions are deemed very low risk and have a less restrictive routine. The incarcerated individuals in these institutions are responsible for their own meals and can organize their schedule according their activities. These facilities prepare individuals for life in the community (CSC, 2015).

1.2.4 Community Supervision:

These programs provide the structure to assist individuals to integrate into society safely and successfully. They contribute to public safety by the administration of community operations, which include the provision of accommodations for incarcerated individuals, establishment of community partnerships, and by the provision of health services as necessary (CSC, 2017).

1.3 Profile of Individuals Who Are Prisoners in Canada

In the years 2015/2016, an average of 120,568 individuals were in Canada's correctional system, either in custody or in a community program on any given day (CSC, 2017). The majority of these, approximately 80%, were under Community Supervision, while 20% were in custody. Compared to the previous years, the rate of adults under Community Supervision continue to decline (CSC, 2017).

Out of all the provinces and territories in Canada, Québec reported the lowest rate of adults under Community Supervision in 2015/2016, which was approximately half of the overall average. The highest rates were seen in the Territories followed by Manitoba, Saskatchewan and Prince Edward Island. In 2015/2016 on any day, 40,147 adults remained in custody and 14,742 of these were in federal institutions, 25,405 were in a provincial or territorial facility, and 14,899 were being held on remand (detained in prison until a later date, when a trial or sentencing will take place). Less than one percent of adults were in custody for other temporary detainments such as immigration holds (CSC, 2017).

Manitoba has had the highest incarceration rate for the past 20 years and Nova Scotia has had the lowest rate. Approximately 76% of the overall crimes committed by adults admitted to either the provincial or territorial institutions were of a non-violent nature. The majority of adults in custody are single males under 25 years of age (CSC, 2017). The most over-represented ethnic group in custody across all provinces and territories is Aboriginal (La Prairie, 2002). A comparison of nine major cities in Canada, known as Consensus Metropolitan Areas, demonstrated that the prairie cities have a higher representation of Aboriginal people, or people who identify as First Nation in the criminal justice system (La Prairie, 2002) . Aboriginal over-representation in prisons has been steadily increasing over the past decade. Incarceration data

taken from provincial databases along with demographic data demonstrates that Aboriginal Canadians on average also spend more time in custody when compared to non-Aboriginal Canadians (Owusu-Bempah et al., 2014). Furthermore, a survey of nine major cities demonstrated that Aboriginal individuals are generally more disadvantaged when compared to the general population (La Prairie, 2002).

1.3.1 Profile of Individuals Who Are Prisoners in British Colombia

On any given day in 2015/2016 in British Columbia (BC), 2,652 individuals were in custody in the provincial correctional system (CSC, 2017) and 1610 individuals were on remand. The use of remand has increased 83%, from 5,300 to 9,600 adults, over the last decade. Consistent with the rest of Canada, Aboriginal people are over-represented in the criminal justice system in British Columbia (Dauvergne, 2012). In BC, Aboriginal women account for 29% of all female admissions (CSC, 2015).

1.3.2 Women Who Are Prisoners in BC

Women make up approximately 10% of the prison population in BC (Martin et al., 2012). Incarcerated women, when compared to the general population, tend be younger and less educated (Braithwaite et al., 2005). In BC the annual provincial admission of women into the criminal justice system is approximately 3700 and a disproportionate number of incarcerated women are Aboriginal. One of the biggest problems for these women, who are mostly of childbearing age, is the separation from their children. This led to the establishment of a Task Force for Federally Sentenced Women by the Government of Canada by an expansion of the infant and mother health initiatives in correctional facilities (Martin et al., 2012). The Collaborating Center for Prison Health and Education (CCPHE) developed guidelines to

facilitate best practices for the Mother-Child Units; these guidelines have been mailed to every Canadian Member of Parliament (MP) and every provincial/territorial Minister of Justice, Health and Child Protection, and to every Canadian woman's correctional facility (CCPHE, 2015).

1.3.3 Infant and Mother Health Initiative

For the years 2005 to 2007, British Columbia Corrections, the Ministry of Children and Family Development and the BC Children's Hospital's Fir Square combined care unit formed a partnership, which led to an infant and mother initiative at a major BC Corrections Center for women (Granger-Brown et al., 2012). Incarcerated women who gave birth in prison were allowed to keep their babies. During the program, thirteen babies were born to incarcerated mothers, out of which nine returned to the correctional center and remained there until their mother's release. The longest stay of any baby at the correctional center was fifteen months (Brown et al., 2009). Previous research has shown that programs that enable the parent and child to stay together in populations that are high-risk, such as prison populations, promote positive developmental outcomes for the child (Pollock, 2003).

1.4 Youth Corrections System in Canada

Youth correctional services are for adolescents aged between 12-17 years old. In 2015/2016, a total of 8,455 youths between the ages of 12 to 17 were supervised either in a community program or in custody in Canada (CSC, 2017; Malakieh, 2017). For every 10,000 youth in Canada, there was a total of 49 youth in correctional system (CSC, 2017). The overall rate of youth in correctional services has gone down in the past five years, however Aboriginal over-representation is also seen in this population (Malakieh, 2017). Three quarters of the youth admitted in the correctional services are male (Malakieh, 2017). Delinquent and antisocial

behavior was observed in youth whose parents were incarcerated in studies conducted in the United States, most notably a longitudinal study that followed 1000 boys, yearly for 10 years (Murray & Farrington, 2005). The study found that those children who had a parent incarcerated in the first 10 years of their life, were involved with delinquent and antisocial behavior in their adolescence (Murray & Farrington, 2005). They hypothesized that parental imprisonment is a predictor of anti-social and delinquent behavior in children partly due to the parents criminality, partly due to the trauma of parental separation and partly because of the increased childhood risks associated with incarcerated parents (Murray & Farrington, 2005). Similar findings were also seen in Cambridge, United Kingdom in a longitudinal study of 412 youth, conducted over a period of 40 years (Farrington, 2003).

1.5 Health Status of Incarcerated Individuals

Individuals who are prisoners are relatively younger than the general population and have poorer physical and mental health status (Heidari et al., 2014). The factors that contribute to this situation could be a history of smoking, alcohol or drug abuse, mental and medical comorbidities combined with high sugar diets and poor engagement with routine-health services (Heidari et al., 2014). Other factors that contribute to their poor health status are low socio-economic status, ethnic status, female gender, intravenous (IV) drug use and addiction (Braithwaite et al., 2005). In the United States, prisons have become the primary health care facility for some of the poorest as well as the sickest women (Harner & Riley, 2013). The health of women who are prisoners can be compromised as they are at a greater risk for blood borne infections such as HIV, hepatitis B and hepatitis C (Rothon et al., 1994). This problem is more prevalent in incarcerated women as compared to incarcerated men and can be explained almost entirely by the higher proportion of females who are incarcerated with a history of IV drug use (Rothon et al., 1994). Mental illness

is also higher in incarcerated women compared to men and they tend to have more post-traumatic stress disorder (Martin et al., 2012), which could be due to a history of abuse, violence and victimization by a spouse or partner. Incarcerated males also have poorer health than the general population. They tend to have more mental illness compared to the general population, especially if they are substance users (Swartz & Lurigio, 2014). The younger male populations in juvenile facilities have a health profile that is much worse than youth in general; they tend to have more risk-taking and anti-social behaviours when compared to youths still in schools (Forrest et al., 2000).

1.5.1 Health Services in BC Prisons

The health services provided to incarcerated individuals differ whether they are in provincial or federal custody. It is the responsibility of Correctional Services Canada (CSC) to provide federal incarcerated individuals with essential health care and reasonable access to non-essential mental health care (CSC, 2015). Correctional institutions in BC offer a variety of health and educational programs for provincially incarcerated individuals, including mental health services, drug and alcohol counselling, liaison services and Narcotics/Alcoholics Anonymous meetings (Granger-Brown et al., 2012). The provincial institutions health care system is predominantly privatized or funded by the institution (Granger-Brown et al., 2012). According to the BC Ministry of Justice, more than half (56%) of the incarcerated individuals admitted to the correctional system are suffering from mental illness or substance abuse (Ministry of Justice, 2015). The assessment and treatment of incarcerated individuals is coordinated and done by the corrections branch staff (Ministry of Justice, 2015). Those individuals in provincial custody suffering from mental illness are identified and seriously ill patients are treated during their incarceration period, and also after their release (CCPHE, 2017).

The prevalence of chronic medical conditions in incarcerated individuals in prison populations is higher than that of the general population (Binswanger et al., 2009). Despite this fact, the access to medical care for these individuals is difficult, and usually delayed. The main complaints made by individuals in prisons in Canada, (both federal and provincial) is difficult access to and unavailability of medical care (CCPHE, 2017). Even after release from prison, access to medical and dental care for individuals with an incarceration history is worse than the general population, despite having similar health and insurance status (Kulkarni et al., 2010). Limited access to dental care has been found to be associated strongly with a history of incarceration, with fewer adults utilizing dental care compared to those who had not been incarcerated, despite having similar dental benefits (Kulkarni et al., 2010). The experience of having a parent incarcerated and away from home for several months or years can have an impact on the overall social, mental, physical and educational well-being of the child as well (Gordon, 2009). The following sections will discuss in detail the effects of parental incarceration on children.

1.6 Children of Incarcerated Persons in Canada

Children of individuals who are prisoners are far more likely to become prisoners themselves, when compared to the children of non-incarcerated persons (Farrington et al., 2009). Children with an incarcerated mother, have been considered one of the most at risk and vulnerable populations (Dallaire, 2007). Several risk factors have been identified with negative outcomes in this particular population such as multiple home and school displacements and the experience of many stressful and traumatic events (Dallaire, 2007). There is an increased risk to the children of incarcerated individuals as a whole, as more and more developed nations are increasing their imprisonment criteria, and increasing numbers are becoming incarcerated (Mukamal, 2007). Intergenerational recidivism is motivating many organizations that work with

the children of individuals who are prisoners to develop their central missions, which is to stop the cycle of imprisonment.

1.6.1 'Invisible Children'

The concept of 'invisible children' has been derived from international literature and relates to how children tend to appear 'invisible', and become increasingly vulnerable during the entire process of a parent's incarceration including the arrest, trial, sentencing, imprisonment, and visitations (Gordon, 2009). These children tend to be non-entities in both policy and practise, and their overall needs have not been considered a priority. Effects of the incarceration process on the health and well-being of these children, is significant (Murray & Farrington, 2008). From being witnesses of their parent's arrest, to the completion of a parent's sentence, the fear, uncertainty and instability can cause detrimental effects on the child's health and developing psyche. According to the literature, a child is present at about one-in-five arrests (Gordon, 2009). Children who face the incarceration of both parents usually have to move in with relatives or become permanent wards of the government and be placed in foster or group homes. Paternal incarceration is associated with child homelessness; the majority of these homeless children live at shelters (Wildeman, 2014).

1.6.2 Physical and Mental Health of Children of Incarcerated Parents

In the United States, approximately one in 25 Caucasians and one in four African American young adults born in 1990 have experienced parental incarceration (Roettger & Boardman, 2012; Wildeman, 2009). Research correlating the physical health of adolescents and parental incarceration has been lacking, however, a link has been found between parental incarceration and obesity in female adolescents likely as a result of internalizing stress (Roettger

& Boardman, 2012). Young boys appear to internalize this stress differently and tend to exhibit more anti-social and even delinquent behaviour (Murray & Farrington, 2005). Other physical health problems of both boys and girls include asthma, eczema, psoriasis and a range of allergic and nervous disorders (Murray & Farrington, 2008). The lack of adequate nutrition has also been noted as a health issue related to parental incarceration (Gordon, 2009). The mental health problems of these children tend to change over time. During middle childhood, physical problems and issues with attachment and emotional upset are seen (Gordon, 2009). These problems include bed-wetting, nightmares, anger, violence and a tendency for at-risk behaviors. As the child ages, the physical and mental problems may change into drug addiction, acting out and sexualised behaviour placing the growing child at even more risk (Murray et al., 2012). Children of incarcerated individuals may also develop personality and behaviour disorders, more often observed in boys as phobias and anti-social behaviour due to deep psychological stressors (Murray & Farrington, 2005). Furthermore, since dental anxiety and phobias are related and driven by deeper underlying psychological stressors, fear of going to the dentist may be due to an underlying personality disposition and not only general fearfulness (Armfield, 2008).

