

**ETHICS AND YOUTH GENDER HEALTH CARE:
HORMONE THERAPY INITIATION DECISION-MAKING OF
TRANSGENDER YOUTH, PARENTS, AND HEALTH CARE PROVIDERS**

by

Drew B. A. Clark

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The following individuals certify that they have read, and recommend to the Faculty of Graduate and Postdoctoral Studies for acceptance, the dissertation entitled:

Ethics and Youth Gender Health Care: Hormone Therapy Initiation Decision-Making of Transgender Youth, Parents, and Health Care Providers

Submitted by Drew B. A. Clark in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the Faculty of Graduate and Postdoctoral Studies (Interdisciplinary Studies).

Examining Committee

Dr. Elizabeth Saewyc (Supervisor)

Dr. Sheila Marshall (Supervisory Committee Member)

Dr. Alice Virani (Supervisory Committee Member)

Dr. Jean Shoveller (University Examiner)

Dr. Patricia Rodney (University Examiner)

Dr. Annie Pullen Sansfaçon (External Examiner)

Abstract

Many transgender (trans) youth require hormone therapy to bring their bodies into alignment with their gender; however, these youth frequently experience barriers to needed health care. Health care providers supporting trans youth encounter challenges of their own, including unresolved ethical dilemmas, a lack of consensus surrounding clinical practices, and a limited body of empirical research. Increased understanding of youth and parent experiences with decision-making around hormone therapy initiation could serve to inform clinical practices, but this topic remains unexamined in the literature. Existing research on trans youth experiences with hormone therapy generally includes youth who are enrolled in gender clinics, without attention to those actively experiencing barriers to care. Therefore, the aim of this study was to explore how trans youth with a broad range of health care experiences, parents of trans youth, and health care providers made decisions around hormone therapy initiation. This constructivist grounded theory study was conducted in British Columbia, Canada. Trans youth (aged 14-18), parents of trans youth, and health care providers offering hormone therapy readiness assessment/care planning services participated in semi-structured interviews. Youth and parents responded to questions and created lifeline drawings detailing their experiences both making and enacting decisions related to hormone therapy initiation. Health care provider interviews focused on ethical dilemmas and decision-making. Three-phase temporal models of decision-making processes were generated based on youth and parent interviews, highlighting common experiences before, during, and after engagement with health care providers. Decision-making processes varied; some decisions were made independently and some were shared. Five conditions necessary for engagement in shared decision-making within youth gender health care

emerged, focused on strong relationships, strong communication, role agreement, decision agreement, and time. The Belief-Dilemma-Action Model was developed to illustrate three key constructs relevant to health care provider ethical decision-making processes. Beliefs, dilemmas, and actions were found to interact with one another, influencing the construction and resolution of ethical dilemmas in practice. Key dilemmas identified centered around family conflict, potential harm (e.g., regret), youth capacity to consent to care, and resource scarcity. Recommendations are given for clinical practice, ethical decision-making approaches, health care provider education, and future research.

Lay Summary

This study explored how transgender (trans) youth, parents of trans youth, and health care providers who work with trans youth made decisions around initiating hormone therapy.

Decision-making processes of youth and parents, as well as challenges faced by youth when trying to access hormone therapy, were documented. Analysis of how youth, parents, and health care providers made decisions led to identification of five conditions necessary to support shared health care decision-making: strong relationships, strong communication, role agreement, decision agreement, and time. The ethical dilemmas and ethical decision-making approaches of health care providers working with trans youth were complex. The Belief-Dilemma-Action Model was developed to illustrate these processes, then used to better understand the ways health care provider predicted they would respond to a youth with complex a family situation. Recommendations for clinical practice, ethical decision-making practice, health care provider education, and future research are provided.

Preface

This dissertation is an original intellectual product of the author, B. A. Clark. The fieldwork reported in Chapters 4-5 was covered by the following certificates: University of British Columbia Behavioural Research Ethics Board (H16-01146), the University of British Columbia Children's and Women's Health Centre of British Columbia Research Ethics Board (CW16-0169), the Vancouver Coastal Health Research Institute (V16-02246), and Northern Health Research Review Committee (RRC H 2016-0042).

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This study took place on Turtle Island, on lands also known as British Columbia, Canada. Interviews and other research activities took place on traditional and unceded territories throughout the province. As a non-Indigenous person, I undertook this project as an uninvited guest on these lands, with great appreciation for this opportunity and for the guidance of my Indigenous colleagues who supported me to engage in this work. I acknowledge that the work presented here is in large part bound in a western, colonizing medical framework, and the

language and social constructs used may not represent the experiences and understandings of Indigenous trans and Two-Spirit people. I offer this research as my interpretation of current practices and humbly remain committed to continued decolonization of my work.

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Chapter 1: Introduction

Transgender (trans) youth are living in their authentic genders at younger ages and in greater numbers (Alegria, 2016; Olson J, Forbes C, & Belzer M, 2011). While stigma and discrimination remain pervasive, increasing societal awareness and acceptance, along with expanding access to medical interventions, are shifting the possibilities for youth to live comfortably in their authentic genders (de Vries et al., 2014; Hidalgo et al., 2013; McFarling, 2016; Olson, Durwood, DeMeules, & McLaughlin, 2016; Taylor & Peter, 2011; Veale, Saewyc, Frohard-Dourlent, Dobson, & Clark, 2015). A growing body of research indicates endocrine care (e.g., hormone therapy) is beneficial, however youth routinely experience barriers to accessing this medically necessary care (Clark, Veale, Greyson, & Saewyc, 2017; de Vries et al., 2014; Gridley et al., 2016; Khatchadourian, Amed, & Metzger, 2014; Vance, Halpern-Felsher, & Rosenthal, 2015). Access to health care and social support is crucial for trans youth wellbeing; in their absence, highly concerning outcomes are documented, including mental health challenges, self-harm, and suicidality (Clark et al., 2017; Khatchadourian et al., 2014; Mallon & DeCrescenzo, 2006; Travers et al., 2012).

Health care providers encounter challenges as they seek to provide the best possible care for trans youth. There is a lack of consensus in the literature about clinical practices, driven in part by limited empirical research (Gridley et al., 2016; Leibowitz & de Vries, 2016; Spack et al., 2012; Vance, Ehrensaft, & Rosenthal, 2014; Vrouenraets, Fredriks, Hannema, Cohen-Kettenis, & de Vries, 2015). In the absence of robust evidence, and within a sociocultural context that is not fully supportive of trans youth accessing medical interventions, health care providers are faced with an array of ethical dilemmas (Abel, 2014; Bernal & Coolhart, 2012; Giordano, 2007;

Holman & Goldberg, 2006; Milrod, 2014; Stein, 2012; Swann & Herbert, 2000; Vrouenraets et al., 2015). Delivery of youth gender health care is further impacted by variable approaches to youth health care in general, which range from paternalistic to informed choice, and are influenced by the disparate legal contexts in which health care decisions are made (Cavanaugh, Hopwood, & Lambert, 2016; de Vries, Steensma, Doreleijers, & Cohen-Kettenis, 2011; Infants Act, 1996). As trans youth, their parents/caregivers, and their health care providers attempt to navigate health care decision-making, substantial consequences for youth wellbeing are held in the balance. The goal of this study was to contribute to the expanding youth gender health care literature with a novel investigation exploring how youth, parents/caregivers, and health care providers made decisions regarding initiation of hormone therapy for trans youth, and specifically, to generate theory about ethical and shared decision-making processes.

1.1 Background of the Problem

The precise nature and etiology of gender are unknown (Erickson-Schroth, Gilbert, & Smith, 2014; Olson et al., 2016). When genders exist outside socially constructed norms (e.g., binary genders that align with presumed binary sex categories of male and female), scholars and clinicians differ in their interpretation of this phenomenon. Diverse genders may be interpreted as normal variations, social constructs, medical diseases, and/or mental illnesses (Olson J et al., 2011; Vrouenraets et al., 2015). Viewing gender diversity as a normal part of human diversity is consistent with a movement to depathologize gender, following a long history of harm inflicted on trans communities through interventions aimed at changing a person's gender (i.e., conversion therapy or reparative therapy) to conform with sex-based expectations (Mallon & DeCrescenzo, 2006; Pyne, 2014; Wallace & Russell, 2013). Intertwined with understandings of

gender as a pathology (e.g., medical or mental illness) are cisnormative, heteronormative, and bionormative biases within society that privilege cisgender experiences, heterosexual relationships, and creating families with biological children, respectively. These biases are all part of a sociocultural context that fosters stigma, discrimination, and violence in the lives of trans people and creates barriers to health care services in the forms of inappropriate and inadequate care, uncomfortable experiences with health care providers, denial of service, and experiences of violence (Barrett, 2016; Bauer, Zong, Scheim, Hammond, & Thind, 2015; Clark et al., 2017; Gorton & Grubb, 2014; Kenagy, 2005; Lyons et al., 2015; Sperber, Landers, & Lawrence, 2005).

Health care access barriers lead to health disparities for trans people, including trans youth. In a recent survey, Canadian trans youth reported low health status and high rates of foregone care, which were striking in comparison to general Canadian youth health survey data (Clark et al., 2017). One key area of concern in the literature is mental health outcomes of trans youth, which include high rates of depression, anxiety, self-harm, and suicidality (Khatchadourian et al., 2014; Mallon & DeCrescenzo, 2006; Veale et al., 2015). For many trans youth, hormone therapy is medically necessary to alleviate gender-related distress through facilitating development of secondary sex characteristics consistent with their gender; for others, hormone therapy is not necessary. Research supporting the safety and effectiveness of hormone therapy for trans youth has emerged over the last 20 years, and withholding this care for those who require it is now considered a potentially harmful, rather than neutral, approach (Antommara, 2014; Coolhart, Baker, Farmer, Malaney, & Shipman, 2013; de Vries et al., 2011, 2014; Delemarre-van de Waal & Cohen-Kettenis, 2006; Khatchadourian et al., 2014; Kreukels & Cohen-Kettenis, 2011; Vrouenraets et al., 2015).