1.6.3 Adverse Childhood Experiences (ACE) and Medical and Dental Health in Adulthood

Experiences such as child abuse/neglect, parental divorce, domestic violence, caregiver mental illness, caregiver/parental incarceration, exposure to drug/alcohol abuse, and struggles with family income have been identified as adverse childhood experiences (ACEs), and are associated with poor overall and dental health outcomes (Felitti et al., 1998; Bright et al., 2014). Furthermore, an ACE such as parental incarceration can have a negative effect on health related Quality of Life (QOL) outcomes in adulthood and is considered a major risk factor for morbidity and mortality (Brown et al., 2009; Felitti et al., 1998). To date, we know little about how

incarceration affects the long-term health of the individual or their children. It is unclear also how the experience of parental incarceration influences oral health either in childhood or through the life-course. Currently, more and more research is striving to find links between ACE, health and quality of life in adulthood (Brown et al., 2009). The findings of these studies suggest that certain childhood experiences are considered major risk factors for poor quality of life, illness and even death in adulthood (Felitti et al., 1998). The Adverse Childhood Experiences study is one of the largest studies conducted to investigate associations between ACE and later-life well-being; the childhood experiences that were investigated included abuse, neglect and family dysfunction as well as parental imprisonment (Felitti et al., 1998).

Living with a household member who has been incarcerated during one's childhood, has an association with adverse health outcomes in adulthood, which include chronic depression and other depressive disorders and also ischemic heart disease (Lundberg, 1993). In a population based study of childhood exposure to household member (not necessarily parental) incarceration it was determined that children would be at a higher risk for poor health-related quality of life into adulthood (Gjelsvik et al., 2014). Young adults who reported parental incarceration during their childhood had positive significant associations with mental and physical health problems, which include: depression, posttraumatic stress disorder, anxiety, cholesterol, asthma, migraines, HIV/AIDS, and fair to poor overall health (Lee et al., 2013). Childhood experiences (such as ACE) may play a role in adult oral health by influencing psychosocial and behavioural development (Lundberg, 1993; Sanders & Spencer, 2005).

1.6.4 The Social Effects of Parental Imprisonment on Children

The number of children who experience parental imprisonment in North America is unprecedented. These children experience many difficulties after the incarceration of their

parent/s, including traumatic separation, social stigma, shame, loneliness, unstable arrangements for childcare, living in poverty, relocation to new neighbourhoods and schools, the loss of friends and strained parenting (Murray et al., 2012). These consequences that children face due to parental incarceration can cause poor school performance and increased delinquency as well as increased risk of substance use (Aaron & Dallaire, 2010). Children may also develop a negative perception of the criminal justice system and the police, and feel that their parents were 'victimized by the system'; many children also have difficulty coping with future stress and traumatic situations (Farrington et al., 2009).

Having a low socioeconomic upbringing during childhood is considered a risk factor for poor overall health in adulthood. Socioeconomic disadvantage is also considered a type of ACE with toxic stress and housing instability contributing to the overall experiences (Danese et al., 2009). A longitudinal prospective study conducted in New Zealand investigated children's experiences of socioeconomic disadvantage and health risk factors and outcomes in adult life (Poulton et al., 2002; Thomson et al., 2004). A birth cohort of approximately 1000 children was followed from 1972 onwards. Children who grew up in low socioeconomic status families had poorer health and oral health outcomes in adult life, even if their socioeconomic conditions changed (Thomson et al., 2004). The dental outcomes for those with lower SES were even poorer with a threefold increase in adult periodontal disease and dental caries in adulthood (Thomson et al., 2004). These findings highlight the importance of protecting children against the adverse effects of socioeconomic disadvantage, in order to reduce their burden of disease as adults.

1.6.4.1. Financial Burden of Incarcerated Families

Incarceration can worsen a previously existing financial constraint in a family due to the costs associated with the imprisonment such as attorney fees, cash for the incarcerated individual and other needs. Often parents, prior to incarceration, have considerable socioeconomic disadvantages (Kjellstrand & Eddy, 2011; Poulton et al., 2002). The financial difficulties may also continue after the parent has been released from prison as they may find it difficult to find employment due to having a criminal record (Pager et al., 2009). The shift from a stable source of income in most situations to state or government benefits may cause financial hardships in families impacted by the criminal justice system (Gordon, 2009). If the main earning member of the family is incarcerated, financial difficulties follow due to the loss of regular income. The need to move from place to place, or live with family members, who may already be low-income and may be on limited benefits, causes a further financial strain (Johnson & Waldfogel, 2004). The incarcerated individual may leave a heavy financial debt that the remaining family may need to bear; including the costs associated with visiting the incarcerated individual. Such expenses contribute to the overall family financial burden, which can eventually affect the child (Gordon, 2009).

1.6.4.2 Social Stigma and Shame

Many children feel that the social stigma, and the shame associated with having a parent in prison is a burden, and therefore may keep their situation a secret (Murray & Farrington, 2005). In this way they are denied a supportive environment, which may help them cope with their overall situation. Parental incarceration has thus, been classified as an ACE with unique circumstances due to the shame, trauma and stigma associated with it (Hairston, 2007). Some children face bullying when their situation becomes known which leads to a further decline in

their physical and mental development leading to emotional, psychological or conduct disorders (Murray et al., 2012). Social stigma associated with parental incarceration is also a cause of increased delinquent behaviour in children (Shlafer & Poehlmann, 2010). Some of these children may resent their parents and may be alienated from them if they are unable to visit, while others continue to bond and continue to maintain a relationship. Children who continue to remain in contact with their incarcerated parent may be able to cope however this may not always be the case (Poehlmann, 2005).

1.6.4.3 Effects of Parental Separation on Child Development

Children who have been exposed to parental separation during their childhood have a detectable increase in the risks of a variety of adolescent problems, including substance use or dependence, mood and anxiety disorders, conduct or oppositional disorders, and early-onset sexual activity (Fergusson et al., 1994). It has been suggested that parental separation or family breakdown occurring prior to, or during pre-school years is associated with higher risks of problem behaviors later, however this view is contested by various researchers who suggest that parental separation at any stage of a child's development increases the risk of behavior problems in adolescence and early adulthood (Fergusson et al., 1994). Three relevant areas have been identified as a result of parental separation: economic hardship, psychological distress and diminished parenting, which can collectively have detrimental effects on child development (Clarke-Stewart et al., 2000).

1.6.4.4 Foster Care / Other Caregiving

The American Academy of Pediatrics (AAP) considers children living in foster care to be: "*A discrete pediatric population with more intensive service needs than the general pediatric population or even other children who are poor"* (AAP, 2005). Children who have one or both

parents incarcerated either move in with relatives or may move into foster care. Over the past two decades the number of children who live with a relative due to parental incarceration has increased (Denby, 2012). If one or both parents are incarcerated, and there are no relatives able to care for the child they typically enter the foster care system (Wildeman, 2014). According to the 2011 Canadian Consensus report, there are roughly 29,500 children aged 14 and younger living in foster care (Milan & Bohnert, 2011). In these households 45.1 % had one foster child, 28.8% had two to four, and approximately 26.5% had three or more foster children. Aboriginal children make up almost half (48%) of the children in foster care in Canada even though they make up roughly 7% of the overall population under the age of 14 (Turner, 2016).

Children individually cope and adapt to the foster system. While adjusting to foster care, many children go through an initial period of good behaviour, when they start to adapt to their new foster home (Simms et al, 2000). Usually this period may be one of emotional turmoil, especially if the parent(s) of the child are going through the incarceration process. After a short period of approximately one to three months, the foster parents may notice an increase in negative behaviour. Such behaviour may manifest as acting out, or testing established limits. Children may also withdraw, become depressed, or become angry or aggressive (Simms et al., 2000). In any of these situations foster parents may need additional support to manage the psychological challenges that they may incur in raising the child.

1.6.4.5 Health and Dental Care Needs of Children in the Foster Care System

Children tend to enter the foster care system in a poor state of health, which may or may not be a result of abuse and neglect (Simms et al., 2000). Their health also tends to reflect the parental and child's exposures to extreme poverty, substance use by parents, pre-natal infections, family and neighborhood violence, and parental mental or psychological illnesses (Risley-Curtiss

et al., 1996). The health needs of these children include speech delays, developmental delays, incomplete immunization, behavioral problems and educational difficulties (Raman & Sahu, 2014) indicating that early identification and intervention pathways for these children need to be developed. The oral health status of children living in foster care has also been shown to be poor, with many children unable to get timely oral care according to studies conducted in the United States (Melbye et al., 2013). The potential determinants of oral health influencing the utilization of dental care by children who live in foster care in the United States include linguistic and cultural barriers, lack of resources, large case load for the government, lack of medical and dental insurance, lack of systematic record keeping, lack of dental homes, lack of funding, child behavior problems and lack of dentists willing to accept Medicare (Melbye et al., 2013). The oral health status of children of incarcerated individuals in Canada is mostly unknown and many of these children live in foster care as well. Furthermore, no differentiation has been made between children of incarcerated individuals living in foster care in Canada compared to children living in foster care for other reasons.

1.7 The Importance of Childhood Dental Care

Many medical practitioners and the public are unaware that the most chronic disease in children is dental decay (Selwitz et al., 2007). Oral health is one of the most prevalent unmet health care needs in children, with one in one hundred children undergoing treatment under general anaesthetic in Canada (CIHI, 2013). This makes it the leading cause of day surgery for Canadian children (CIHI, 2013). Early Childhood Caries (ECC) can cause suffering to the child due to pain, sleeplessness, difficulty eating and thus predisposing to malnutrition, and difficulty concentrating in school (Casamassimo et al., 2009; Smith et al., 2014). According to the American Academy of Paediatric Dentistry (AAPD): *"ECC is the presence of one or more*

decayed (cavitated or non-cavitated lesion), missing (due to caries) or filled tooth surface in any primary tooth in a child 71 months of age or younger" (AAPD, 2005). This condition is almost entirely preventable with early dental visits as the most important steps for prevention. However for some children, access to dental care is not always possible for a variety of reasons. Oral health is an important aspect of overall health and access to dental care should be given a high priority especially for children and youth. Dental care and adequate oral health during childhood plays an integral role in predicting better oral health outcomes in adulthood (Thomson et al., 2004). In Canada, children continue to have a high rate of dental disease, primarily children of lower socioeconomic status, from Aboriginal communities and new immigrants (Rowan-Legg & Committee, 2013). The fact that low-income families disproportionately represent this burden of illness also illustrates the financial pressure that these families face due to the decrease in public funding for dental care. There is sound evidence that preventive dental visits, especially those in childhood, decrease the rate of dental decay (Beauchamp et al., 2008). Fluoride therapy also reduces the rate of dental decay, which includes water fluoridation, tooth brushing with a fluoridated toothpaste and professional fluoride applications (dos Santos et al., 2013). The consequences of lack of dental care can also be carried forward in adulthood, with untreated dental caries during childhood causing preventable premature tooth loss (Selwitz et al., 2007). The establishment of good oral care habits is also necessary from childhood. The importance of regular dental visits cannot be understated as they provide anticipatory guidance for parents during their child's infancy and support for regular preventive well child visits that can identify initial stages of tooth decay as well as deter dental emergencies that may potentially occur. In young children dental pain is also not always obvious, and the development of a dental emergency in the presence of a decayed tooth may be rapid, and interfere with their overall

quality of life (Sheiham, 2006). Dental pain in very young children may cause malnourishment and is overall detrimental to a child's wellbeing (Casamassimo et al., 2009). Currently in BC, the number one reason for day surgery under general anaesthesia in the BC Children's Hospital (BCCH) for children under the age of 5 is dental caries (CIHI, 2013).

1.8 Rationale/ Knowledge Gap

Oral health is the most prevalent unmet health care need among children (Smith et al., 2014). Oral health in childhood is also a strong predictor of adult oral health (Thomson et al., 2004). ACE may play a role in adult oral health by influencing psychosocial and behavioural development (Bright et al., 2014). However, it is unclear how the experience of parental incarceration influences oral health either in childhood or throughout life. Therefore, in this study we explored the oral health and dental care experiences, knowledge, perceptions and behaviours of men and women whose parents were incarcerated during their childhood. This study also aimed to broaden our understanding of what oral health and dental care concepts exist in families that suffer from ACE such as parental imprisonment.

1.9 Research Question

How does parental incarceration influence dental care experiences and perceptions of oral health?

1.10 Specific Aims

1. To explore childhood oral-health and dental care experiences of men and women whose parents were incarcerated during their childhood;
2. To explore how these childhood experiences influence current perceptions and behaviours of oral health and dental care in adulthood.

Chapter Two: Methods

2.1 Interpretative Phenomenology

Interpretive approaches in qualitative research are rooted mostly in phenomenology, and the writings of the philosopher Edmund Husserl and sociologist Alferd Schutz (Green & Thorogood, 2013 ; Husserl, 1970). This approach has two components, the experiences of the participants and how the researcher interprets that experience (Pietkiewicz & Smith, 2014).
IP is used to understand how a given person in a given context makes sense of a given phenomenon (Smith, 2007). In this approach the 'reality' of the world is investigated from the participant's point of view, and their perceptions and 'lived experiences' are studied (Green & Thorogood, 2013). The aim of IP analysis is to explore how individuals make sense of their experiences (Van Manen, 2002). IP uses purposive sampling in an attempt to find a more closely defined group of individuals for whom the research question is significant (Smith, 2004).
We chose this method because it enabled us to elicit the perceptions of the individuals about the question of interest based on their own experiences (Chapman & Smith, 2002). Interpretive phenomenology offers to help make interpretive sense of a phenomenon, within a 'life world'. The IP researcher tries to study the phenomenon itself, by using two viewpoints, that of the participant and that of the researcher (Pietkiewicz & Smith, 2014 ; Svenaeus, 2001). It is actually the phenomenon and its context that frame the interpretive undertaking by the researcher, of understanding the world of the participants (Benner, 1994). IP researchers attempt to understand what it is like to stand in the shoes of their subject (although recognizing this is never completely possible) and, through interpretative activity, make meaning comprehensible by interpreting it (Pietkiewicz & Smith, 2014).

2.2 Ethics Approval and Participant Recruitment

The ethical approval for this study was received from the University of British Columbia, Behavioural Research Ethics Board (H15-01408). In this study, eight participants were purposively selected to participate in face-to-face, semi-structured interviews. The interview guide (Appendix 1) was designed after we completed a thorough literature review. The questions aimed to explore the lived experiences of the selected participants and the questions were framed in an open-ended manner.

2.2.1: Inclusion Criteria

The inclusion criteria for this study were any individual over the age of 18, (male or female) with a history of parental incarceration. If the individual had been incarcerated himself or herself, they should have been released from prison for at least two years. Each recruitment organization was provided with a letter of introduction that explained the purpose of the study. Upon agreement to allow recruitment to take place at the organization, staff posted the letter of invitation publically within their organization and if requested, provided the letter and consent forms to potential participants who met the inclusion criteria. Those individuals who were interested in the study were directed to contact me (the co-Investigator). I conducted a brief interview over the phone to determine if the participant was eligible for the study. All those who met the inclusion criteria (stated above), were briefed on the purpose of the study, and any risks involved. Those who agreed to participate arranged to meet with me in a convenient location for a face-to-face interview. At the time of the interview, written consent was obtained after the purpose and conduct of the study were further explained as well as a description of potential risks and benefits, the management of confidentiality and who they could contact if they had any questions about being a research participant. Compensation of fifty dollars was provided to each

participant for his or her time. Access to the participants was sought through the University of British Columbia's, Collaborating Center for Prison Health and Education, the John Howard Society of the Lower Mainland, Women in2 Healing and the Elizabeth Fry Society of Greater Vancouver.

2.2.2 John Howard Society of Canada

The John Howard Society was established in 1867 and currently has 65 branches all over Canada. The society enables individuals who have come in conflict with the law to access resources that they may need in order to adjust back into society. They also advocate for change in the criminal justice system and aim to enhance public education about criminal law and its application (John Howard Society, 2015).

2.2.3 Elizabeth Fry Society

The Elizabeth Fry Society of Greater Vancouver provides support services to women, girls and children at risk or who have been involved or affected by the criminal justice system (Elizabeth Fry Society, 2015). This organization helps hundreds of women and children break the cycle of imprisonment, poverty, mental illness, homelessness, addiction and crime. It has developed programs for children such as the JustKids program that holds summer camps, storybook programs and Saturday clubs. The Elizabeth Fry Society of Greater Vancouver (EFry) organizes these activities and also provides support services to the families of individuals impacted by the criminal justice system (Elizabeth Fry Society, 2015).

2.2.4 Women in2 Healing

Women in2 Healing is the participatory action research network of the Women's Health Institute in BC's Women's Hospital (Women in2 Healing, 2015). This network is composed of a not-for-profit group of women who were formerly incarcerated, volunteers from the community and academics who seek to improve the emotional, social and physical healing of women who are inside and outside prison by engaging them into participatory research (Women in2 Healing, 2015).

2.2.5 UBC Collaborating Center for Prison Health and Education (CCPHE)

The CCPHE, established in the University of British Columbia in 2006, aims to address the distinct health needs of incarcerated and formerly incarcerated individuals (CCPHE, 2015). The center actively seeks to foster collaborations and partnerships between universities, the justice system and prisons across Canada.

2.3 Data Collection

2.3.1 Semi-Structured Interviews

In the semi-structured interview, the researcher sets the agenda in terms of the topics covered, but the interviewees' response determines the kind of information produced about those topics and the relative importance of each of them (Green & Thorogood, 2013). This makes the semi-structured interview a less rigid format that through the use of open-ended questions allows the participant to discuss personally relevant issues that pertain to the questions. We developed the questions in the interview guide from existing literature and based on the research question, aims and objectives of the present study (Appendix 1).

Personal interviews were conducted with eight individuals (four men and four women) who met the inclusion criteria. The interviews lasted between 52 to 78 minutes. Four interviews were conducted at the John Howard Society of the Lower Mainland; one interview was conducted at the BC Children's Hospital interview room and one in the participant's home. One interview was conducted via Skype, and one via telephone when the Skype connection failed. The participants were asked questions about their childhood experiences of having a parent incarcerated, their childhood experiences with dental care, their perceptions of dental care and oral health, and their current practices and behaviours related to oral health for themselves and their children if they had any. An unexpected difficulty faced in this exploratory study was access to the participants. Recruitment for the participants took approximately six months, until data saturation was achieved. There were several instances when participants were interested, and met the inclusion criteria. However due to personal circumstances the particular participant could not commit to the travel time required for the interview or could not meet me in a secure and confidential location for the interviews to be conducted. To accommodate the inability to travel an attempt was made to conduct the interview either by phone or computer, however some participants did not have access to computers, or the Internet, and some did not have access to a phone for the required amount of time. It was obvious also that personal lives were busy and possibly disrupted as there were several instances when a date, location and time were agreed upon; however the participants were unable, for various reasons to attend the interview. A further attempt to accommodate a participant's request included one interview being conducted in the participant's home. However due to this being a shared accommodation, the confidentiality of the interview may have been somewhat compromised and therefore this strategy was not repeated.

2.3.2 Field Notes

I took field notes both during and after the interview to help capture non-verbal information and observations to add context to the narratives of the participants and aid in the interpretation of their experiences. The non-verbal information includes body language, facial expressions and tone of voice and other relevant observations. These notes were then utilized during the analysis to ensure that the essence of the narrative was better captured. Field notes are also integral in interpreting observations that add context to the answers that an interviewee makes during the recording process (Mack et al., 2005).

2.4 Data Preparation and Analysis

Each audio recording was transcribed verbatim by a professional transcription service and I verified the transcript with the audio recording to ensure data accuracy. The transcripts were read and re-read by myself in order for me to become familiar with the data. Transcripts were imported into the data management program, NVivo 10™ (QSR International), which was utilized to organize all the data and to aid in coding and theme development (Creswell, 2002). Thematic analysis was used to analyze the data using a 'bottoms-up' approach (Eatough & Smith, 2017). The primary purpose of such an approach is to allow research findings to emerge from the data to identify themes (Thomas, 2006). The data underwent detailed readings by myself to derive dominant themes. This type of thematic analysis approach allowed me to establish clear links between the research objectives of this study, and the summary of the findings derived from the raw data (Dey, 2003).

2.4.1 Coding Schemes

My supervisor and I developed a coding framework from the data. Coding is the first step of qualitative data analysis which starts with the development of a qualitative codebook, an example of which is in Appendix II . The codebook that I used was organized in NVivo, and also on a secure laptop computer. Notes were added at this time as well as later to help develop the codebook and identify emerging themes. The codes, for the data come from phrases that I found to be relevant to describe them. These codes were then grouped into major themes. The themes were then interrelated, or abstracted into smaller sets, or sub-themes.

2.5 Trustworthiness

Trustworthiness in qualitative research consists of four areas credibility, transferability, dependability and conformability (Lincoln & Guba, 1985; Clark & Creswell, 2011). Typical methods employed to ensure trustworthiness of data analysis include peer debriefings, independent parallel coding and stakeholder or member checks, which can be done formally or in-formally (Creswell, 2002). Researcher bias can also be overcome with the help of stakeholder checking and peer debriefing which enable the interpretations of the data to be validated by going back to the respondent and also co-investigators (Creswell & Miller, 2000).

The following methods were utilized to ensure trustworthiness in this study:

- **Peer debriefing** sessions were held between my supervisor and me on a weekly basis, and with other members of the thesis committee less frequently. During these meetings the timeline of the project was discussed as well as recruitment issues that came up. The relevant literature surrounding our topic was also reviewed in addition to the analysis of the data.

- **Independent parallel coding**: My supervisor, a non-dental professional committee member, and I independently coded one transcript to determine similarities and differences in how each had assigned codes to the narratives. Our coding framework was compared and found to be matching.
- **Stakeholder Check or Member Checking**: Each participant was offered the opportunity to review their transcript, however due to time constraints none chose to do so. I also attempted to review initial study findings and my data analysis with the participants individually, and again due to time constraints and the difficulty of contacting them, as they did not have a permanent phone number or access to e-mail, this process was not as successful as I had planned. A major staff and administration change occurred during the study that further hampered my ability to contact participants. In the end I was able to contact one participant (Participant Four) by telephone after the data was summarized, coded and analysed. The findings of the study were provided to her along with interpretations. She was given the opportunity to correct errors or challenge interpretations made by me and add further insight into the analysis. She agreed with my interpretation of her interview.
- **Reflexivity:** This is the attitude of systematically attending to the context of knowledge construction at every step of the research process. This processes takes into account the background of the researcher, the angle of the investigation and the findings and conclusions based on the researchers judgement (Malterud, 2001).

  In this context my own background as an immigrant female, university educated in both clinical dentistry and research influenced my interpretations of the findings. My socio-economic status and ethnic background were different from my participants,

however I have worked extensively with vulnerable populations both in Canada (Montreal) and during dental out-reach missions abroad in Pakistan including refugee camps and isolated rural villages. I kept the focus of the interview on the participant, and ensured each one that this is a safe place to discuss their past dental experiences and anything they choose to eliminate from the interview would be eliminated. I strived to not allow my dental training to influence my analysis of the data by keeping an open mind and being cognizant of the fact that under life circumstances, dissimilar to my own, dental care may not be an individual's first priority. Working at the BC Children's hospital (BCCH) and serving special needs and vulnerable children was a privilege granted to me in the Pediatric Dentistry Specialty Program. During my time at BCCH, my fellow graduate students and I provide patient care to a wide variety of children from all across the province, from the Lower Mainland to Northern BC and the Yukon. In this way we gained a deeper understanding of dental and social needs of children from all ethnic and socio-economic backgrounds.

The process of data collection for me was insightful. After the first interview, I rephrased some questions making them more open-ended. I also developed a 'feel' for the directions of the interview. I did not have any *a-priori* assumptions about the participant and tried not ask any leading questions. Being a clinician I tried to stay away from very clinical information, which would at times arise during the interviews, such as questions about the participants' current dental cavity or fillings or dental advice that they were seeking.

Chapter Three: Results

3.1 Socio-Demographic Data

Self-reported socio-demographic information (Table 3.1) that did not emerge out of the interviews was collected at the end of each session to provide insight into the background of each participant. This included the age, ethnicity, sex, education, employment, period of self and parental incarceration and number of homes and schools changed during childhood.

Table 3.1: Demographic data

Factor	Number of participants
	No.
Age (years)	
18-30	3
31-40	1
41+	4
Ethnicity	
Caucasian	4
Aboriginal	4
Other	0
Sex	
Males	4
Females	4
Period of parental Incarceration	
<10 years	6
>10 years	2
Period of self Incarceration	
0 years	1
<10 years	3
>10 years	4
Number of homes	
<5	3
5 or >5	5
Education	
Competed high-school or GED	2
Did not complete high school	6
Number of children	
0	2
1-3	5
4+	1
Number of schools	
>5	3
<5	5
Employment	
Employed/volunteer	3
Unemployed	5

3.2 Themes

The IP analysis of the interviews with eight adults (four males and four females) who in their childhood experienced parental incarceration, revealed four prominent themes: 1) Instability; 2) Poverty, stigma and shame; 3) Past dental experiences; and 4) Value of empathetic dental professionals. Multiple sub-themes were also identified and will be discussed in relation to the theme where they were best represented. In the following sections, the results will be described starting with the effects of parental incarceration on the participant's childhood and how this experience impacted their dental care. Sub-themes highlighting important findings that are relevant to the research question, which add important context to the analysis, will be presented.

3.2.1 Theme One: Instability

Instability in the home emerged early on in each interview. Participants described their childhood with either one or both parents incarcerated, as a childhood of little to no consistency at home. All participants except one were moved frequently. They described being taken away from the care of their families and being placed into foster homes or youth correctional facilities during their adolescence due to delinquent behavior. One participant (Participant Two) lived with his mother, who was never incarcerated throughout his childhood; he was not removed from her care. However, he was placed in youth correctional facilities during his adolescence and eventually in prison as an adult. One participant, (Participant Seven) was taken from his First Nations reserve and involuntarily registered in Indian Residential School, along with several of his cousins, however this was not related to his parental incarceration. Some of these individuals engaged in behavior that resulted in their placement into youth correctional facilities during adolescence (Participants Two, Seven and Eight).