Within the literature, parental support is a second factor, in addition to health care access, frequently associated with trans youth wellbeing (Bernal & Coolhart, 2012; Mallon & DeCrescenzo, 2006; Raj, 2008; Simons, Schrager, Clark, Belzer, & Olson, 2013; Travers et al., 2012). Provision of hormone therapy for trans youth who need this care may appear to be a straightforward intervention, as it is highly effective in promoting wellbeing. However, many youth have complicating factors in their lives that impact access to this care, such as parents who disagree with their health care decisions. While current practices in youth health care decision-making typically involve encouraging youth to include parents, it is recognized in many areas of health care (e.g., mental health, reproductive health) that mandating parental involvement for certain types of care may be more harmful than beneficial (English, 2005; Jones & Boonstra, 2004; Morreale, Stinnett, & Dowling, 2005). In gender health care, parents may disagree with their child's decision to access hormone therapy, however this conflict is often overlooked in the literature on youth hormone therapy, as this body of work primarily comprises studies from clinics where parental support is requisite for enrollment (de Vries et al., 2011; Edwards-Leeper & Spack, 2012; Reisner, Vettters, et al., 2015).

When viewed through an ethics lens, many issues arise in the provision of hormone therapy for trans youth. Issues of autonomy and the capacity of youth to make their own health care decisions, as well as the need to balance the relative benefits of hormone therapy (e.g., development of secondary sex characteristics congruent with gender, reducing suicidality, reducing unmonitored hormone use) with the potential harms of initiating hormone therapy, such as family rejection, unknown long-term effects of hormone therapy, and the possibility of future regret, all arise in the literature (Abel, 2014; Baltieri, Prado Cortez, & de Andrade, 2009; de Vries et al., 2014; Finlayson et al., 2016; Giordano, 2007; Holman & Goldberg, 2006;

Khatchadourian et al., 2014; Nahata, Tishelman, Caltabellotta, & Quinn, 2017; Stein, 2012). Ethical issues related to autonomy, confidentiality, capacity to make health care decisions, and the best interests of youth with complex family situations mirror those found in the general youth health care literature, particularly in the area of sexual and reproductive health (English, 2005; Jones & Boonstra, 2004; Morreale et al., 2005; Parker, 2011; Tillett, 2005; Unguru, 2011; Weithorn & Campbell, 1982). However, limited evidence about long-term clinical outcomes of trans youth who initiate hormone therapy and differing philosophical approaches to gender make this area of practice unique, and contribute to a lack of consensus about how to address the ethical issues present in youth gender health care (Vrouenraets et al., 2015). Furthermore, understanding of these ethical issues is bound by the legal context in which the clinical encounter occurs (Bernal & Coolhart, 2012; Cavanaugh et al., 2016; Giordano, 2007; Holman & Goldberg, 2006; Stein, 2012; Swann & Herbert, 2000). In British Columbia, Canada, youth have the legal authority to consent to health care determined by their health care provider to be in their best interests, based on their capacity to do so (Infants Act, 1996). However, much of the published literature on trans youth health care ethics comes from jurisdictions with age-based criteria for consent to care (e.g., The Netherlands, United States, Australia), leaving capacity-based consent to youth gender health care relatively unexplored.

Research related to youth gender health care ethics is not consistently guided by specific ethical decision-making frameworks. Although a North American bioethics framework is fundamental to scholarship examining current ethical debates, with analyses frequently structured around the principles of autonomy, beneficence, non-maleficence, and justice (Abel, 2014; Giordano, 2007; Stein, 2012; Vrouenraets et al., 2015), this body of work does not attend to the ethical decision-making processes of health care providers. Given that many barriers to

gender health care are directly related to health care providers, such as inappropriate and inadequate care, uncomfortable experiences, and service denial (Barrett, 2016; Bauer et al., 2015; Clark et al., 2017; Gorton & Grubb, 2014; Kenagy, 2005; Lyons et al., 2015; Sperber et al., 2005), understanding how health care providers make ethical decisions is of interest in exploring ways to improve access to care. While there is a growing body of literature addressing clinical ethical issues in youth gender health care, very little of this is based in empirical research. Therefore, empirical research on clinical ethical decision-making may be warranted to investigate the processes underlying health care provider decisions within a youth gender health care context (Beauchamp & Childress, 2013; Diekema, 2004; Friedman Ross, 2016; Jonsen, Siegler, Winslade, & Access Medicine, 2015).

The processes surrounding health care decision-making of trans youth and parents/caregivers of trans youth are also largely unexplored. While there are robust literatures on decision-making that can inform clinical practice in other areas of health care, they generally do not intersect with the youth gender health care literature. Drawing on health care decision-making scholarship, including models such as paternalism, informed choice, and shared decision-making, may provide a foundation for better understanding practice issues related to autonomy (Charles, Gafni, & Whelan, 1999; Crickard, O'Brien, Rapp, & Holmes, 2010; DeMeester, Lopez, Moore, Cook, & Chin, 2016; Makoul & Clayman, 2006). For example, shared decision-making provides an alternative to paternalistic and informed choice models of health care decision-making, and is often viewed as a viable approach for supporting autonomy in work with youth and families, as well as with racial, sexual, and gender minority individuals (Coyne, Amory, Kiernan, & Gibson, 2014; Crickard et al., 2010; DeMeester et al., 2016; Foglia & Fredriksen-Goldsen, 2014; Hetrick, Simmons, & Merry, 2008; O'Brien, Crickard, Rapp, &

McDonald, 2011; Peek et al., 2016). Decision-making approaches of health care providers, as well as youth and parents/caregivers, are of interest in better understanding the ways in which parents/caregivers and health care providers facilitate or impede access to needed youth gender health care.

Lastly, investigations in youth gender health care most relevant to hormone therapy have focused on quantitative measures of youth health outcomes in gender clinic samples. Youth included in these clinical studies of hormone therapy outcomes are youth who have been able to access this care; there is minimal representation of youth experiencing barriers to care, those who are undecided about hormone therapy, and trans youth who decide not to access hormone therapy (Corliss, Belzer, Forbes, & Wilson, 2008; Gridley et al., 2016). Ethical dilemmas may arise while health care providers are engaged with youth and parents/caregivers in decision-making about initiation of hormone therapy involving issues of autonomy, beneficence, non-maleficence, and justice. However, studies in this have area focused on clinical issues raised by health care providers and ethicists, without attention to ethical decision-making processes of health care providers or to perspectives of youth or parents/caregivers regarding the identified ethical concerns (Abel, 2014; Bernal & Coolhart, 2012; Vrouenraets et al., 2015). The paucity of youth and parent/caregiver perspectives in this literature is problematic, as evidence is lacking to bridge health care provider understandings of the youth and parent/caregiver hormone therapy initiation decision-making processes with the perspectives of youth and parents/caregivers themselves. Multiple scholars have identified a need for research that focuses on youth and parent/caregiver perspectives and experiences, includes diverse youth representation (e.g., genders, races/ethnicities, those not accessing health care), supports health care decision-making, and informs health care provider education (Corliss et al., 2008; Grossman & D'augelli, 2006;

Leibowitz & de Vries, 2016; Menvielle & Hill, 2010). While quantitative studies dominate the youth gender health care literature, qualitative methods are well-suited to examination of ethical and health care decision-making processes (Charmaz, 2014) and methods such as constructivist grounded theory hold promise for informing evidence-based practices aimed at improving the wellbeing of trans youth.

1.2 Purpose of the Study

The overarching purpose of the current investigation was to explore how youth, parents/caregivers, and health care providers made decisions about trans youth hormone therapy initiation. This was a constructivist grounded theory study (Charmaz, 2014), augmented by an ethical analysis employing a North American bioethics framework (Beauchamp & Childress, 2013). Research was conducted on Turtle Island, in the region today known as British Columbia, Canada. The study addressed three gaps identified in the literature. First, it explored the ethical concerns and decision-making processes of health care providers. Second, the decision-making processes of health care providers were examined in concert with those of youth and parents/caregivers. Third, this study included trans youth typically excluded from studies of youth gender health care: those undecided about accessing hormone therapy; those experiencing barriers to care; and those who had decided not to access hormone therapy. Research inclusive of the three participant groups—youth, parents/caregivers, and health care providers—was undertaken with the intention of informing clinical and ethical decision-making practices within the field of youth gender health care.

1.3 Research Questions

This study was designed with five initial research questions:

1. How do trans youth make decisions about hormone therapy initiation?
2. How do trans youth, parents/caregivers of trans youth, and health care providers engage (or not engage) in shared decision-making practices around hormone therapy initiation?
3. What ethical issues do health care providers find challenging in hormone therapy readiness assessment/care planning practice with trans youth?
4. How do health care providers construct and resolve ethical dilemmas that emerge in hormone therapy readiness assessment/care planning practice with trans youth?
5. How can trans youth, parents/caregivers, and health care providers be better supported in ethical and shared decision-making processes related to hormone therapy initiation?

Two additional questions emerged over the course of this research:

6. How do youth experience barriers and facilitators to enactment of decisions regarding hormone therapy initiation?
7. How are health care provider approaches to hormone therapy readiness assessment/care planning experienced by trans youth?

1.4 Definition of Terms

Gender (also called gender identity) is a person's internal sense of themselves as woman/female/girl, male/man/boy, both, in between, or neither (Simmons & White, 2014).

Transgender/trans is an umbrella term for genders that are not aligned with sex assigned at birth; these genders may be *binary* (i.e., female/woman/girl or male/man/boy) or *non-binary* (e.g., agender, genderfluid, genderqueer) (Frohard-Dourlent, Dobson, Clark, Duoll, & Saewyc, 2016).