Overall, participants described the experience of having at least one incarcerated parent during their formative childhood years as emotionally traumatic with effects that persisted into adulthood. Several sub-themes emerged within the theme of instability and are discussed in the following sections.

3.2.1.1 Multiple Home and School Relocations

The multiple relocations were a result of changing foster homes or having to live with different relatives. As Participant Five commented:

> *"I don't think I've ever had the same neighbourhood growing up, or even the same town. I've lived all over B.C."*

When asked about how these experiences made them feel, the participants answered that the experience was upsetting with feelings of confusion. Due to being moved around frequently they found it difficult to make friends and establish roots, as Participant Four described:

> "*I was really upset to leave my friends and my family, and I felt alone every time I switched a school, to have to make new friends again and I didn't really have much time to set any roots*".

The instability at home had an effect on her school attendance as well:

> *"I didn't fully drop out of high school, but I didn't attend very regularly... I stayed back with my mother, and she still wasn't clean or sober at that time, so I didn't have rules".*

Participant Three had to leave her school in order to take care of her siblings, as her mother was incapable of caring for them due to her substance use and would disappear for several days at a time:

> *"My mother decided to go on benders for a week and she'd never be home and I'd be with my siblings, I remember quitting school in grade 5 to take care of them".*

The inability of parents to provide boundaries and guidance left some participants to feel as though they had the freedom to do as they pleased, which was described as a reason for engaging in delinquent behaviour. None of the participants in this study were able to finish high school in time, however two out of eight did achieve the General Education Diploma (GED) in later years. Having no rules or authority figure at home led seven out of eight participants to partake in criminal behaviour that led to future incarcerations. Some of these participants (three out of eight) were placed in juvenile correctional facilities from a young age adding to feelings of instability. The cycle of imprisonment continued for these individuals and they described being in and out of correctional facilities for most of their lives, as Participant Eight described:

"I would go off and get in trouble with the police. I was either not welcome at the [foster home] anymore and I would end up in detention or they would find me another home".

The multiple homes and relocations impacted oral health and dental care as well. Most participants (six) mentioned that they had little to no instructions at home on how to care for their teeth, while others who did get some instruction, tended to ignore them as a way of rebelling against their caregiver or parent as Participant Eight describes:

> *"My mom's very big on her dental hygiene. She brushes like 5 times a day and flosses... I was stubborn…so when she pressured me to brush my teeth she was just being a [expletive]… and not doing [the brushing] is a sense of defiance, rebellion."*

His expression however was one of sadness as he relayed this information to me. He discussed how he regretted his actions as it caused his oral health to suffer.

3.2.1.2 Foster Care and Youth Correctional Facilities

All eight participants indicated that they had been placed for some time in foster care, group homes (which house multiple foster children), or youth correctional facilities. This was an emotionally difficult time for the participants, as they felt a great deal of uncertainty as Participant Three described her foster care experience:

> *"There was this social worker that always kind of told us, it's not permanent, and it's not even a long-term kind of a thing… There was no trust between me and the foster parents, like, anywhere I have ever gone. Just not knowing how long I'll be there".*

This participant, who had been placed in several foster homes as a child, went on to describe to me how this left her feeling insecure about her future and that of her siblings as she had a constant fear of them being separated. This fear eventually came true when she and all her siblings were placed in different foster homes. Others found the foster homes to be adequate such as Participant Eight who offered his account of foster care and group homes:

> *"My needs were met like food and healthcare and school and stuff, a roof over my head. I accepted it. I just took it as another place to camp really".*

Foster homes were not a negative experience for other participants as their health care and dental care needs appeared to be met. Participant One described his foster parents as kind and was thankful that they would take both him and his brother to the dentist and the family doctor as needed. Participant Two, Seven and Eight spent some time in youth correctional facilities for adolescents, followed by prison in adulthood.

For Participant Eight, his move to a correctional facility for adolescents was the time when he remembered that he started getting dental work done:

"*Most of my work was done when I was 14 and I probably was more [grown up] than as a kid because that's when I started going to Boy's School [correctional facility] and that's probably when I started taking care and looking after my teeth more. Going to Boy's School and jail".*

Three participants out of eight were placed in youth correctional facilities as adolescents and one out of the three went to Residential School. Running away from foster homes and petty crimes was frequent for them, which continued the cycle of admitting them into correctional facilities.

3.2.1.3 Parental Absence and Suffering from Abuse

Each participant had his or her own unique perception about having one or both parents incarcerated and how it affected them. Not having a 'constant' in the home and some sense of stability caused them to feel like they were lacking something as Participant Three commented:

"Well there was no constant…so the books I've read say that, you know, by the age of five, it's really important for kids to have that, but I didn't have it… so… you know, I don't know maybe I'm lacking something as a result of that".

She has six children of her own and makes sure she creates a stable environment for her children so that they do not experience what she had to. The participants described to me that they made an effort to hide their parental incarceration from others. They also described to me how they felt embarrassed and ashamed due to the fact that their parent/s were in prison. They also described a sense of confusion since they often did not understand why their parent was away. Some were too young when their parent was first incarcerated, so they did not understand

what ‘jail’ was. They had more questions than answers and felt betrayed by the parent who was away, such as Participant Five who stated:

> *“I think I was just confused about the whole not knowing what incarcerated is, or them being locked up, or in jail. I didn't know really why, so I couldn’t answer, explain even why”.*

Others felt embarrassed and unless specifically asked, they kept their parent’s incarceration to themselves. They avoided discussing their parent’s situation and became more and more socially withdrawn during childhood. Participant Six mentioned that in her small town, everyone knew where her mother was and why she was incarcerated as it was in the news: *“It's just embarrassing. I just couldn't believe that she would do that to my dad and to me*.” Participant Seven experienced racism in new schools he was placed in as a child with a low First Nation population and how he felt he could not fit in:

> “*I think I was isolated, sometimes, just being Aboriginal, going to certain schools my mother would put me in, and then the fact that my father was in jail.”*

He went on to describe how he still feels that he is stigmatized due to the fact that he himself also went to jail, is a First Nation individual, and finds it difficult to adjust to life outside prison, which will be discussed in later themes. Two individuals in this study disclosed that they suffered from mental health issues during childhood, childhood anxiety, and the eating disorder Bulimia Nervosa. They described to me the suffering that these conditions caused them, and how it took them several years of medical counseling to overcome these conditions.

One participant out of two, also suffered from post-traumatic stress disorder due to being sexually abused at home during her childhood when she was left alone with ‘trusted’ family members, while her mother was in prison. With her mother gone, and no one to take care of her

she felt a lack of control over her life, which likely contributed to the development of her eating disorder and hospitalizations for treatment:

"*I also had an eating disorder [bulimia nervosa] that I was throwing up a lot. That really hurt my teeth a lot, as well, with all the acids and such".*

She went on to describe how this condition was something she needed to overcome so her teeth would not be harmed more. One individual was sexually abused and given alcohol by his stepfather at the age of 11. He still struggles with alcoholism. However he has been able to remain sober for 18 months, after speaking about the sexual abuse in his past for the first time since he experienced it:

"He is the one that first fed me alcohol. That's my issue to this day. I'm an alcoholic thanks to him. I missed a lot of my childhood opportunities because of his actions".

He mentioned that his stepfather was the one who taught him how to care for his teeth and oral health, and after suffering the abuse he stopped caring for his teeth. I could see that this was a topic that was very painful for him to discuss from his expression. He still suffers from anxiety and depression as an adult, as a consequence of the abuse he experienced as a child. Three participants had suffered through sexual abuse as an adolescent or as a child. One participant who was placed into an Indian Residential School, experienced physical as well as sexual abuse:

"Mostly we were sexually abused by the priest, and probably physically and more abused by the nuns with their sticks, whether we spoke our language or cut our hair".

As a consequence of the abuse, this participant described to me his inability to trust authority figures such as doctors, dentists and prison guards as he exclaimed:

> *"I did get [anxiety] the first time [visiting the dentist], because they were people I got left alone [with]… and I had a problem with that [authority], obviously, from residential [school], so I didn't know what to experience".*

3.2.1.4 Drug and Alcohol Use

All the participants that I interviewed in this study (eight out of eight) used substances at some point in their lives, and some still do. They started using street drugs, alcohol or painkillers early in life, such as Participant Two who stated:

"I took [drugs] from the time I was 12 up to 10 years ago. I was a severe heroin addict".

He also mentioned to me, that despite injecting himself with intravenous (IV) medications for many years, he still had fear of needles, especially dental injections and avoids dental visits despite having unmet dental needs. He is no longer using and he mentioned to me with pride the challenges he faced and overcame to become clean. In this study, there were three participants who self-medicated in order to alleviate dental pain, or 'escape' their reality in order to cope. Participant Four mentioned she wanted to '*stuff all her feelings and ignore them*' and did not want to talk to anyone about what she was experiencing. During their late teen years, four participants moved out of their homes and moved in with friends or became homeless for a short period (participant One, Four, Seven and Eight) due to various reasons including drug use, rebelling against parent/guardian and running away from foster homes.

Participant One recalls witnessing violence and open drug use in a house where he lived during his teen years. He was hesitant at first during his interview with me, but opened up afterwards. He described that this was a place where various people came to use drugs and lived

on a temporary basis, he recalls:

> "*The house I lived in was basically like, a crack shack, so…people would go in and out of there doing drugs, and I mean the place got shot up like a whole bunch of times…it was not a good experience"*.

Participant Eight however used alcohol to cope with his dental pain. He mentioned to me that he suffered from dental pain most of his life, and used alcohol to 'numb' the pain. He also mentioned that he could not even brush his teeth due to the pain he suffers from all over his mouth as he elaborated:

> "*It is was just easier to just let my teeth [continue] breaking. My quick fix was [alcohol] because I was drinking…I was numb. Eventually the nerve would die"*.

He mentioned that he did not feel that previous dentists that he had seen paid any attention to the pain he suffered from, and gave him extra strength Tylenol that did not work for him. He did however finally find a dentist with whom his experience was better:

> *"I had a good experience with Vancouver General [Hospital]. I ended up going to the emergency there. Paid $100 to have a molar ripped out, but the doctor was friendly. He was nice. He was responsive. He was focused on my pain issues... I did have a good experience there under the circumstances*."

He is currently waiting for an appointment at a free dental clinic offered in conjunction with the University of British Columbia, to get his treatment completed.

3.2.2 Theme Two: Poverty, Stigma and Shame

A second theme that emerged in the interviews was of poverty with the majority of the participants (seven out of eight) describing the hardships they faced while growing up. Five participants are still facing financial difficulties, especially with regards to affording dental care. Seven individuals who were in the foster care system were able to get most of their dental needs met either during childhood or later on in correctional institutions (youth and adult). One participant (Participant Two) who lived with his mother, and later on went to correctional institutions also recalled no financial difficulty in getting dental treatment done during his childhood. However, those in the foster system, without First Nation status (four participants) faced difficulty affording dental care as soon as they aged out of government-funded care.

3.2.2.1 Poverty During Childhood

Growing up in poverty with difficult access to food, clothes and other essentials were experienced by six participants. When asked about access to dental/oral-care products during their childhood, Participant One replied:

> "*Both my parents were on welfare right, so I mean they didn't have a lot of money…and I think probably most of it would go to food and stuff instead of like hygiene stuff*".

This participant clearly remembers the struggles of growing up in poverty with his younger sibling. Despite not having enough financial means to make ends meet, he and his brother were able to get dental care during their childhood due to their First Nation status. He recalled regular visits to the dentist for routine examinations as well as treatment. He still has dental coverage through his NIHB (Non-Insured Health Benefits program) and mentioned he can access care in any dental office that is willing to accept his coverage.

3.2.2.2 Poverty in Adulthood

This sub-theme emerged as a common finding for five of the participants in this study. Those individuals who aged out of government-funded or caregiver-funded dental care mentioned to me the difficulties they face currently in accessing dental care due to financial hardships as Participant Four described:

> *"I don't have any medical coverage for the dentist. I only have emergency extraction [coverage]. In the way of importance, the most important thing for me right now isn't any extractions; it would be having my root canal done. I have to save up enough money, which is hard because I'm on income assistance, and I'm a single mom of two kids, and any money that I do get goes to my children."*

Participant Eight revealed that he lost most of his permanent teeth due to his inability to afford dental care:

> *"During the years I just couldn't afford it especially going into the institution and then getting out of the institution not having a secure lifestyle. Welfare doesn't cover a lot, mostly extractions".*

3.2.2.3 Housing Instability

The majority of the participants (five out of eight) had experienced periods of housing instability during their adolescence and adulthood that made it difficult to have a stable oral hygiene regime. Participant One described his experience of being homeless with his mother and sibling as a teenager, and as a result of that being placed into the foster care system:

"My dad had passed away at that age and then my mom tried looking for a place but she was unable to, and then she went homeless and then I was put in foster care from 16 up all the way till I was 19."