Cisgender refers to a gender that does align with sex assigned at birth (Erickson-Schroth & Boylan, 2014a). *Gender health* is a newer term, defined by Diane Ehrensaft as “the opportunity for children to live in the gender that feels most real and/or comfortable...to express gender without experiencing restriction, criticism, or ostracism” (2016, p. 16).

Gender transition “refers to the process during which [trans] people may change their gender expression and/or bodies to reflect their gender” (QMUNITY, 2013). This may involve *social transition* (e.g., change in physical appearance, speech, hair style, name, pronouns, binding, packing, tucking, padding) and/or medical transition (e.g., pubertal suppression, hormone therapy, gender-affirming surgery) (QMUNITY, 2013; Trans Care BC, 2017a). For some people, the process of having their gender recognized by others is experienced as one of *affirmation* of who they know themselves to be, rather than a process of transition (Trans Care BC, 2017c). Gender affirmation and transition can be important steps for trans people in terms of their gender health and overall wellbeing.

Building on Ehrensaft’s (2016) definition of gender health, *gender health care* is defined for the purposes of this study as the provision of health care interventions intended to improve or maintain an individual’s gender health (e.g., hormone therapy). *Hormone therapy* is an intervention that uses sex hormones to bring a person’s secondary sex characteristic in line with their gender (Trans Care BC, 2017a). Prior to initiating prescribed hormone therapy, a trans person must meet with a health care provider to discuss their care. This process may be called a *hormone therapy readiness assessment*, defined as an “evaluation conducted by a healthcare professional to determine if a patient is ready to begin hormone therapy” (Trans Care BC, 2017a), or *hormone therapy readiness care planning*, an individualized process that may involve clarifying gender health goals, identifying strengths and needs, developing a plan, and/or

determining the capacity of a youth to consent for gender health care (Trans Care BC, 2017b). Due to inconsistent use of terminology, these terms will be combined for the purposes of this study, as *hormone therapy readiness assessment/care planning*.

The sociocultural context in which decisions are made about gender health care is complex. Normative assumptions permeate North American society regarding sociocultural expectations of gender, sexual orientation, and family creation. *Cisnormativity* and *heteronormativity* refer to assumptions that all people are cisgender and heterosexual, respectively (serano, 2017). *Bionormativity* describes norms that center on creating families with biological children (Baylis & McLeod, 2014). These normativities contribute to stigma, which can be enacted in the lives of trans people via erasure, microaggressions, discrimination, and violence. *Pathologization* is a long-standing stigma-related issue in trans communities, used to describe the practice of diagnosing trans people with medical or mental health disorders solely on the basis of their gender; however, there is currently a movement to *depathologize* gender, or remove diagnoses associated with being trans (Erickson-Schroth & Boylan, 2014a).

Health care decision-making can be undertaken in accordance with a variety of approaches. *Paternalism* involves health care providers taking full responsibility for diagnosing health conditions and making treatment decisions (Charles et al., 1999). This contrasts with *informed choice* (or informed consent), which involves providing patients with the information they need to make their own, independent health care decisions (Makoul & Clayman, 2006; O'Brien et al., 2011). *Shared decision-making* practices involve engagement of health care providers and patients in information-sharing and collaborative decision-making (Crickard et al., 2010; Hetrick et al., 2008; Langer & Jensen-Doss, 2016; Makoul & Clayman, 2006). It should be noted that informed consent has a particular connotation in gender health care. An *informed*

consent model of care was developed approximately a decade ago in response to an identified need to depathologize gender health care practices, with the goal of eliminating “unnecessary barriers to hormone therapy, including restrictions specifying prolonged mental health evaluations and ‘real life tests’” (Reisner, Bradford, et al., 2015a, p. 586). It has been suggested in the literature that this model could also be applied with youth, however in many jurisdictions this is not possible due to restrictions such as laws that require parental consent until an individual reaches a specific age (Cavanaugh et al., 2016). Ethical decision-making is needed when ethical dilemmas arise in practice. *Ethical dilemmas* are defined in this study as clinical situations in which ethical principles, such as autonomy, beneficence, non-maleficence, and justice, come into conflict, resulting in no clear path forward without significant drawbacks (Banks & Williams, 2005).

According to the British Columbia *Infants Act* (Infants Act, 1996), a minor may consent to health care if the health care provider:

(1) has explained to the [minor] and has been satisfied that the [minor] understands the nature and consequences and the reasonably foreseeable benefits and risks of the health care, and (2) has made reasonable efforts to determine and has concluded that the health care is in the [minor’s] best interests.

The British Columbia College of Physicians and Surgeons states that “the capacity of a minor is determined by assessing the extent to which the minor’s physical, mental, and emotional development will allow for a full appreciation of the nature and consequences of the proposed treatment, including the refusal of such treatment” (College of Physicians and Surgeons of British Columbia, 2015). The *Infants Act* provides no further definition of best interests; however the *Family Law Act* in British Columbia states that acting in a child’s best interest means to protect, “to the greatest extent possible, the child’s physical, psychological and emotional safety, security and well-being” (Family Law Act, 2011; Infants Act, 1996).

1.5 Overview

This manuscript-based dissertation will explore how hormone therapy initiation decision-making processes unfold and the ways in which trans youth, parents, and health care providers can be better supported through application of new theoretical understandings. In chapter 2 literature on gender health, sociocultural context, health care decision-making, and ethical issues relevant to youth gender health care are explored in greater detail. The methodology of the study is outlined in chapter 3. Two manuscripts are presented in chapter 4, focused on: (1) youth and parent/caregiver health care decision-making processes and (2) shared decision-making processes among youth, parents/caregivers, and health care providers. Chapter 5 comprises two manuscripts, both addressing ethical issues in youth gender health care. In the final chapter, potential applications for the findings from this dissertation are discussed in terms of addressing the health and wellbeing of trans youth through improved health care practices and systems.

Chapter 2: Review of Literature

There is a growing body of research related to clinical practices, health outcomes, and ethics in youth gender health care. As trans youth come out in greater numbers and at younger ages, the need for evidence-based practices and comprehensive supports for youth and families is quickly growing, while clinicians, researchers, and policy makers struggle to keep up with demand (Alegría, 2016; de Vries & Cohen-Kettenis, 2012; Mallon, 2009; Olson J et al., 2011; Spack et al., 2012). The following review of literature is focused on gender health, sociocultural context, health care decision-making, and health care ethics.

2.1 Gender Health

Gender health describes the state of living freely in the gender that feels most real and/or comfortable (Ehrensaft, 2016). Trans children exhibit early understanding of their own gender and display gender stereotypic preferences, gender stereotyping, and gender constancy similar to gender-typical youth (Hidalgo et al., 2013; Olson & Gülgöz, 2017), and affirming children and youth to live in their authentic genders is crucial for gender health. Evidence is clear that parental support and access to culturally safer health care can play vital roles in supporting positive health outcomes for trans youth (Bernal & Coolhart, 2012; Cavanaugh et al., 2016; Clark et al., 2017; Gridley et al., 2016; Olson J et al., 2011; Olson et al., 2016; Travers et al., 2012). Each person should be supported to achieve their individualized gender health goals, which for youth may or may not include medical affirmation or transition, such as hormone therapy (Mallon, 2009; Wylie et al., 2016).

Gender health care for trans youth has evolved greatly over the past three decades. Changing views of gender and what it means to be trans in present-day society, combined with medical advances and empirical data on health outcomes, have led to philosophical changes in how health care is delivered to this population (Pyne, 2014). Recently the landscape has shifted as professional organizations have declared reparative approaches (e.g. attempting to change gender to match sex assigned at birth) to be unethical and these practices have been outlawed with minors in several jurisdictions (Canadian Association of Social Workers & Canadian Association of Social Work Educators, 2015; CBC News, 2015; New York State, 2016). There is presently a lack of consensus among health care providers concerning clinical practices with trans youth, and consequently approaches to gender health care delivery vary widely (Cavanaugh et al., 2016; Chen et al., 2016; Coolhart et al., 2013; Edwards-Leeper, Leibowitz, & Faii Sangganjanavanich, 2016; Leibowitz & de Vries, 2016). However, an approach that is being widely adopted in North America is the gender affirmative model of care (Ehrensaft, 2014; Hidalgo et al., 2013).

Taken directly from the work of Hidalgo and colleagues (2013), the premises underlying this model are:

(a) gender variations are not disorders; (b) gender presentations are diverse and varied across cultures, therefore requiring our cultural sensitivity; (c) to the best of our knowledge at present, gender involves an interweaving of biology, development and socialization, and culture and context, with all three bearing on any individual's gender self; (d) gender may be fluid, and is not binary, both at a particular time and if and when it changes within an individual across time; (e) if there is pathology, it more often stems from cultural reactions (e.g., transphobia, homophobia, sexism) rather than from within the child. (Hidalgo et al., 2013, p. 285)

Ehrensaft (2016) adds, “gender variations are healthy expressions of infinite possibilities of human gender” (p. 15). In approaching research involving youth gender health, it is important to have clarity on whether diverse genders are framed as internally located mental health disorders

or natural parts of human diversity. This research centers the latter perspective, aligned with the gender affirmative model of care (Ehrensaft, 2016; Hidalgo et al., 2013).

2.1.1 Gender Affirmation/Transition

Gender transition is often used to describe a shift from living in one gender to living in another, while *gender affirmation* focuses on recognizing the gender a person knows themselves to be. Social affirmation/transition can include altering speech, changing name and/or pronouns, and changes to physical appearance, such as hair style, clothing, binding, packing, tucking, padding (QMUNITY, 2013; Trans Care BC, 2017a). Medical affirmation/transition options are typically classified as endocrine (i.e., pubertal suppression, hormone therapy) or surgical. None of these steps is mandatory for gender affirmation/transition, but for many people some, or all, of these are necessary to achieve optional gender health (Mallon, 2009; Wylie et al., 2016).