His father had been in and out of prison, however while he was alive, they still had a place to live. After he passed away, the family was homeless for a while. He recalled his mother also using drugs and alcohol and therefore unable to care for her children. Participant Four decided to leave home during her teenage years due to building tensions at home with her mother going in and out of prison and using drugs:

"From [the age of] 15 to 17, I didn't really have a stable home. So, therefore, not having a toothbrush, and not really living places where I had the comfort to say, 'Hey, could you get me a toothbrush?' or stuff like that".

She mentioned to me that she used to stay with friends and 'couch surfed' until she finally decided to move in with her boyfriend during her late teens/early twenties and had children. She did not have access to dental care during this time, except for emergencies, such as extractions, that are covered by the Medical Services Plan (MSP) in BC. When asked about finances during her teenage years she replied:

"I got some money from my dad every once in a while, money from my mom every once in a while…I was still bouncing around from house to house - and all the houses that I was staying at were not… they weren't homes, they were just houses and people did drugs".

Two more participants experienced homelessness living in Vancouver's Downtown East Side during adulthood (Participants Seven and Eight). These participants spent much of their time in

shelters and hotels that house the homeless in the area. Participant Seven in particular described how being homeless impacted his oral health:

> *"Lack of discipline in taking care of my mouth, but the reality was…everything went downhill with my teeth when I became homeless. I did suffer with a bunch of cavities during the years, but it wasn't till I was homeless that I didn't have a sink, I didn't have a toilet, I didn't have a bathroom. I was surviving, struggling, day-to-day for over 10 years. I wasn't on disability at the time either so the dentist thing was almost the last thing on my mind."*

3.2.2.4: Stigma and Shame

Participant Two mentioned that once he started getting in and out of prison, people started treating him differently. He experienced some time living without dentures, which he felt was very difficult for him: *"Well the first time I got arrested, I never got a chance to get my teeth [dentures] and I wound up losing them…*" When he got arrested, in the ensuing rush, he was unable to retrieve the dentures, and was taken directly to prison. He ended up losing his dentures and it took several months before replacement dentures were given to him. He described this time as challenging, and being unable to afford dental care outside of prison he had to go a long time without receiving new dentures:

> "*I avoided things, I avoided talking to people, I avoided all kinds of things, it's hard to talk and everything! I looked terrible, and it sucked…just drove me crazy, I hated it"*.

In addition to his lack of finances that precluded him from seeing a dentist outside the prison system, he also avoided the dental office due to the fact he felt embarrassed describing his previous incarcerations to anyone, where he got most of his dental treatment. Participant Seven mentioned that he feels uncomfortable going to doctors or dentists as they may judge him for his

time in jail. He felt more comfortable going to clinics in Downtown East Side, because he felt he would not be judged or stigmatized: "*I relate to them down there because I lived down there"*. He said that he could relate better with individuals who had been through circumstances similar to his own. Participant Eight described his experiences of feeling uncomfortable in stores and afraid of embarrassing himself by not knowing how to live outside of prison:

> *"I still have problems going into places now, because I feel that I'm not going to do something right…or I'm not going to punch in my checking account right and it's going to come back a void, and I'm going to be embarrassed.*"

I could see that he was even uncertain about how to conduct himself during the interview, and tried his best to appear as professional as possible by using formal terms to describe his experiences.

3.2.3 Theme Three: Past Dental Experiences

The effects of childhood dental fear and anxiety prevented the development of a therapeutic relationship with a dentist in adulthood for those participants who experienced them. In this group, two participants described their childhood dental experiences as good; one as fair and the remaining five as poor.

3.2.3.1 Dental Experiences As a Child

Three participants recalled seeing the same dentist during their childhood (Two, Three, and Five) while the rest were scheduled with different dentists for every appointment. Usually, a non-incarcerated parent, relative or foster parent was responsible for taking the participants to the dental clinic. Two participants recalled visiting the dentist on their own as teenagers (Participant One and Five). Participant Three vividly remembers, each time she was taken to the dentist who was a '*no-nonsense type'* man. She recalled being frightened, in pain and being threatened: '*you better be quiet or I'll…*' These experiences during her childhood established a fear of dentists and needles. I interviewed her at her home, where she started smoking and I could perceive the anxiety she was experiencing. As an adult, she still cannot cope with any medical or dental procedure that requires needles. She described her mother taking her to see the dentist:

> *"I remember being mad at her, screaming and saying 'don't make me go, don't make me go!' and pretty much, she'd drive me there, but I always was terrified of needles".*

Dental pain and trauma were common in the group that had poor experiences during their childhood, as Participant Two remembers:

> *"It was painful! It was terrible! It was excruciating! I think one of the first major things I had done when I was young was a root canal. I think about it now and almost make myself sick. I still remember it, oh yea I remember it".*

As he described this experience, I observed that he was gripping the chair so tightly that indentations from his hands were visible on the armrests. His facial expression was also one of fear. Four participants recalled their experiences with dental injuries, such as fracturing or breaking their front teeth while growing up due to accidents. These experiences were also distressing as Participant Three recalls*:*

> *"I remember, I broke my front tooth when I was about 12 or 13…I guess half my tooth was gone, and they ended up putting like a cap or something, and I kept that thing forever. It wasn't meant to stay that long but I just didn't [fix it]. I would rather not go to the dentist, and then when I started having kids, I'd get a toothache."*

She described to me how her childhood dental experiences deeply affected her and that to this day she requires anti-anxiety medication for routine dental examinations and IV sedation for dental treatment. She recalled not being regular with her examinations due to her fear, and ignored dental pain to the extent that she tolerated it until it was unbearable. In most instances, it had become too late to save those teeth, and she ended up with multiple extractions. Much of this fear and avoidance was attributable to her fear of dental injections, as she mentioned that anytime she underwent any kind of medical intervention that required needles, she had to prepare herself mentally, and it was difficult for her.

In this study, out of eight participants, seven of them had regular dental examinations and treatment as a child. Only one participant (Participant Seven) who did not get regular dental examinations for some time was the one who grew up for a few years on a First Nation community. He remembers suffering from dental pain, due to an infection and described to me how it was dealt with:

"I remember my grandfather pulling out teeth when I was like nine years old… He just pulled it out. It was broken…it was rotten. He said, 'No use going to the [dentist]'… It was just pliers. That's all it was".

He remembers crying a little after, and being given some ice-pops and being sent outside to play. His expression was one of nonchalance, as if it was no big deal and this was the way things were normally done. When I asked about seeing the dentist as a child, the participants had different experiences based on whom they lived with during the time. The ones who lived for longer periods in foster care or who had some consistency in their home life saw the same dentist as Participant One remembers:

"I remember my foster parent at the time was just like 'ok well here we set you up with an appointment here' and they basically I guess filled out all the paperwork and then every time after that I would come back in like, six months or whatever, I would just go by myself".

Being able to see the same dentist and having good experiences with him enabled this participant to receive all his needed treatment. To this day he continues to attend regular dental exams without hesitation or anxiety. Similarly, Participant Five recalled:

"I haven't had any bad experiences with dental care. Bringing up my kids, I constantly tell them how important it is to have dental care, and taking care of their teeth."

Even though she was placed in the foster system, with both parents incarcerated, her past dental experiences were good. She always saw the same dentist, the dental office that she was taken to was inviting and the staff was friendly. She recalled being given prizes after her visits and actually enjoyed her visits. She emphasized that she was able to take care of her teeth as an adult through her NIHB funding, and is very regular with her own, and her children's routine

dental exams. She was relaxed and did not have any visible anxiety, as she causally mentioned to me that she actually had a dental appointment the following day.

3.2.3.2: Dental Experiences in Jail

Out of eight participants in this study, seven had experienced incarceration for different periods of time, ranging from three months, to several years. The participants described their dental experience in jail as generally poor, with the exception of Participant Seven, who described it as excellent. The factors that made their experiences negative included the long waiting period to see the dentist, the tedious paper work and the general non-caring attitude of the dentists in jail as Participant Six explains:

> "*He was poking needles all over my mouth…He didn't know what he was doing, he was looking for other places to freeze it, you know? He is not a very good dentist. He just believes in pulling the tooth out*".

Participant Seven however, had a much different experience as he describes:

> *"I find dentists more professional than doctors, I find even inside [jail], we call our doctors inside corrections 'Horse doctors' but we'd rather go to the dentist because they seem to do such a good job, but it's more difficult in there because you can either get a filling or get a tooth pulled".*

The unavailability of options made other participants hesitant about having dental care in jail as they felt extractions would be their only choice.

3.2.3.3: Dental Care Seeking Behaviours

When asked about regular dental visits now, the participants mentioned they either felt too anxious to visit the dentist (Participant Two, Three, Four, Seven), could not afford to get

treatment (Participant Two, Four, Six, Seven) or felt too embarrassed about visiting the dentist (Participant Three, Four, Seven, Eight) as Participant Four mentioned:

> *"I just have a sensitive mouth so even the simplest of procedures hurt, and then I have a fear connected to the dentist just from the pain, and then there's also an embarrassment that comes with not having taken proper care of my teeth. So in my experiences, I don't like going to the dentist and even now, because my teeth are pretty bad, I do need a lot of work done."*

Participant Two mentioned that he would lose sleep prior to the visit to the dentist:

> *"It was always okay up till like, the day before [the visit] and then I started thinking, 'Oh God I gotta go to the dentist tomorrow' and it started running through my head. I'd usually have a rough sleep the night before*."

In this study, some participants faced difficulty in accessing dental care even if their NIHB provided them with funding due to the tedious amount of paperwork it took as Participant Seven described:

> *"It's sometimes a hassle going to get anything because there is that federal, provincial overlap. The provincial government really, if you're not living on the reserve, they have nothing to do with you medically, or dentally, but if you come to the city, they're supposed to, but if you're not registered in the city, and you're registered still on the reserve, it just gets complex…It has been a little bit easier here because I go to downtown ... There's a Hastings's one, where you go and there's free dental there."*

In addition to being easier to get treatment from this clinic, he described how he felt more comfortable in the Downtown East Side as it was a neighbourhood he was familiar with and had come to call home when he lived there on parole.

3.2.3.4 Perceptions of Oral Health

The majority of the participants were able to receive needed dental care during their childhood (seven out of eight), many (five out of eight) had poor experiences and similarly these same participants perceive their current oral health to be poor. Participant Six described her experiences as fair, and considers her oral health to be fair as well, however she still needs dental treatment. The remaining five participants mentioned that they have poor oral health, with outstanding dental treatment needs as Participant Two described:

> *"I have a hole in the back of one of my teeth, I only have seven of my own teeth left, and I have a hole in the back of one of them and it bothers me all the time".*

He not only suffered from dental anxiety, but also cannot afford dental care. Participant Three mentioned that she knows that she needs to get dental work done, but she keeps delaying it:

> "*I know right now I have a cavity, okay? And I know I should go see somebody, but there's a big part of me that's just like 'oh it'll be fine, it'll be fine'".*

The participants who mentioned that they have good oral health also have regular dental examinations, low dental anxiety, and a good oral hygiene regimen as Participant One describes:

> *"I brush every day, I floss, I have like, you know this mouthwash that I use. I think I'm doing a good job."*

He appeared confident and comfortable when speaking about his dental health and past experiences. Out of eight participants that I interviewed in this study, six mentioned to me that they were unhappy with how their teeth looked, and that they knew they needed dental work.

They described feeling depressed, ashamed and isolated due to their appearance and how it affected their everyday life and ability to get jobs. Due to their poor dental aesthetic self-perception, Participants Three, Four, Seven and Eight felt that they cannot get jobs that require face-to-face interactions with people; such as front desk jobs, even if they are qualified for them. Participant Four described how the way her front teeth appear impacts her:

> *"It causes me to have low self-esteem and low confidence…it makes me nervous to meet new people, and it makes me nervous to go for job interviews, and things like that. And even just to laugh around anybody, I cover my face because I don't want everybody to see my bad teeth."*

She was not the only participant who described covering her front teeth. Participant Three also mentioned that she felt self-conscious smiling at friends and family due to the way her front teeth looked. Participant Eight mentioned that he feels regret about neglecting his dental health and the consequences of not taking good care of his teeth:

> *"I kind of wish that I didn't struggle with this dentist thing in the past because it's really affecting me now like really bad. I'm more isolated. I don't communicate much with people because I know that even though I'm not smiling and that I'm talking you can still see my teeth."*

He went on to describe how he cannot work in customer service and relegates himself to jobs that do not involve interactions with people due to the way his teeth look, despite being skilled in communication:

> *"I've been with this one place for almost a year, but I'm volunteering and I do excellent work, but on the other hand I'm at a bench and I stare into computer*

monitors and so forth. When…I'm talking with customers and staff explaining technical things to them, I'm very self-aware that they notice my mouth and they take a quick glance to the left or to the right. Then all of a sudden my self-esteem and my confidence start to deteriorate because I'm self-conscious that way."

Participant Seven is a leader of a local First Nation support group, and disclosed that the way his front teeth look is very important for him to be in this position of authority:

"I don't talk to people…I feel like to show them my teeth that should be fixed up...they're constantly probably thinking: what's wrong with me?"

3.2.4 Theme Four: Value of Empathetic Dental Professionals

The participants who are parents are Participant Two, Three, Four, Five, Six and Seven. Participant Two and Seven did not have custody of their daughters but were an active part of their lives. Participant Six lost one child to illness in infancy, and gave one up for adoption. Although most of the participants did not have childhood dental experiences that promoted a positive perception of oral health and dental care for themselves; their past experiences appeared to have a better impact on their children. According to the participants, all of their children were cavity free. They were up to date on their dental exams and not experiencing dental anxiety during visits. The participants described to me how they value kind, and understanding dental professionals when it comes to taking their children to the dentist or even themselves. The following subthemes emerged:

3.2.4.1: Valuing Oral Health of Own Children

For the participants who have children, their oral health was described as a high priority. They established dental homes for their children early on and placed effort in maintaining their oral health. Participant Three describes how she started taking care of her children's mouth even before they had teeth:

> *"When they were first born I remember using a piece of cloth just to like, rub the gums and all and that was even before they had teeth…I didn't want them to be really sensitive about their gums."*

She went on to describe how she started brushing their teeth as soon as they erupted:

> *"They were too little at first.... all they'd do is chew on it [toothbrush] so I would put them on my knee and brush their teeth".*

She explained how none of her six children have ever had cavities and how she makes sure that they brush their teeth. To model good dental habits, she also brushes her own teeth in front of them even though the act of brushing was painful for her. As she explained this, she winced, which demonstrated to me that she still has pain in her teeth. Participant Four also described how important it was for her to make sure her children brush their teeth:

> *"I have this fear that my kids will have bad teeth if I don't [brush]. So, we don't miss days of brushing teeth, ever".*

She described how she did not have a similar experience while growing up:

> *"I think I should have been supervised, and made to brush my teeth correctly, and I think that it should have been made a big deal like I do with my kids. I make it very fun and I give them a lot of praise so that they know they are doing a very good job. And I think that if I had had that, then it would have been more exciting for me."*

She explained the reasons for this being her mother's incarceration and being moved from home to home to live with different relatives, without stability. She also described that she was proud of the fact that her children have no cavities. Participants Three, Four and Five were also very regular with their children's dental visits. Participant Five elaborated how she cared for her children's dental health*:*

> *"They brush every day and they floss every day, and we bring them to see the dentist. If they ever have any issues we bring them as soon as possible".*

She mentioned that she took her children to the dentist for their first visits even before they had teeth. Participants Two and Seven do not live with their children, but still ensured that their daughters had a stable childhood, growing up with their grandparents, and not going down a

similar path as themselves. They also told me how they believed that good oral health, and overall health of their children were important for them as Participant Seven elaborated:

> *"She had a good upbringing with her grandparents, she turned out better than all of us… whether it's dental or [general] health, because if you don't feel good about yourself, then everything else seems to be more troubling in your life."*

3.2.4.2 Dental Professionals and Their Role

The sentiment that kind, empathetic and gentle dental professionals were important was shared by all the participants in this study, but described as especially important for children. Participant Eight mentioned:

> *"I wish the attitudes of dentists were a little more compassionate*".

He does not have any children, but he mentioned how his past childhood dental experiences shaped all his future dental experiences and behaviors. Participant Three said that the dental anxiety from her childhood that she still suffers from makes it difficult for her to get the dental care that she needs. She described how important it was for her to find a gentle dentist for her children and for them not to experience what she did during her childhood.

> *"When my kids were little I took them to a pediatrician right? And I tried to find one that would be really soft and engaging for the kids, so why would I go to a dentist that wasn't like that for my kids? Because I know what it's like to be terrorized."*

Participant Five elaborated what made it easy for her to go to the dentist during her childhood and why she does not suffer from dental anxiety:

"I think it's just how friendly the dentist was that made it fun. They had a huge selection of toys".

This was important for other participants in the study as well; to ensure that the dentist was fun, engaging and above all empathetic and kind as participant four describes her children's dentist:

"*She was very gentle and very comical, really animated for the kids, and it made it a really fun experience."*

Participant Four described how she loves taking her children to the dentist who made the experience fun for them:

"I love taking my child to the dentist…my kids' teeth and mine are completely different. They have nice straight, white, healthy teeth- my six-year-old boy doesn't have any cavities. He loves brushing his teeth. He likes going to the dentist. And he's proud of his teeth and I have never been proud of my teeth, ever."

Figure 3.1

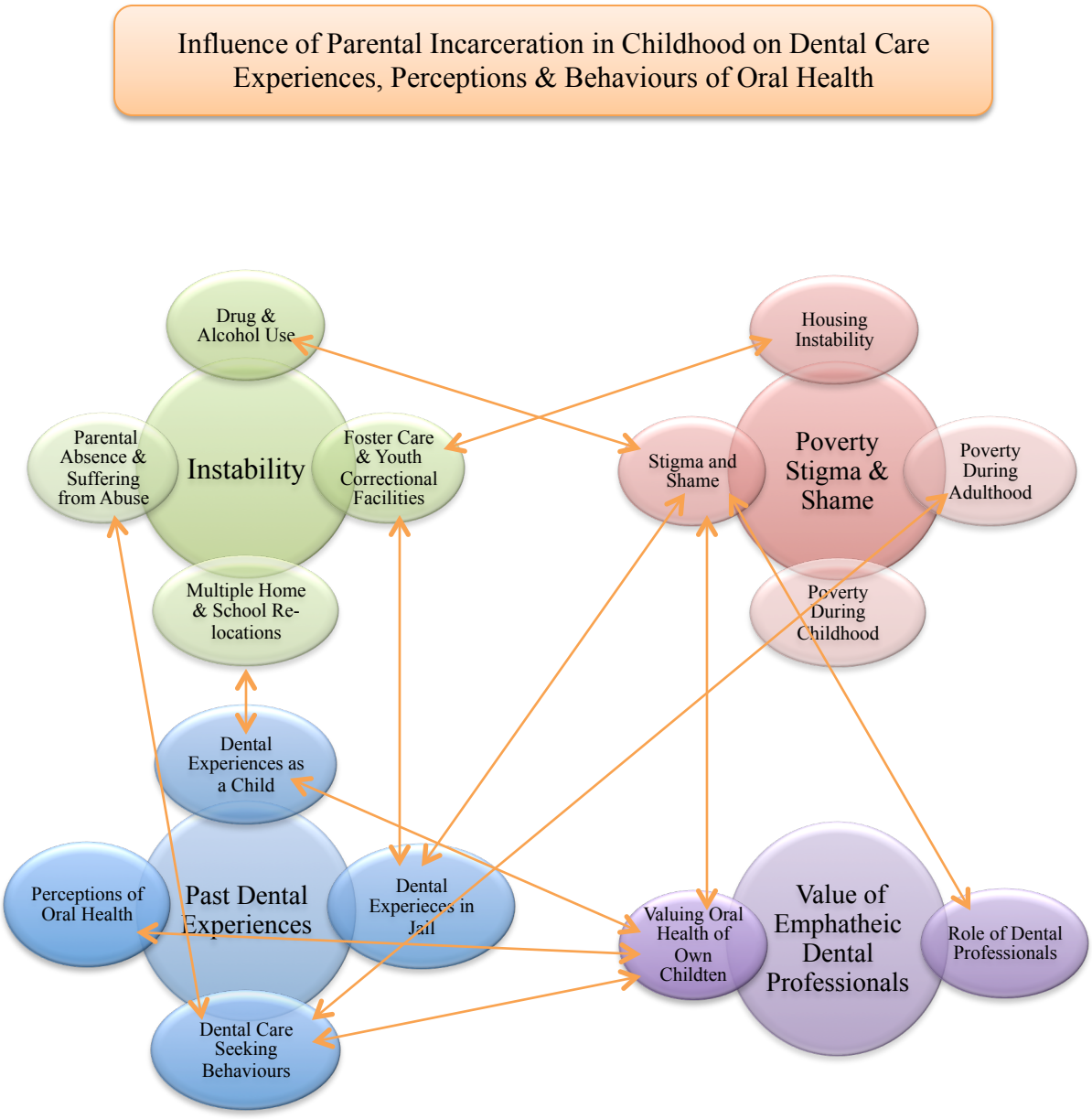
Influence of Parental Incarceration in Childhood on Dental Care Experiences, Perceptions & Behaviours of Oral Health
Drug & Alcohol Use
Parental Absence & Suffering from Abuse
Instability
Foster Care & Youth Correctional Facilities
Multiple Home & School Re-locations
Housing Instability
Stigma and Shame
Poverty Stigma & Shame
Poverty During Adulthood
Poverty During Childhood
Dental Experiences as a Child
Perceptions of Oral Health
Past Dental Experiences
Dental Experieces in Jail
Dental Care Seeking Behaviours
Valuing Oral Health of Own Childten
Value of Emphatheic Dental Professionals
Role of Dental Professionals

Figure 3.1 illustrates the overall themes and subthemes represented in separate colours. The arrows demonstrate the relationships between subthemes. The large circle represents each theme, with its subthemes in ellipses of the same colour.

The subthemes of multiple home and school relocations impacted the participants' dental experiences as a child; with their relocations influencing which dentist they saw. Similarly foster care and youth correctional facility experience are related with housing instability as some participants experienced housing instability prior to being placed in foster care. Youth correctional facility experiences are related to dental experiences in jail. Parental absence and suffering from abuse in childhood impacted dental care Seeking behaviours in adulthood, with avoidance of dental care due to mistrust of authority figures.

The subtheme of stigma and shame has a relationship with drug and alcohol use and dental experiences in jail, as the participants experienced stigma and shame due to their incarceration history and coped by using drugs, which also has stigma associated with it. This subtheme also has a relationship with valuing oral health of own children as the participants ensured that they did not repeat similar experiences for their own children. The role of dental professionals also has a relationship with stigma and shame, with participants in this study valuing dental professionals who are empathetic and understanding.

Poverty during adulthood has a relationship with dental care seeking behaviours as inability to afford dental care in adulthood influenced the participants' dental care seeking behaviours. Valuing oral health of own children is a sub-theme with relationships with many other sub-themes namely, dental experiences as a child, perceptions of oral health, dental care seeking behaviours and stigma and shame. This is due to the fact that participants in this study

did not want similar experiences to repeat for their children, and they prioritize their children's oral health the most.

Chapter 4: Discussion

Although the ACE under investigation was parental incarceration, others also emerged. This highlights that individuals studied in this population did not necessarily suffer from one type of ACE. The combination of poverty, parental absence, experiences of stigma and shame contributed to their childhood experiences and therefore most likely increased the number of ACE. Each theme will be discussed in the following sections.

4.1 Instability

Instability in the participant's lives during childhood was in part due to the multiple relocations that they experienced, and the difficulties that they endured adjusting to new neighborhoods and schools. The absence of their incarcerated parent also contributed to their feeling of instability during childhood. There is a critical knowledge gap due to the lack of official protocols in Canada regarding where and under what conditions children reside following the arrest of a primary caregiver (McCormick et al, 2014). Therefore, it is unknown how many children are placed in foster care or under the care of relatives (McCormick et al, 2014). Incarceration can cause multiple issues for families of individuals who are prisoners. These include traumatic separation from their parent, childcare arrangements that are unstable, family income that is reduced, shame, stigma, and home and school relocations (Geller & Franklin, 2014).

Individuals in our study experienced embarrassment during childhood due to their parental incarceration and lived in constant fear of someone finding out about their situation. Most recalled growing up as anti-social individuals with few friends and little contact with family and siblings. It has been previously demonstrated that parental absence due to incarceration has a detrimental effect on the child's well-being, mental and physical health well

into adulthood (Lee et al., 2013 ; Shlafer & Poehlmann, 2010 ; Denby, 2012). Six out of eight participants in our study did not finish high school, with instability at home causing them to either drop out of school or have poor attendance in order to take care of their siblings. The long-term impact of parental incarceration and the instability that it causes affects also the individual's drug use, educational performance and social dysfunction (Murray, 2012). Seven out of eight participants in our study were involved with the criminal justice system. This finding is not uncommon as others have found that children of incarcerated parents are at a higher risk of delinquent behaviour and at risk of involvement in the justice system (Shlafer & Poehlmann, 2010). Criminality in the family can lead to delinquent behaviour in the child, who often observes a parent modeling such behaviour and then repeats it (Murray & Farrington, 2005). Family factors that contribute to inter-generational offending include dysfunctional and unstable home environments (Farrington et al., 2009).

Individuals placed in foster care had mixed experiences. Those who were moved often such as Participant Five, recalled her foster care experiences to be poor, however those who were placed in the same home for several years recalled their experiences to be good such as Participant One and Seven. Older foster youth who had a mentor for at least one year have been seen to have better educational outcomes (Munson & McMillen, 2009), and these two participants, despite being incarcerated themselves did get their Graduate Education Diploma.