Pubertal suppression is a fully reversible intervention that blocks sex hormones from producing unwanted secondary sex characteristics, developments that can be highly distressing for trans youth (Edwards-Leeper & Spack, 2012). Documented benefits of pubertal suppression include: more time to explore gender identity; the opportunity to confirm gender dysphoria diagnosis; and improved physical and psychological outcomes (Antommara, 2014; de Vries et al., 2011, 2014; Edwards-Leeper & Spack, 2012; Kreukels & Cohen-Kettenis, 2011). This intervention is available to youth who have started puberty (i.e., stage 2 on the Tanner scale of pubertal development) and may be continued into the early teen years, at which time the youth will need to decide whether to start hormone therapy (de Vries et al., 2011; Wolf & Long, 2016). Pubertal suppression is fully reversibly in that it may be stopped at any time and puberty will resume with endogenous hormones (Olson J et al., 2011).

Hormone therapy is the provision of sex hormones that facilitate the development of desired secondary sex characteristics (Trans Care BC, 2017a). Similar to pubertal suppression, the benefits of hormone therapy include improved physical and psychosocial outcomes, for example, development of secondary sex characteristics consistent with gender and relief of distress stemming from development of unwanted pubertal changes (de Vries et al., 2011; Delemarre-van de Waal & Cohen-Kettenis, 2006; Khatchadourian et al., 2014). The age at which youth start hormone therapy varies, but may occur throughout the teen years. The benefits of hormone therapy are significant for trans youth who require it and it is well-recognized that the harms associated with withholding this care can be substantial (Antommara, 2014; Coolhart et al., 2013; de Vries et al., 2014; Delemarre-van de Waal & Cohen-Kettenis, 2006; Vrouenraets et al., 2015). Research studies on longer-term effects of hormone therapy in trans populations have been conducted, indicating that the risks overall are minimal and can be well-managed (Dahl, Feldman, Goldberg, & Jaber, 2015). However, much of this research has been conducted with individuals who initiated hormone therapy in adulthood; hormone therapy initiation for youth has become available more recently, resulting in limited available research on longer-term outcomes for this population. This intervention is considered partially reversible, in that some effects will remain and other changes will revert if the therapy is stopped.

Gender affirming surgeries include chest and breast construction, and genital, facial, tracheal, and voice surgeries. Current standards of care establish the age of majority in a given country as the minimum for genital surgery, but leave room for chest construction to be accessed earlier (Olson J et al., 2011). All surgeries are classified as irreversible.

The focus of this dissertation is on hormone therapy for 14 through 18 year-old youth. Prior to accessing hormone therapy, youth must engage with a health care provider for *hormone*

therapy readiness assessment/care planning. Assessors (health care providers offering this care) vary in their approaches, and may incorporate various elements, such as gender self-determination, medical screening, standardized psychological measures, and family involvement (Cavanaugh et al., 2016; Chen et al., 2016; Coolhart et al., 2013; Edwards-Leeper et al., 2016; Edwards-Leeper & Spack, 2012; Gridley et al., 2016; Leibowitz & de Vries, 2016). The intent of this process is for a health care provider to determine whether hormone therapy is in the best interests of a youth, however there is no standardized procedure or established set of universal practices (Trans Care BC, 2017a, 2017b).

2.1.2 Health Outcomes, Parental Support, and Access to Care

A substantial area of concern is ongoing health disparities of trans youth, including high rates of depression, anxiety, self-harm, suicidality, poor self-esteem, social isolation, and substance use (Corliss et al., 2008; Edwards-Leeper & Spack, 2012; Huft, 2008; Khatchadourian et al., 2014; Mallon & DeCrescenzo, 2006; Ryan, Russell, Huebner, Diaz, & Sanchez, 2010). A recent survey of Canadian trans youth aged 14-18 found that 75% had engaged in self-harm without wanting to die, 65% had seriously considered suicide, and over a third had attempted suicide within the previous 12 months (Veale et al., 2015). Current research focuses on two key factors that are correlated with better health outcomes for trans youth: parental support and access to gender affirming health care (Clark, Veale, Greyson, & Saewyc, 2017; Delemarre-van de Waal & Cohen-Kettenis, 2006; Khatchadourian et al., 2014; Olson J et al., 2011; Ryan et al., 2010).

A growing body of research is focused on parental support as an important protective factor for trans youth (Bernal & Coolhart, 2012; Brill & Kenney, 2016; Edwards-Leeper &

Spack, 2012; Mallon, 2009; Olson J et al., 2011; Olson et al., 2016; Raj, 2008; Simons et al., 2013; Travers et al., 2012; Wallace & Russell, 2013). Multiple authors offer recommendations, based on research or clinical experience, on how to support parents so that they can better support their trans youth, focusing on both counsellor competencies and principles for gender-affirming parenting (Bernal & Coolhart, 2012; Brill & Pepper, 2008; Coolhart et al., 2013; Coolhart & MacKnight, 2015; Lev, 2004; Mallon, 2009; Menvielle & Hill, 2010; Menvielle & Rodnan, 2011). Empirical studies on counselling approaches with parents and families are limited; however, researchers studying parent support groups have documented benefits related to reduced conflict, increased acceptance, and development of ongoing lay support networks for both parents and their children (Malpas, 2011; Menvielle & Hill, 2010; Menvielle & Rodnan, 2011; Sansfaçon, Dumais-Michaud, & Robichaud, 2014). These studies are restricted to the realm of counselling; no similar research has been identified on physician support for parents and families.

Outcomes associated with parent and family support for trans youth are receiving increasing attention in the research literature. Significant differences have been found in self-reported levels of mental health, self-esteem, adequate housing, and life satisfaction; youth with very supportive parents fared better on these measures than those with parents who were somewhat to not at all supportive (Travers et al., 2012). Trans youth with higher levels of family connection have also reported less engagement in self-harm and lower rates of suicide contemplation and attempt (Veale et al., 2015). However, relationships among parental support, health care access, and youth well-being have gone largely un-interrogated. While data indicate that youth who are well-supported by their parents have better health outcomes, it is unclear what role parent-facilitated access to gender health care may play in these findings.

Many studies confirm the health benefits of access to hormone therapy, particularly in the areas of mental health and overall quality of life (Connolly, Zervos, Barone II, Johnson, & Joseph, 2016; de Vries et al., 2014; Khatchadourian et al., 2014). It is clear that youth benefit from access to gender health care and can suffer serious consequences when this care is denied or unavailable; however, significant barriers to gender health care remain (Gridley et al., 2016; Veale et al., 2015). These include a lack of trained health care providers; inconsistently applied protocols; use of incorrect names and/or pronouns by health care providers; gatekeeping and lack of care coordination; delayed and limited access to pubertal suppression and hormone therapy; and insurance exclusions (Gridley et al., 2016). Non-binary youth, whose health care needs and outcomes are often overlooked in the clinical literature, have been found to experience even greater barriers to hormone therapy than binary trans youth (Clark, Veale, Townsend, Frohard-Dourlent, & Saewyc, 2018).

Several authors have addressed access issues through exploration of specific system and health care provider barriers (Cavanaugh et al., 2016; Dietz, 2016; Sherer, Baum, Ehrensaft, & Rosenthal, 2015; Snelgrove, Jasudavicius, Rowe, Head, & Bauer, 2012; Stoddard, Leibowitz, Ton, & Snowdon, 2011; Vance et al., 2014; Wylie et al., 2016). In adult care, health care provider bias, scarcity of training opportunities and gender health services, pathologization, and ethical uncertainties (e.g., potential treatment regret, pathologization, reproductive rights) can constitute barriers to care (Dietz, 2016; Snelgrove et al., 2012). Recommendations to address these issues include expanding access through primary care, increasing training opportunities for health care providers, practicing cultural humility, and ensuring trans people have leadership roles in gender health care services (Dietz, 2016; Wylie et al., 2016). Researchers focusing on youth gender health care echo these ideas, highlighting the need to improve access to care

through delivering services in primary care settings, creating safer¹ clinic spaces, implementing evidence-based policies and practices, and increasing clinical and cultural competencies of health care providers through expansion of medical school curricula, residency training, and continuing education (Clark et al., 2017, 2018; Gridley et al., 2016; Sherer et al., 2015; Stoddard et al., 2011; Vance et al., 2014).

Amidst concerning statistics on trans youth mental health and foregone health care, the need to address health disparities clear. There is a lack of information to guide clinical practices for youth whose parents/caregivers do not support their gender health goals, and anecdotal evidence indicates that even with strong parental support, youth without access to gender health care are at risk for suicide (Waldon, 2017). Research is emerging on barriers (e.g., training, system) to gender health care; however, youth and parent/caregiver perspectives are rarely included. Furthermore, studies on youth gender health care typically take place within gender clinics in urban centers, where parental support is required to access care (de Vries et al., 2011; Edwards-Leeper & Spack, 2012). Comprehensively addressing the health disparities of trans youth will require research inclusive of those who cannot access gender clinics due to geographical, financial, and parental support considerations.

2.2 Sociocultural Context

When trans youth attempt to access care to address gender health needs, they interact with health care systems within a particular sociocultural context. It is important to examine

¹ The term “safer spaces” is used, rather than “safe space”, to acknowledge that complete safety cannot be guaranteed for every individual in any space; however, efforts should be made to intentionally create spaces that are safer for those who have experienced marginalization, discrimination, and violence.

contextual factors to understand how health care decisions are made and how the actions of health care providers are experienced by trans youth and parents. Five such factors are addressed in this section: pathologization; normativities; stigma; gender minority stress theory; and consent law.