Participant Seven mentioned for him the fear and anxiety related to dental care was due to the lack of trust of 'authority figures' due to the sexual and physical abuse he suffered during his time in Residential School. A review of the literature conducted by Larijani & Guggisberg (2015) found to various degrees, that a history of sexual violence victimization is associated with dental fear that most often results from a perceived lack of control, being placed in a horizontal

position, feelings of embarrassment, and difficulties with the physical proximity of the dentist. Dental fear in turn has been associated with lack of regular dental attendance, which further affects the dental health of individuals (Meng et al., 2007).

All the participants in this study were using drugs or alcohol by the age of 12. This finding has been demonstrated in a systematic review that parental incarceration may be associated with future drug use (Murray et al., 2012). Participant Seven also self-medicated himself through street drugs instead of seeking dental treatment. Drug users have been known to self-medicate instead of seeking dental treatment, as it is an easier way to diminish their suffering from dental pain (Robinson et al., 2005).

4.2 Poverty, Stigma and Shame

Our findings highlight the fact that children of incarcerated parents might experience poverty and housing instability that can each contribute to poorer oral and overall health in various ways. The overall childhood poverty rate in Canada is 18%, though unevenly distributed with First Nations children experiencing the most at 51% and 60% off and on reserve respectively (MacDonald & Wilson, 2016). Poverty may also contribute to malnutrition or incorrect diets, which can contributes to poor dental health. Poverty may also have an effect on the behaviour of the child in the dental office due to the toxic stress that poverty invokes (Da Fonseca, 2012).

In our study, participants described that their dental needs during childhood were mostly met, however they did experience overall financial hardships growing up. Four out of eight participants experienced growing up in poverty and also experienced housing instability or homelessness during childhood. The rise in homelessness seen as a result of parental incarceration may cause children to move into a shelter with a parent, into the care of another

family member or into foster care (Wildeman, 2014). This situation has been seen more in relation to paternal imprisonment as compared to maternal imprisonment (Wildeman, 2014). In Canada, one third of households live in sub-standard conditions or in housing need and Canada is the only country in the G8 (group of eight developed nations) without a national housing strategy (Waterston et al., 2015). Those individuals who experienced housing instability or homelessness in adulthood did not have regular access to a sink, toothbrush, toothpaste or a toilet for the times they were displaced. They mentioned that they could not care for their teeth during this time and their oral health suffered as well. Significant relationships have been observed between poor self-reported oral health and vulnerabilities such as housing instability among individuals in Canada (Wallace et al., 2015).

Participants in this study who lived for long periods with their non-incarcerated parent or relative recalled no difficulty in accessing dental care financially during their childhood. This could be due to the BC Healthy Kids program, or other government funded benefits that fund dental treatment for children under the age of 19 (Children & Development, 2011). In provinces such as British Columbia, Healthy Kids funding covers dental care for up to 1400$ every two years, in children (under 19) of low socio-economic families. Those participants who went to foster care indicated that their basic dental needs were met in their homes. Toothpaste, toothbrush and other hygiene supplies were provided in the foster homes and regular dental visits were also maintained. This could likely be due to the check on foster parents by social workers to ensure the child's needs are met, including medical and dental needs. Other programs such as the NIHB (Non-Insured Health Benefits) have been established for Aboriginal children who are not eligible for Healthy Kids funding (Children & Development, 2011).

Once the children age out of government funded care, they are dependent upon personal financial resources or work-related dental insurance benefits, which proves detrimental for low-income and unemployed individuals (Moeller, 2013). Those with First Nation status experienced less financial barriers to accessing dental care in adulthood. However, they do face other barriers to access to dental care such as bureaucracy, and not finding a clinic that accepts payments made by NIHB.

Seven out of eight participants in this study were incarcerated themselves. A study conducted in Florida with a sample of more than 64,000 youth in custody demonstrated that ACE was highly prevalent in their lives (Baglivio et al, 2014). Not only does ACE increase the chances of youths to become involved in the juvenile corrections system, but it also increases their risks of re-offence (Baglivio et al, 2014). Participants who had experienced incarceration themselves in this study felt stigma and shame due to it. Shame, embarrassment and loss of self-esteem can have a profound effect on the individuals' social functioning (Caspi et al., 2006). Social isolation, as experienced by participants in this study, may lead to depression, which leads to poor overall health (Caspi et al., 2006).

Aboriginal individuals in our study felt discriminated against when they were released from prison, such as Participant Seven. Marginalization and alienation of Aboriginal individuals after release from prison has been reported historically (La Prairie, 2002; Vanhooren et al., 2017). Qualitative studies investigating the experiences of individuals who have been incarcerated and re-enter society have found that feelings of loss, guilt, shame and despair along with being rejected by former friends, as experienced by Participant Two (Vanhooren et al., 2017). Stigmatization has also been deemed a fundamental cause of health inequalities in marginalized populations such as individuals with HIV positive status, older adults, and

individuals with mental illness (Hatzenbuehler, 2013; Brondani et al., 2017). Stigma among these populations has also been shown to impact dental care seeking behavior (Donnelly et al., 2016; Brondani et al., 2017). Findings from this study indicate that similar dental care seeking behavior due to stigma from incarceration occurs. Participants in this study who were incarcerated for a longer period of time avoided seeking dental care in clinics that cater to the majority of the population, but instead preferred to get medical and dental treatment, in clinics in Downtown East Side where they felt more 'at home'. The finding of barriers to access to care due to stigma and shame has also been seen with other marginalized populations such as People Living with HIV/AIDS (PLWHA) (Donnelly et al., 2016; Brondani et al., 2016). A qualitative study conducted with 25 PLWHA in Vancouver, BC concluded that self-stigma and public stigma exist in these populations with regards to dental care (Brondani et al., 2016).

4.3 Past Dental Experiences

Participants' in this study described how their past dental experiences influence their current dental perceptions and behaviors. Past dental experiences are closely associated with current and future dental attendance of individuals (Seligamn et al., 2017). This in turn can affect how a person views their oral health and its importance (Armfield et al., 2007). Past dental experiences tend to influence future dental care for most individuals, which is why it is important for these experiences to be positive during childhood (Mendoza-Mendoza et al, 2015).

Participants in this study described fear of needles; which caused many to delay dental treatment until the pain became unbearable and the only viable option left was dental extractions and thus premature tooth loss. The fear of dental injections or a general needle phobia are known to be significantly associated with delaying dental treatment and can lead to avoidance of necessary dental treatment (Berge et al., 2016). Presence of dental pain and dental caries have

been seen to be associated with dental fear in adults, regardless of their socioeconomic origin and utilization of dental services in childhood (Torriani et al., 2014). Some participants in this study were also IV drug users, but despite this, needle phobia still existed for these individuals. Barriers to dental care for drug users include needle phobia, fear of dentists, acceptability of the dental services and the ability to self-medicate (Robinson et al., 2005).

During childhood all the participants had a caregiver and funding for dental care, therefore their dental needs were met for the most part, and non-financial barriers did not seem to impact them during their childhood. However, six out of eight individuals faced non-financial barriers to dental care during adulthood. These barriers were discrimination, dental fear, bureaucracy and embarrassment over the way their teeth look; and these influenced their dental care seeking behaviours during adulthood. They felt uncomfortable going to the dentist either due to neglecting their own teeth or the time they spent in prison. One study found that despite having financial means, access to medical and dental care for individuals with an incarceration history was worse due to the non-financial barriers of stigma and embarrassment as a result of their incarceration history (Kulkarni et al., 2010). Participants described the impact their dental aesthetics had on their lives. They felt unhappy and socially isolated themselves due to the way they looked. Self-perception of smile attractiveness has psychosocial importance for individuals and can affect their everyday life (Pieter Van der Geld et al., 2007), which in the case of these five participants was negative. Dental problems that are associated with difficult access to dental care also tend to influence self-perceived oral health (Chi & Milgrom 2008).

Overall, the experiences of individuals in the current study had a strong influence on informing their current dental perceptions and dental care seeking behaviors. In general, those participants who had good experiences maintained their dental care, with low dental fear and

anxiety, while those with poor dental experiences still suffered from dental anxiety and were unable to maintain their oral health. This may be true for those individuals who do not suffer from parental incarceration as well, however the fact that these individuals suffered from more than one ACE compounds the effects of their poor experiences, and makes it difficult for them to recover.

4.4: Value of Empathetic Dental Professionals

The participants in this study who had either custody or a relationship with their children valued the oral health and dental care of their children. This was due to a combination of their past dental experiences and due to the pain and suffering they still experience on account of their own teeth. A qualitative study with a focus on low-income parents and not on adult children of incarcerated parents, showed results similar to ours. This study with 28 low-income parents demonstrated that parent's experiences influenced their oral health related behaviours, intentions and beliefs. Similar to our participants, these parents had received little attention to their own home oral health care during childhood. They did not have supervised brushing or instructions on how to care for their teeth. However they wanted their own children to have better oral health and felt motivated to place a high value on their children's preventive oral care (Lewis et al., 2010).

In the present study, the individuals who are parents placed the highest value on their children's oral care, and gave it more priority versus their own. However, others have suggested that adults who have a childhood dental experience that was 'uneasy' or uncomfortable, tend to delay the dental treatment needs for themselves and their children (Smith & Freeman, 2010). Five participants in our study who had poor dental experiences were of an older age group. This could be due to the fact that paediatric dentistry has evolved and approaches were different at

that time. An early study describes how dental professionals of that time try to interrupt or prevent a child's resistive behaviour as they find managing the 'child patient' time consuming, slow paced and costly (Venham & Gaulin-Kremer, 1983). Rushing through treatment, as Participant Three described leads to a child being traumatized or fearful of dentists, which is detrimental to their future oral health. Dental fear in children is strongly associated with inadequate dental management, with the dentist rushing through treatment causing the parent and the child's anxiety levels to increase (Mendoza-Mendoza et al, 2015). Although this is not only true for the participants in this study, but can be applied universally to children without parental incarceration, it needs to be stated that children with an incarcerated parent are at a higher risk for emotional and psychological effects due to their unique circumstances and experiences (Hairston, 2007).

4.5 Trauma Informed Care and Universal Trauma Precautions

The American Academy of Pediatrics has described children of incarcerated parents as a "*vulnerable population*" (AAP, 2007). This is not only due parental incarceration, but also compounded by the fact that these children can suffer from more than one ACE (Gordon, 2009). The need for dental professionals to practise Trauma Informed Care (TIC) for children as well as adults who have experienced ACE was evident from our study. In Canada, 76% of adults have reported some form of trauma exposure occurring in their lifetime (Van Ameringen et al., 2008). In British Columbia, among youths who use substances, 25% have a history of trauma (Torchalla et al., 2012).

TIC is a treatment framework that involves the understanding, recognition and appropriate response to the effects of trauma on individuals (Harris & Fallot, 2001). TIC aims to understand connections between a person's behaviours and a previous history of trauma (Hodas,

2006). However not all individuals or caregivers of children who have suffered from traumatic experiences will disclose this history to dentists or dental professionals. For this reason the adoption of TIC can provide a framework for dental care providers to treat children and adults who may have suffered from traumatic events (Reeves, 2015).

The TIC pyramid, proposed by Raja et al., (2014) can be utilized to integrate TIC into daily practise in the dental setting. According to the TIC pyramid, the following play an important role in treating patients who have suffered through childhood trauma, such as parental incarceration: strong behavioural and communication skills, understanding that traumatic experiences will have effects on an individual's health and engaging in inter-professional collaboration (Raja et al., 2014). Examples of behavioural and communication techniques in the TIC pyramid are start-and-stop signals such as hand raising, tell-show-do and taking breaks when a patient gets overwhelmed. In paediatric dentistry Tell-Show-Do is an excellent behavioural tool that is used to alleviate dental anxiety, and it can be applied to patients of all ages.

Universal Trauma Precautions (UTP) can be used with all dental patients, to make them more comfortable and to lessen apprehension. UTP assume that we do not know what adverse experiences an individual has gone through, and by displaying understanding, and empathy we avoid re-traumatizing them (Reeves, 2015; Raja et al., 2014). UTP do not require patient screening or any knowledge of it, instead UTP involve making small changes to the dental practise, such as displaying empathy, patience and trying to understand why a patient's behaviour is unusual, in order to establish trust with potentially traumatized patients (Raja et al., 2014).

It is quite clear from our participants that parental incarceration may have far reaching effects on children that carry on into adulthood. To our knowledge this is the first study to explore this ACE as it relates to oral health among adults. Though small in scale, our findings can be used to design larger studies to help inform appropriate strategies and interventions to aid this vulnerable population in achieving adequate oral health. Our results also suggest that dental professionals undertake a TIC approach and practise UTP for all children, especially those who live in foster care, as they may have suffered from an ACE such as parental incarceration.

4.6 Limitations

This study did have some limitations. First of all the study sample size, although typical for a qualitative study using Interpretive Phenomenology, does not produce results that are generalizable, though they may be transferable to a similar population. This study was designed to be exploratory and therefore a non-uniform participant pool was selected to offer maximal variation in experiences. While this may limit the transferability of the findings, it offers insight into a focus for future in-depth studies with sub-samples of the target population. The findings of this study show that some of the themes discovered in this study are not necessarily restricted to children of incarcerated individuals, but are also seen in other vulnerable populations such as children who experience other types of ACE.

The ability to confirm my data analysis and findings with only one participant is also a limitation. I would have liked to have more of the participants review my findings and confirm or clarify my analysis, however it was not possible due to their inability to do so due to time constraints, the inability to meet, lack of access to a phone or internet and not having a permanent address to send documents. It is also possible that the participants were not interested in the findings. Another reason could be due to the mistrust of dental and medical professionals

that individuals in these circumstances have. These issues need to be considered in the design of future studies to ensure that this aspect of rigor does not limit the trustworthiness of the analysis. Recall bias is also a limitation that I possibly faced. This may affect the accuracy of the individual's accounts of their childhood.

Chapter Five: Conclusion

5.1 Conclusion And Recommendations

This study aimed to provide awareness into the concepts that exist about oral health and dental care in adults that have experienced parental incarceration. We found that for the most part, these individuals were able to receive dental care on a regular basis during childhood, whether it was urgent or general dental care; however preventive dental care at home was lacking. Of particular importance we found that the manner in which dental care was delivered in childhood had a strong influence on dental behaviours in adulthood. Financial issues experienced by the participants were also expressed, including: growing up in poverty, experiencing housing instability and ageing out of government sponsored dental care and being unable to afford dental insurance.

Some participants' revealed that they experienced shame and stigma due to their parents' and their own incarceration. This inhibited them from seeking dental care from regular clinics as adults. They overcame this by going to dental clinics that are accustomed to treating individuals with similar circumstances. Participants also stressed upon loss of self-esteem and depression that they experience due to their perceived poor dental aesthetics and difficulty in finding jobs that require customer interactions.

We were also able to document beliefs, behaviours and practises of these individuals in caring for their own oral health and that of their children, and found that the oral health of their children is given more priority than their own. This is a positive finding as it shows that the cycle of poor oral health between generations can be broken. Those individuals who had poor dental experiences in their childhood, made sure that their children do not have similar experiences.

The findings of our study indicate that, it is important for dental practitioners to understand and practise TIC, and UTP and to be cognizant of a child's potential vulnerability.

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Appendix A: Interview Guide

I. Childhood experience of parental incarceration

1. Can you tell me a bit about what was like to grow up with your mom or dad in prison?

- Who was in prison, for how long or how often?
- Who did you live with during the time your parents were away?
- Were you living with family or placed in a foster home? How many homes did you have during this time period?
- What was it like to change homes and neighbourhoods, schools, friends?

II. Medical and Dental care experiences during childhood

1. Can you tell me a bit about what it was like to go to the doctor when you were a child?

- How often did you go to the doctor?
- For anything in particular?
- Do you remember who used to take you?

2. Can you tell me a bit about what it was like to go to the dentist when you were a child?

- How often did you go to the dentist?
- For anything in particular?
- Do you remember who used to take you

3. Who did you approach when you had medical/dental problems and was this person willing to listen/help?

- Do you remember if you ever had tooth pain during your childhood
- What did you do for the pain (seek help? bear it…?)
- What was it like to cope with this feeling?
- Who showed or taught you how to care for your teeth in your childhood?

- Were you aware of having any insurance for medical and dental care during this time?

III. Current perceptions of oral health and dental care:

1. How would you describe the health of your mouth now?
2. How does it affect your life? (Work, relationships, social contexts)
3. How do you feel about going to the dentist now?
4. How would you prioritize the health of your mouth now?
5. (Applicable to those with a history of incarceration) When you were incarcerated, what type of dental care if any, did you receive?
6. What type of care do you think you needed or wanted?
7. What type of oral care products were you provided with?
8. What do you think about dental care now?
9. How do you care for your teeth now?

IV. Current perceptions of dental care for children:

1. While you were in prison what type of dental care did your children receive that you are aware of?
2. What dental care do they receive now?
    - How do you care for your children's teeth?
3. What do you think about taking your child to the dentist now?
    - How do they cope with going to the dentist?

V. Barriers and facilitators to obtaining oral health services for themselves and their children

I would like to spend a few minutes talking about your experience of trying to access oral health services **in general**.

1. Who do you usually seek oral health services from? Why?
2. Who do you usually receive oral health services from? Why?
3. What type of services are you usually seeking? Why?
4. Is there anything that makes it easier for you to get the services that you want or need?
5. Is there anything that makes it more difficult to get the services that you want or need?

VI. Summation

Before we end today I would appreciate it if you could answer a few questions about yourself (demographics). If there are any questions, I would be happy to answer them.

Thank you.

Demographics, these can be collected before or after the interview and include:

- Age:
- Ethnicity:
- Highest level of education:
- Employment (Y/N):
- Number of children:
- Period of parental incarceration:
- Primary care provider during parental incarceration:
- Period of incarceration (if applicable):
- Number of homes and schools changed:

Appendix B: Consent Form

INFORMATION AND CONSENT FORM FOR STUDY PARTICIPANTS

STUDY TITLE:

Exploring childhood oral health and dental care experiences of adults whose parents were affected by the criminal justice system

I. WHO IS CONDUCTING THE STUDY?

Principal Investigator: Dr. Leeann Donnelly.

Co-investigator: Dr. Nida Amir

II. WHY SHOULD YOU TAKE PART IN THIS STUDY AND WHY ARE WE DOING IT?

You are being invited to take part in this research study because you have experienced parental incarceration during your childhood, and you also have a child. Our study team wants to learn more about your dental care experiences during your childhood and what you think about going to the dentist now.

If you wish to participate, please sign on Page 5. You do not have to provide any reason for your decision not to participate. You are still free to withdraw at any time without giving any reasons for your decision by contacting the Principal Investigator.

Please take time to read the following information carefully and to discuss it with your child, family, friends, and doctor/dentist before you decide.

III. WHAT HAPPENS IF YOU SAY, "YES, I WANT TO BE IN THE STUDY"?

If you say yes here is how we will do the study:

- We will contact you and set up a time and date for a meeting with you in the privacy of your home or any other location where you are comfortable.
- An interview will be conducted with you, which will be recorded using audio-visual media.
- During the interview we will ask you about your childhood experiences with dental care and health care.
- We will ask about how you feel about going to the dentist now.
- You will also be asked about your perceptions about oral health and dental care for yourself and your children.
- We will require 1-1.5 hours of your time one time, for which you will be compensated $50.
- Your name or any identifying features will not be revealed.
- You can opt out of the study at any time.

IV. STUDY RESULTS: what will we do with the information we collect?

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

V. POTENTIAL RISKS OF THE STUDY: is there any way being in this study will be bad for you?

We do not think there is anything in this study that could harm you or be bad for you. If you feel a question seems sensitive or too personal you do not have to answer it. Please let one of the study staff know if you have any concerns.

VI. POTENTIAL BENEFITS OF THE STUDY: what are the benefits of participating?

No one knows whether or not you will benefit from this study. There may or may not be direct benefits to you from taking part in this study. This study will help children and adults in a similar situation as yourself benefit from the information you provide. We hope that the information learned from this study can be used in the future to benefit other people in a similar situation.

VII. WHAT HAPPENS IF I DECIDE TO WITHDRAW MY CONSENT TO PARTICIPATE?

You may withdraw from this study at any time without giving reasons. If you choose to enter the study and then decide to withdraw at a later time, you have the right to request the withdrawal of your information collected during the study. This request will be respected to the extent possible. Please note however that there may be exceptions where the data will not be able to be withdrawn for example where the data is no longer identifiable (meaning it cannot be linked in any way back to your identity) or where the data has been merged with other data. If you would like to request the withdrawal of your data, please let your study doctor know.

VIII. HOW WILL MY TAKING PART IN THIS STUDY BE KEPT CONFIDENTIAL?

Your confidentiality will be respected. However, research records or other source records identifying you may be inspected in the presence of the Investigator or his or her designate and by representatives of UBC Behavioural Ethics Board for the purpose of monitoring the research. No information or records that disclose your identity will be published without your consent, nor will any information or records that disclose your identity be removed or released without your consent unless required by law.

You will be assigned a unique study number as a participant in this study. This number will not include any personal information that could identify you (e.g., it will not include your Personal Health Number, SIN, or your initials, etc.). Only this number will be used on any research-related information collected about you during the course of this study, so that your identity will be kept confidential. Information that contains your identity will remain only with the Principal Investigator and/or designate. The list that matches your name to the unique study number that is used on your research-related information will not be removed or released without your consent unless required by law.

Your rights to privacy are legally protected by federal and laws that require safeguards to insure that your privacy is respected. You also have the legal right of access to the information about you that has been provided to the sponsor and, if need be, an opportunity to correct any errors in this information. Further details about these laws are available on request to your study doctor.

IX. WHAT HAPPENS IF SOMETHING GOES WRONG?

By signing this form, you do not give up any of your legal rights and you do not release the study doctor, participating institutions, or anyone else from their legal and professional duties.

X. WHAT WILL THE STUDY COST ME?

There are no costs for participating in this study and you will be compensated $50 for your time.

XI. WHO DO I CONTACT IF I HAVE QUESTIONS ABOUT THE STUDY DURING MY PARTICIPATION?

If you have any questions or would like further information about this study before or during participation, you can contact, the Principal Investigator, Dr. Leeann Donnelly.

XII. WHO DO I CONTACT IF I HAVE ANY QUESTIONS OR CONCERNS ABOUT MY RIGHTS AS A SUBJECT DURING THE STUDY?

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the University of British Columbia Office of Research Ethics by e-mail at RSIL@ors.ubc.ca.

XIII. CONTACT INFORMATION FOR SUPPORT NETWORKS:

The following societies provide a wide range of services and support and can be contacted if you require help: Womenin2healing, Elizabeth Fry Society of Greater Vancouver and John Howard Society British Columbia. These societies have a far-reaching support network.

- Womenin2healing: http://www.womenin2healing.org

- John Howard society: http://www.johnhowardbc.ca
- Elizabeth Fry Society of Greater Vancouver: https://www.elizabethfry.com

STUDY TITLE:

Exploring childhood oral health and dental care experiences of adults whose parents were affected by the criminal justice system

XIV. PARTICIPANT CONSENT:

- I have read and understood the information in this consent form.
- I have had enough time to think about the information provided.
- I have been able to ask for advice if needed
- I have been able to ask questions and have had satisfactory responses to my questions.
- I understand that all of the information collected will be kept confidential and that the result will only be used for scientific purposes.
- I understand that my participation in this study is voluntary.
- I understand that I am completely free at any time to refuse to participate or to withdraw from this study at any time, and that this will not change the quality of care or services that I receive.
- I authorize access to my health records as described in this consent form.
- I understand that I am not waiving any of my legal rights as a result of consenting to participate.
- I understand that there is no guarantee that this study will provide any benefits to me.

- I have read this form and **I am giving consent for my participation by signing this form**.

The participant and the investigator are satisfied that the information contained in this consent form was explained, that all questions have been answered, and that the participant assents to participating in the research.

SIGNATURES

_____	_____	_____
Participant's Signature (consent For audio recording)	Participant's Printed Name	Date
_____	_____	_____
Participant's Signature	Participant's Printed Name	Date

_____	_____	_____	_____
Signature of Person Obtaining Consent	Printed name	Study Role	Date

Appendix C: Recruitment Poster

WOULD YOU LIKE TO PARTICIPATE IN A RESEARCH STUDY?

Principal Investigator:

Dr. Leeann Donnelly

Co – Investigator:

Dr. Nida Amir

Title of the study:

Exploring childhood oral health and dental care experiences of adults whose parents were affected by the criminal justice system

What is the purpose of the study?

We want to know about the childhood dental care experiences of individuals whose parents were impacted by the criminal justice system. We also want to know about current perceptions and beliefs that individuals have about dental care and oral health for themselves and their children.

Who do we want to talk to?

We want to talk with adults who as children had parents who were impacted by the criminal justice system.

What will you do?

Participate in a private and confidential interview that will last about one hour with the investigators.

What will we talk about?

- What you know about oral health
- Your past dental experiences during your parent's incarceration
- Your past and current access to dental care
- Your beliefs about oral health
- Your thoughts on visiting the dentist for yourself and your child
- Your perceptions about dental care and oral heath for your children

Where and when will the interviews take place?

The interviews will take place at a time and place convenient for you that is both, private and confidential:

DATE _____ TIME _____.

Who can you contact for more information or to participate in the study?

If you wish to participate in this study, have any questions or require any further information in regard to this study please contact:

Dr. Nida Amir

Thank you for your consideration

Appendix D: Sample From Codebook