2.2.1 Pathologization, Normativities, and Stigma

In western medicine, gender nonconformity has traditionally been viewed as a disorder and gender dysphoria is included in the current edition of the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013; Ware & Marshall, 2014). Classification of gender dysphoria as a mental health disorder is a contested issue, seen by many as pathologizing a normal aspect of human diversity (Carmel, Hopwood, & dickey, 2014; Corliss et al., 2008; Menvielle & Gomez-Lobo, 2011). Treatment practices such as conversion or reparative therapy, which seek to change a person's gender identity, are part of this legacy; now considered ineffective, harmful, and unethical, these practices have been outlawed for youth in some North American states and provinces (Canadian Association of Social Workers & Canadian Association of Social Work Educators, 2015; CBC News, 2015; New York State, 2016; Substance Abuse and Mental Health Services Administration, 2015). In recent years, the rise of affirming health care practices (e.g., gender affirmative model, informed consent model) have been part of a societal movement away from pathologization toward recognition of all genders as a natural part of human diversity (Reisner, Bradford, et al., 2015a). However, the effects of this history live on through the enacted stigma that trans people face in society and in interactions with family, peers, and health care providers (Carmel et al., 2014).

Pathologization can only occur in the context of normativity. For something to be pathological, it must exist outside the bounds of what is constructed as normal. Three such normativities come into play in gender health care. Cisnormativity is bias based on the notion that all people are cisgender (serano, 2017), and by extension that all people have binary genders. Erroneous assumptions about people's genders and bodies can negatively impact provision of gender health care. Heteronormativity is intertwined with cisnormativity, in that the presumption that all people are heterosexual is associated with binary ideals of gender (serano, 2017). The final form of bias is bionormativity, referring to the value placed on creating families via biological children (Baylis & McLeod, 2014). Valuing families with cisgender, heterosexual parents who have created biological children above other kinds of families can have implications for treatment of trans people, especially those who create families in other ways.

The pathologization of gender, along with normative assumptions about gender, sexuality, and family creation, arguably contribute to a sociocultural context that is rife with stigma, bias, discrimination, and violence directed at trans people. Globally, trans people experience stigma, discrimination, and abuse leading to exclusion from opportunities in society, engagement in higher-risk behaviors, and exposure to violence and other health risks (Winter et al., 2016). Survey research in the United States has revealed strikingly high rates of discrimination, harassment, violence, unemployment, underhousing, and poverty, with nonbinary participants and people of color reporting the greatest challenges (Harrison, Grant, & Herman, 2012; James, Rankin, Keisling, Mottet, & Anafi, 2016). While there appears to be growing awareness and acceptance of trans people in terms of family, peer, and co-worker support, trans youth continue to experience significant challenges in daily life (GLAAD, 2017; Huft, 2008; James et al., 2016). Verbal, physical, and sexual harassment and assault are common in schools

and can result in youth leaving school early (James et al., 2016; Taylor & Peter, 2011; Veale et al., 2015). These experiences can have direct impact on physical and mental health, and enacted stigma or fear of discrimination by health care providers can also contribute to youth forgoing needed health care (Clark et al., 2017).

The minority stress model positions minority status as a precipitator of stress and distress (Brill & Kenney, 2016). Meyer (2003, p. 676) developed this conceptual framework to explain higher rates of mental health concerns among sexual minority groups, identifying three levels of stressors that contribute to compromised health outcomes: external events, expectations of and vigilance around such events, and internalization of negative attitudes present in society. Building on this work, scholars have since developed the gender minority stress theory, paying particular attention to outcomes related to suicidality (Hendricks & Testa, 2012; Testa et al., 2017). Testa et al. (2017) provide empirical support for this model, finding suicide ideation among trans and gender nonconforming adults to be linked to both external and internal stressors (e.g., rejection, victimization, negative expectations, and nondisclosure).

Within queer and trans communities, one strategy that has emerged to counter a lack of support from biological families has been the creation of chosen families (Knauer, 2016). Family structures among non-related queer and trans individuals have been developed in response to both family rejection and lower likelihood of having children, allowing queer and trans individuals “to build community and provide support and solidarity in the face of a hostile society” (Knauer, 2016, p. 159). Awareness of resilience strategies (e.g., chosen families) and conceptual frameworks (e.g., gender minority stress theory) can assist trans people and those seeking to support them in both understanding how stigma, violence, and trauma can impact

mental health and in developing strategies that further support resilience (Brill & Kenney, 2016; Carmel et al., 2014; Keo-Meier & Fitzgerald, 2017).

2.2.2 Consent Law

Sociocultural context includes norms that govern behavior and interactions in both informal and formal ways. Codification of sociocultural values and norms can take the form of declarations of rights or government legislation (CBC News, 2015; Infants Act, 1996; New York State, 2016; United Nations, 1989; World Health Organization, 2006). The ability of youth—both developmental and legal—to consent to their own health care impacts how health care decisions are made and the ethical issues that arise in clinical practice. Literature on youth gender health care is primarily generated outside of Canada (e.g., The Netherlands, United States, Australia), where youth ability to consent to their own gender health care is limited by age (Beh & Diamond, 2005; Cavanaugh et al., 2016; Delemarre-van de Waal & Cohen-Kettenis, 2006). While youth may be allowed to consent to their own health care under certain conditions in places such as the United States, access is variable and based on meeting specific requirements (e.g., emancipated, married, pregnant, parenting, incarcerated) or accessing a particular type of care, such as emergency, sexual and reproductive health, mental health, substance use treatment (Coleman & Rosoff, 2013; English, 2005; Moon, 2012).

In Canada, the mature minor doctrine informs youth consent to health care, allowing “children who are sufficiently mature to make their own treatment decisions” (Department of Justice, 2016). Many provinces and territories have legislation addressing youth consent to health care, which in some cases gives a minimum chronological age and in others allows for youth consent based on capacity (Bala & Houston, 2015). British Columbia’s *Infants Act* (Infants Act,

1996) permits youth to consent to their own health care, provided they have the capacity to do so and that the treating health care provider determines that the care is in the youth's best interests. Since much of the extant literature on trans youth health care, and ethics in particular, is situated in legal contexts in which youth are not allowed to consent to their own health care on the basis of capacity, conducting research in a jurisdiction without these constraints is of benefit in informing clinical practices, particularly within Canadian contexts.

2.3 Health Care Decision-making

2.3.1 Health Behavior Models

Several models to explain individual health behavior have been developed in recent decades. One of the foundational models is the Health Belief Model, which seeks to “predict whether and why people will take action to prevent, detect, or control illness conditions” (Skinner, Tiro, & Champion, 2015, p. 76). The main constructs of interest are modifying factors (e.g., age, gender, ethnicity, personality, socioeconomics, knowledge) which influence individual beliefs, beliefs that in turn influence action. The Theory of Reasoned Action/Theory of Planned Behavior models are intended to generate understanding of the interrelationships of attitudes, intentions, and health behaviors (Montaño & Kasprzyk, 2015). The primary predictor of behavior within these models is intention. An Integrated Behavior Model has also been developed, incorporating constructs from the Theory of Reasoned Action/Theory of Planned Behavior models, again centering motivation and intention as precipitators of action or behavior (Montaño & Kasprzyk, 2015). In this model, the intention to act is impacted by attitude toward a specific health behavior (both emotional and cognitive), perceived norms (pressure due to what

others think one should do and others within personal networks are doing); and personal agency (self-efficacy, perceived control). While intention is the primary driver, behavior is also determined by knowledge, skills, salience of the behavior, environmental constraints (i.e., barriers to care), and habit (i.e., behavior has been performed before).

Anderson's (1995) Behavioral Model of Health Services Use has evolved since the 1960's as an explanatory model for health outcomes. While many iterations have been developed, the contemporary version includes four constructs which interact in various ways to influence outcomes. These include the environment (e.g., health care system, external environment), population characteristics (e.g., predisposing characteristics, enabling resources, need), health behavior (e.g., personal health practices, use of health services), and outcomes (e.g., perceived health status, evaluated health status, consumer satisfaction).

In several studies of youth and parent health care decision-making, conceptual understandings align with the constructs found in many of these models (i.e., demographics, socioeconomics, beliefs, social norms). For example, one conceptual model of parental decision-making was developed, in which personal/parental beliefs were the primary influence on parental decision-making; these beliefs were, in turn, influenced by social/environmental factors (e.g., media), interface with health care (e.g., provider attitudes), and institutional factors (Sturm, Mays, & Zimet, 2005). In a later study, Getrick et al. (2014) found socioeconomic and cultural factors to play a significant role in how youth and parents made decisions regarding human papillomavirus (HPV) vaccination. While models vary according to their focus and the populations of interest, common constructs of interest in health behavior and decision-making include: intentions, attitudes, beliefs, behaviors, agency, individual characteristics, norms, and the environment.

2.3.2 Health Care Decision-making Models

When trans individuals seek to access gender health care they encounter a variety of service delivery models. Some health care providers act paternalistically, at times consistent with pathologizing views of gender, while others take an informed choice approach to care. These contrasting strategies are reflective of broader trends in health care decision-making surrounding a shift away from paternalistic health care toward informed choice approaches. In youth health care, complexity is heightened when accounting for the three distinct groups typically involved in health care decision-making processes: youth, parents/caregivers, and health care providers. It is beyond the scope of this dissertation to fully address all the cognitive, affective, and social facets involved in individual and collective decision-making. Instead, the focus is on how actors from these three groups—youth, parents/caregivers, and health care providers—engage in decision-making processes.

Approaches to medical decision-making can be separated into three categories. First, traditional paternalistic approaches involve health care providers acting as expert decision-makers, possessing the information necessary to diagnose conditions and generate treatment plans (Charles et al., 1999). Second, informed choice involves health care providers transferring information to their patients, leaving patients responsible for medical decision-making (Charles et al., 1999; Makoul & Clayman, 2006). While paternalism raises concerns about patient autonomy, informed choice may leave patients feeling abandoned when they would prefer decisional support from their health care provider (Elwyn, Edwards, Kinnersley, & Grol, 2000). Both paternalism and informed choice are inherently unbalanced in terms of information sharing

and decision-making, and both place emphasis on the provider as the primary source of necessary information (Charles, Gafni, & Whelan, 1997).²

Shared decision-making provides an alternative to these extremes. It has emerged as a relationship-centered approach that balances the decisional roles of health care providers and patients, places value on the information and expertise provided by both parties, and involves family members in care (Crickard et al., 2010; Hetrick et al., 2008; Langer & Jensen-Doss, 2016; Légaré et al., 2011; Makoul & Clayman, 2006; O'Brien et al., 2011). As summarized by DeMeester et al. (2016), “shared decision making occurs when patients and clinicians work together to reach care decisions that are both medically sound and responsive to patients’ preferences and values” (p. 651).

2.3.2.1 Shared Decision-making Models

Charles et al. (1997) sought to define four key characteristics of shared decision-making, specifically in the context of treating life-threatening diseases: (1) involve a minimum of two participants; (2) share medical information and patient values; (3) both (or all) parties actively participate; and (4) make a mutual treatment decision. Elwyn et al. (2000) proposed a parsimonious three-step model (choice talk, option talk, and decision talk) for easy application in clinical practice, designed to lead a patient from initial preferences to informed preferences prior to making a decision. Choice talk involves ensuring patients know what their options are and leaving open the opportunity for them to make an informed decision. This leads to option talk,

² *Informed consent* has a particular meaning in gender health care: a low-barrier, accessible, holistic, gender-affirming, and multidisciplinary model that emphasizes personal autonomy in care planning and involves collaboration between the health care provider and the trans individual (Cavanaugh, Hopwood, & Lambert, 2016; Reisner, Bradford, et al., 2015a).

wherein detailed information is provided about potential courses of action, such as risks and benefits. Finally, decision talk supports patients in identifying their value-based preferences and making treatment decisions.

Subsequent research has brought to light additional considerations with respect to shared decision-making models. First, there must be more than one viable option between or among which participants will make a decision (Elwyn et al., 2000). It has also been recommended that all participating parties should agree to an agenda for the shared decision-making process, and that these processes—built on a foundation of relationship and trust—must be allowed to unfold over time (Murray, Charles, & Gafni, 2006). Finally, patient preference and cultural considerations can be crucial in determining whether shared decision-making is an appropriate approach in a given situation; to require engagement in shared decision-making would be a violation of patient autonomy akin to imposing a paternalistic or informed choice model on a patient (Murray et al., 2006).

In recent years, researchers have paid increasing attention to application of shared-decision-making processes with marginalized populations, in particular racial, ethnic, sexual, and gender minorities (DeMeester et al., 2016; Peek et al., 2010, 2016). Minority population have diminished access to shared decision-making due to challenges around communication, relationship, trust, unconscious bias, microaggressions, and lack of cultural competencies on the part of health care providers (DeMeester et al., 2016; Foglia & Fredriksen-Goldsen, 2014; Peek et al., 2010, 2016). Work by Peek et al. (2016) and DeMeester et al. (2016) highlights the need to contextualize shared decision-making processes within larger conceptual frameworks that account for impacts of race, culture, gender, sexual orientation, intersectionality, normative beliefs, cultural competencies, and trust on health outcomes.

Shared decision-making has also made its way into youth care (Coyne et al., 2014; Crickard et al., 2010; Langer & Jensen-Doss, 2016). Recent research has highlighted youth desire to be involved in decisions about their health care and frustration resulting from lack of meaningful engagement in these processes (Coyne et al., 2014; Ruggeri, Gummerum, & Hanoch, 2014). Potential benefits of shared decision-making with youth and parents include: integration of both youth and parent perspectives; youth motivation, empowerment, and healthy development; patient satisfaction and treatment plan adherence; and care that is more culturally competent (Crickard et al., 2010; David, Lo, & Langer, 2017; Edbrooke-Childs et al., 2016; Hetrick et al., 2008; Langer & Jensen-Doss, 2016; O'Brien et al., 2011). However, shared decision-making with youth must account for complexities such as: emerging capacity; appropriate legal authority to make decisions about health care; and the role of parents (O'Brien et al., 2011). The need to balance the rights of youth to make health care decisions with health care provider obligations to protect their best interests can be challenging (Coyne et al., 2014), as can: complex dynamics among youth, parents, and health care providers; effectively educating participants about shared decision-making processes; and working within legal and health care system constraints (O'Brien et al., 2011).

Crickard et al. (2010) also acknowledge that shared decision-making approaches may not be intuitive, and therefore propose a concise three-step model to support health care providers in using a shared decision-making approach with youth. Their framework contains three functional areas—setting the stage, facilitating, and supporting youth decision-making—similar to the model proposed by Elwyn et al. (2000). Crickard et al. (2010) also address many potential challenges of shared decision-making within their model. For example, *setting the stage* includes orienting participants to their roles and setting goals for the process, while *facilitating* involves

identifying decisional conflict areas and engaging all participants in dialogue. Furthermore, Langer et al. (2016) stress the utility of shared decision-making as a model that can accommodate both disagreement among participants and various developmental levels of youth.

In summary, health behavior models have been developed to better understand individual health behavior and decision-making. These take factors such as demographics, beliefs, intentions, agency, norms, and the environment into account when explaining individual health behavior and outcomes. This focus on individual processes is complemented by models that explain how health care decision-making and access are influenced by service delivery models (e.g., paternalism, informed choice, shared decision-making). The shared decision-making models reviewed here describe an approach consistent with patient-centered care, informed consent, honoring patient autonomy, and culturally safer care. While a shared decision-making approach is likely applicable within youth gender health care—given the role of health care providers as prescribers of gender affirming care, the role of parents/caregivers in youth health care, and the imperative to honor youth autonomy in health care decision-making—there are presently no known studies that address shared decision-making in this field. The benefits of shared decision-making for patients in general, as well as the available research on issues specific to minority populations and youth, provide a foundation for further exploration.

2.4 Ethics in Health Care

Ethical dilemmas arise in all areas of health care and diverse approaches can be taken to address these issues. There are many approaches to health care ethics that can inform clinical practice and ethical decision-making, such as relational ethics, justice approaches, queer bioethics, and North American bioethics principles. For example, feminist theory serves to

inform relational ethics approaches, which focus on ethics as they are enacted within health care relationships (Bergum, 2013; Pollard, 2015). Justice-oriented approaches emphasize a range of ideals such as individual rights, fair distribution of resources, and challenging the ways in which power, privilege, and oppression disadvantage certain groups (Reisch, 2002; Reynolds, 2012). Queer bioethics draws on both feminist and social justice approaches through attention specifically to queer issues and normative assumptions about sex and gender (Roen, 2016; Wahlert & Fiester, 2012). North American bioethics (Beauchamp & Childress, 2013) is a principles-based approach, and will be explored in greater detail due to its wide application in health care (DeGrazia, 2003).

Contemporary North American bioethics has four foundational principles: autonomy, non-maleficence, beneficence, and justice (Beauchamp & Childress, 2013; Peel, 2005). The principle of autonomy, or respect for persons, involves supporting people to make free and informed choices about their health care (Beauchamp & Childress, 2013). Non-maleficence is rooted in the Hippocratic oath, requiring health care providers to “do no harm”, while beneficence mandates going beyond avoidance of harm, to provide benefit to others (Beauchamp & Childress, 2013; Peel, 2005). To promote justice, health care providers are obligated to work toward fair, equitable, and appropriate treatment of all people through fair distribution of benefits, risks, and costs (Beauchamp & Childress, 2013).

This approach to bioethics is widely used and provides a foundation for ethical deliberation, though several critiques have been made. In a review of feminist critiques of bioethics, Marway & Widdows (2015) discuss both the overreliance of traditional bioethics on abstractions, individualism, and power, and the need for greater attention to relationality, particularity, and justice. Other critiques of Beauchamp and Childress, focused on the use of

common morality to support a principles-based approach, also highlight the need for a broader interpretation of justice and increased focus on distributive justice (DeGrazia, 2003; Hodges & Sulmasy, 2013). Additionally, on a practice-level, the mid-level principles of North American bioethics do not provide a clear framework to support resolution of specific ethical dilemmas in health care practice. As a result, many scholars have developed ethical decision-making frameworks or models for application in clinical situations (Cottone, 2001; Jonsen et al., 2015).

This review centers the principles of bioethics commonly applied in North American health care settings (i.e., autonomy, beneficence, nonmaleficence, and justice), as this is the approach health care provider participants in this study relied upon, and also the one most prevalent in the youth gender health care literature. In addition to bioethics principles and decision-making frameworks, this section addresses pediatric and cultural considerations relevant to ethical decision-making in health care.

2.4.1 Ethical Decision-making

“The ethical decision-making process begins when a person or group assumes the responsibility for resolving a problem” (Bosek & Savage, 2000, p. 113). There is no prescribed path to resolving ethical dilemmas. Dilemmas arise in clinical care when there is no clear option that is without significant drawbacks. Key to making ethically justifiable decisions is good decision-making process. In this section, legal and professional frameworks are introduced, factors that can influence ethical decision making within health care are examined, and an overview of recently-developed health care decision-making frameworks of relevance to youth gender health care practice is presented.

Health care providers are regulated by various organizations and thus bound by professional codes of ethics as well as legislation. One legislative example is the Canada Health Act, which states: “the primary objective of Canadian health care policy is to protect, promote and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers” (Canada Health Act, 1985, p. 5). The code of ethics of the Canadian Medical Association (2004) mandates that its members not discriminate on any grounds, including gender; though care must be continued for current patients, this code does not prohibit refusing to accept new patients (e.g., based on conscientious objection). While this right of physicians to conscientious objection is widely acknowledged, this right is contested. It is argued that allowing physicians to impose their values on patients can lead to denial of care and creation of inequitable health care systems (Savulescu & Schuklenk, 2017). Antommaria (2014) addresses this issue within youth gender health care, asserting that pediatric endocrinologists would likely be unjustified in refusing to provide pubertal suppression to trans youth if they offered this intervention for other young people (e.g., those with precocious puberty), as this would constitute discrimination. While those delivering health care in Canada should strive to ensure equitable access, it is important to note that health care providers are not obligated to provide a service simply because a patient requests it (Inions, 1989). These legal and ethical frameworks provide guidance for health care providers, however, many complexities emerge in the delivery of health care that are not directly addressed within these documents.

Decisions in response to ethical dilemmas are ultimately made by individuals operating within a sociocultural context that influences values, beliefs, perceptions, and decisions. Bosek and Savage (2000) emphasize values as being central to health care provider decision-making, as they can influence evaluation of options and recommendations for care. Additionally, health care

providers' cultural awareness and identity can impact their perceptions of whether ethical dilemmas are present in various clinical situations (Garcia, Cartwright, Winston, & Borzuchowska, 2003). In a study by Smith et al. (1991), mental health care providers made decisions about what they *should* do in response to an ethical dilemma based on ethical codes and laws; however, the actions these health care providers indicated they *would* take were grounded in values and practical considerations rather than codes and law. This body of research also brings to light the potential impact of unresolved conflicts between personal and professional ethics, an issue that may be important to address through training:

if awareness of one's values is an essential step in making an ethical decision, and if a central goal of ethics training is to help students reconcile personal and professional values, it follows that a goal of counselor education should be to increase students' awareness of the role their values play in their ethical decisions. (Ametrano, 2014, p. 155)

2.4.2 Ethical Decision-making Frameworks

Frameworks for ethical decision-making are designed to assist clinicians in working through ethically challenging situations (Kaposy Chris, Brunger Fern, Maddalena Victor, & Singleton Richard, 2016). In Canada, research indicates that accreditation standards are influential in promoting use of such ethical decision-making frameworks in health care settings (Kaposy Chris et al., 2016). Available frameworks take many different elements into account, from virtues to values, from codes to culture, from philosophy to the pragmatics of practice (Cottone & Claus, 2000; Garcia et al., 2003; Manson, 2012; Wiggins & Williams, 2005). Ethical decision-making frameworks play an important role in procedural justice, that is, promoting equitable treatment in like situations through consistent and fair process that supports robust ethical decision-making inclusive of a range of ethical principles and/or perspectives,

deliberation on the potential consequences of multiple potential paths forward, and evaluation of the selected course of action.

McAuliffe and Chenoweth (2008) organize such frameworks within three categories: process/rational models focused on rules and principles; reflective models balancing the rational with the intuitive; and cultural models that center cultural context. Previous reviews of clinical ethical decision-making models in the counselling literature indicate that many tools are based on clinician experience, as opposed to strong philosophical, theoretical, or empirical bases, though some have sought to bridge these gaps by creating theoretically and/or empirically grounded clinical tools (Cottone, 2001; Cottone & Claus, 2000; Manson, 2012). No frameworks specific to ethical decision-making in gender health care have been identified, therefore the following section focuses on publications that address concepts central to this study: principles, culture, pediatric care, and shared decision-making.

Bioethics principles are foundational to many ethical decision-making frameworks (Ametrano, 2014; Cottone & Claus, 2000; Grundstein-Amado, 1991; Jonsen et al., 2015). One widely known model is Jonsen, Siegler, and Winslade's (2015) four topics (or four boxes) approach, which was developed to operationalize general principles of bioethics, such as those set out by Beauchamp and Childress (2013), to guide ethical decision-making and action in clinical care. The four topics proposed are medical indications, patient preferences, quality of life, and contextual features. Medical indications focuses on beneficence and nonmaleficence, specifically, how a patient's medical issues can be aided through treatment and how harm can be avoided. Autonomy is at the root of patient preferences, concerning informed consent, capacity, and proxy decision-makers. Beneficence, nonmaleficence, and autonomy, as well as the impact of health care provider bias, are considerations in deliberation on past, present, and future quality

of life. The final topic of contextual features addresses the principle of justice. This includes conflicts of interest, resource allocation, religious beliefs, and legal issues, as well as public health and safety. Of particular relevance to the current study is a focus on potential bias of health care providers with respect to quality of life, and health care inequities as a contextual feature. While the text by Jonsen et al. (2015) does not explore normative biases on a societal level as a contextual feature, it seems reasonable to extend this framework to include cisnormativity, heteronormativity, and bionormativity when engaging in ethical decision-making within gender health care, both in terms of bias regarding quality of life and contextual features that impact just treatment of trans people in health care systems and society at large.

Culture can have a strong impact on ethical decision-making processes, for example, influencing how health care providers frame and resolve ethical issues in practice (Garcia et al., 2003). Several cultural models have been developed; while they do not specifically address trans culture, they can serve to inform culturally-focused ethical decision-making more broadly (Garcia et al., 2003; McAuliffe & Chenoweth, 2008; Wiggins & Williams, 2005). For example, the transcultural integrative ethical decision-making model directs health care providers to gather culturally relevant information, ensure actions account for different worldviews, and consult with cultural experts, while the inclusive model of ethical decision making centers accountability, critical reflection, cultural sensitivity, and consultation (Garcia et al., 2003; McAuliffe & Chenoweth, 2008). Common to cultural frameworks is the need to integrate cultural information and seek consultation in order to reach ethical decisions that align with the cultural values of affected patients or clients.

Most ethical decision-making frameworks are developed for use with adults, occasionally providing some limited consideration of practice in pediatric contexts (Friedman Ross, 2016;

Jonsen et al., 2015). Ross (2016) critiques existing frameworks, presenting her own pediatric model based on constrained parental autonomy. While this model addresses several issues relevant to practice in the United States, its transferability to ethical decision-making in Canadian youth health care is limited due to differing legal contexts. Of note, there is one Canadian study involving youth with eating disorders that addresses legal, developmental, and familial considerations within British Columbia (Manley, Smye, & Srikameswaran, 2001). This feminist relational approach focuses on five principles: safety, participatory process, agency, caring, and fairness (Manley et al., 2001). This is strikingly different from the Ross (2016) model which privileges parental authority, a stance grounded in United States law, parental rights, value of the family, and responsibility of parents to cover costs incurred in a private health care system. Relevant guidance for Canadian physicians may be found in the Canadian Medical Association code of ethics which states that physicians have responsibility to “recognize the need to balance the developing competency of minors and the role of families in medical decision-making [and] respect the autonomy of those minors who are authorized to consent to treatment” (Canadian Medical Association, 2004, pp. 2–3).

2.4.3 Ethics in Shared Decision-making

Shared decision-making is intended to support patient autonomy, in particular ensuring control over decision-making processes in line with an individual’s preferences (Elwyn et al., 2000; Tam-Seto & Versnel, 2015). Beneficence is also relevant to this model, as shared decision-making approaches have been shown to improve patient satisfaction and treatment outcomes (Kraus & Marco, 2016; Langer & Jensen-Doss, 2016; Sugarman, 2003; Towle & Godolphin, 1999). In terms of justice, inequities in both health care access and outcomes can be addressed

through culturally competent facilitation of shared decision-making (DeMeester et al., 2016; Foglia & Fredriksen-Goldsen, 2014; Langer & Jensen-Doss, 2016; Peek et al., 2010). In addition to bioethics, other ethics frameworks (e.g., care, relational, and communicative) have also been applied in analyses of shared decision-making methods, with attention focused on how the autonomy of the patient is intertwined with other people in their lives and the moral equivalence of all shared decision-making participants (Daboval & Shidler, 2014; Foglia & Fredriksen-Goldsen, 2014; Nistelrooij, Visse, Spekkink, & Lange, 2017). In summary, shared decision-making has potential to address potential shortcomings of paternalistic and informed choice models, through supporting autonomy, beneficence, and justice.

2.5 Ethics in Youth Health Care

This section explores some of the ethical challenges that arise in the care of youth, organized around the principles of bioethics. The section on autonomy includes concerns about capacity of youth to consent to health care and confidentiality of their health information, as well as parent involvement in health care decisions. Beneficence and non-maleficence are explored in relation to the best interest standard and harm principle. Issues of justice are centered around the rights of all youth to have equitable access to health care services.

2.5.1 Autonomy

Autonomy plays out in discussions of youth capacity, consent, and confidentiality; however, it is important to differentiate autonomy from capacity. The bioethical principle of respect for autonomy means all human beings have the “right to hold views, to make choices, and to take actions based on their values and beliefs” (Beauchamp & Childress, 2013, p. 106). In

pediatric bioethics, is it recognized that the autonomy of children and youth should be respected, and they should be involved in their own health care to the extent possible, within the bounds of developmental appropriateness and applicable law (Canadian Paediatric Society, 2004). As youth develop, they are increasingly capable of taking on new responsibilities, including health care decision-making, an idea referred to as emerging capacity (Diekema, Mercurio, & Adam, 2011). In other words, while youth may not have capacity to independently make a particular health care decision, autonomy—or respect for persons—should always be taken into account. The following discussion will focus on support for and constraints on youth autonomy with respect to health care decision-making.

Consent for health care must be informed and voluntary, that is, free of coercion (Unguru, 2011). Procedures for obtaining informed consent include presenting information about a condition or diagnosis and available treatment options, assessing patient understanding of this information, assessing patient capacity to make necessary health care decisions, ensuring the patient is free to make their own choices, and asking for permission to provide care (American Academy of Pediatrics, 1995; Unguru, 2011). Participation in health care decision-making has benefits including fostering a sense of control, feeling ownership over health care choices, and greater long-term decision satisfaction (Jeremic, Sénécal, Borry, Chokoshvili, & Vears, 2016; Tillett, 2005; Unguru, 2011). In providing developmentally appropriate care, a sliding scale should be applied, requiring a greater degree of capacity to make health care decisions with greater potential consequences (Canadian Paediatric Society, 2004). However, an ongoing area of debate in pediatric bioethics centers around youth capacity to consent to their own health care (American Academy of Pediatrics, 1995; Canadian Paediatric Society, 2004; Coleman & Rosoff, 2013; Kuther & Heights, 2003; Salter, 2017; Tillett, 2005).

Determination of capacity in health care is decision-specific, which refers to an individual's ability to make a particular health care decision at a particular time. "The term *capacity* refers to the degree to which an individual has the ability to understand a proposed therapy or procedure, including its risks, benefits, and alternatives; to communicate relevant questions; and to arrive at a decision consistent with his or her values" (Cummings & Mercurio, 2010, p. 252). With respect to youth, capacity "is determined by assessing the extent to which the minor's physical, mental, and emotional development will allow for a full appreciation of the nature and consequences of the proposed treatment, including the refusal of such treatment" (College of Physicians and Surgeons of British Columbia, 2015). Research, legal precedent, and current practice guidelines support the idea that many youth have the developmental capacity to make health care decisions, with age 14 years frequently cited as the approximate point when such capacity has adequately developed (Canadian Paediatric Society, 2004; Goodlander & Berg, 2011; Larcher & Hutchinson, 2010; Michaud, Blum, Benaroyo, Zermatten, & Baltag, 2015; Weithorn & Campbell, 1982). While concern around youth impulsivity is frequently raised in discussions of youth decision-making capacity, researchers call attention to the kinds of decisions that elicit impulsivity versus those that do not (Grootens-Wiegers, Hein, van den Broek, & de Vries, 2017). "Treatment and research decisions are generally not impulsive decisions, and a certain amount of time for consideration is provided" (Grootens-Wiegers et al., 2017, p. 6).

Confidentiality is another important aspect of youth health care, in large part because failure to respect autonomy through maintenance of confidentiality is linked to youth becoming disconnected from systems of care (English, 2005; Jones & Boonstra, 2004). While current practices generally include encouraging youth to involve parents in their health care decision-

making, it is recognized that requiring parental involvement can, in some cases, place youth at risk of harm (Canadian Paediatric Society, 2004; English, 2005; Jones & Boonstra, 2004; Kuther & Heights, 2003; Morreale et al., 2005). While parent involvement is often seen as ideal, maintaining confidentiality around care for sensitive issues (e.g., mental health, pregnancy, HIV) and for vulnerable populations (e.g., sexual and gender minority youth) is viewed as an important element of youth health care (English, 2005; Morreale et al., 2005; Parker, 2011).

2.5.2 Beneficence and Non-maleficence

The wellbeing of youth should always be at the center of health care and ethical decision-making. Youth, parents/caregivers, and health care providers all desire the best possible health outcomes and avoidance of as much harm as possible, though they may disagree about specific goals and approaches to wellbeing. It is imperative that health care providers strive to do no harm while working to benefit those in their care (i.e., acting in the best interests of youth). However, when health care decision-making conflict occurs among youth, parents/caregivers, and health care providers, it can lead to complex ethical challenges (Canadian Paediatric Society, 2004).

In medicine and in law, the best interests standard is used when making treatment decisions for someone without the capacity to decide for themselves (Diekema, 2011; Rhodes & Holzman, 2014). In such cases, the role of a proxy decision-maker is to “determine the highest probable net benefit among the available options, assigning different weights to interests the patient has in each option balanced against their inherent risks or costs” (Beauchamp & Childress, 2013, p. 228). Decisions should be made based not on the proxy decision-makers own view of the world, but through the eyes of the person they are responsible for (Jonsen et al.,

2015; Salter, 2012). Choices made must “at least meet a minimum threshold of acceptable care”, generally understood to mean that these decisions are aligned with how a reasonable person would balance risks and benefits in a given situation (Kopelman, 2007, p. 189).

In pediatric care, it is generally assumed that parents want what is best for their children and that they understand their children’s unique needs better than others (Unguru, 2011). When acting as a proxy decision-maker for a child without capacity or legal authority to make their own decisions, parents benefit from obtaining health information, talking with others, and having a sense of control over the decision-making process (Jackson, Cheater, & Reid, 2008). Negative impacts on these decision-making processes include attitudes and competencies of health care providers and system barriers, which can result in a parents feeling that they need to protect their child and fight for needed services (Aarthun & Akerjordet, 2014; Alexander, Brijnath, & Mazza, 2015; McNeilly, Macdonald, & Kelly, 2017). As previously noted, parental involvement in decision-making can in some cases be harmful to youth, creating ethical challenges for health care providers in determining how various parties should be involved in health care decision-making (Canadian Paediatric Society, 2004; English, 2005; Jones & Boonstra, 2004; Morreale et al., 2005).

While parents are typically involved in health care decision-making concerning their children in Canada, youth may assume decision-making responsibility when they have developed sufficient capacity (Canadian Paediatric Society, 2004; McNeilly et al., 2017). The laws governing youth consent to health care vary by province and territory in Canada. Central to legislation in British Columbia governing youth consent to health care is the best interest standard (Infants Act, 1996). Not only must youth possess the capacity to make a health care decision, but it is incumbent on the health care provider to determine that the care is in the best

interests of youth. The *Infants Act* does not elaborate on what best interests entails, but further guidance can be gleaned from the *Family Law Act*, which broadly defines best interests as protecting, “to the greatest extent possible, the child’s physical, psychological and emotional safety, security and wellbeing” (Family Law Act, 2011). However, given that the best interests standard is inherently based on perceptions of quality of life, it is subjective and difficult to apply; ethical issues can arise when there is uncertainty or disagreement around values-based judgments regarding another person (Beauchamp & Childress, 2013; Kopelman, 1997; Rhodes & Holzman, 2014).

When decision-makers (i.e. youth and/or parents) and health care providers disagree about best interests, the way forward is often unclear. However, it is established that health care providers should not accept parental refusal when care proposed for a pediatric patient is likely to be highly beneficial (Rhodes & Holzman, 2014). Many examples of parental refusal of health care for their children can be found in the literature, from routine vaccinations to cancer treatment (Diekema, 2005; King, 2013; Okninski, 2016; Pinnock & Crosthwaite, 2005). While refusal of a treatment may not be considered by health care providers to be in a child’s best interest, the potential consequences of that decision matter in terms of the health care provider’s obligations, as detailed below (Diekema, 2005, 2011; Pinnock & Crosthwaite, 2005).

As noted in a systematic review by McDougall and Notini (2014), there are many ethical frameworks that can be applied in cases where parental proxy decisions may be overridden, such as Buchanan and Brock’s range of medically reasonable alternatives (McCullough, 2010). In another approach, Rhodes and Holzman (2004) propose that health care providers have a responsibility to evaluate not only the decision reached by a proxy decision-maker, but also their capacity to serve in this role. One commonly cited framework favors the *harm principle* (over

the best interests standard) as the appropriate ethical standard on which to base decisions about overriding parental authority when medical treatment for a child is refused (Diekema, 2004). According to the harm principle, intervention is warranted when there exists an imminent and significant risk of serious harm to a child that could be prevented through intervention (Diekema, 2011; Schoeman, 1985). Diekema (2004) offers eight conditions that justify such interference, focused on significant risk of harm, imminence of harm, necessity of the intervention to reduce harm, proven efficacy of the intervention, whether the risks of the intervention are significantly less than the refusal, existence of other options, generalizability of state intervention to other situations, and whether most parents would agree to the reasonableness of intervention by relevant authorities. While this approach is used in pediatric care, it is not without criticism, as scholars question whether taking up the harm principle in place of the best interest standard effectively addresses challenges around making consistent judgements in similar cases, given the indeterminacy of both ‘best interests’ and the ‘harm threshold’ (Birchley, 2016; McDougall, 2016; Powell, 2011). Overall, a complex landscape exists for health care providers seeking to ensure youth have access to health care that is in their best interests.

2.5.3 Justice

Justice involves the fair and equitable treatment of all persons. Rights relevant to youth health care are delineated in international human rights agreements, to which Canada is a signatory (United Nations, 1989; World Health Organization, 2006). The World Health Organization (2006) declares in its constitution that every person has a right to the “highest attainable standard of health” (p. 1). The United Nations Convention on the Rights of the Child (United Nations, 1989) addresses child rights to: non-discrimination; have best interests given

primary consideration; survival and healthy development; have their views taken into account in decision-making; freedom of expression, thought, and association; privacy; access to information; protection from violence; and the best health care possible. According to this convention, parents should provide direction and guidance “in a manner consistent with the evolving capacities of the child” (United Nations, 1989). Lastly, the Office of the United Nations High Commissioner for Human Rights (2008) affirms youth rights to “appropriate mental, sexual and reproductive health services and information” (p. 15). These established rights should be considered in the design and delivery of health services, in order to best address the health care needs and ensure just treatment of all youth.

Ethical decision-making requires that health care providers find the most morally acceptable path forward when the principles of bioethics are in conflict. This may concern capacity, confidentiality, best interests, the harm principle, and the just and equitable treatment of youth. The triadic nature of youth care—involving youth, parents, and health care providers—can make this an especially challenging process. This review has addressed common issues arising in pediatric bioethics in order to provide context for the following section on specific ethical concerns raised in the field of youth gender health care.

2.6 Ethics in Youth Gender Health Care

The body of literature on ethics in youth gender health care is primarily informed by a North American bioethics framework, including discussion of capacity, consent, confidentiality, benefits, risks, best interests, and equitable access to care. Vrouenraets et al. (2015) note that clinicians interpret the principles of autonomy, beneficence, and nonmaleficence in contrasting ways and conclude that consensus on many ethical issues will be difficult to reach without

additional longer-term empirical data. Several articles published in the last decade focus on ethical issues arising in the provision of pubertal suppression and hormone therapy; the focus of this review will be on the latter. The following summary addresses the main ethical issues raised in the extant literature, as well as clinician and ethicist recommendations for addressing these concerns.

2.6.1 Autonomy

Discussions of autonomy in the literature focus on whether trans youth are capable of providing informed consent for gender health care, coercion, parental involvement, and legal constraints on decision-making (Giordano, 2007, 2013b; Stein, 2012; Vrouenraets et al., 2015). As part of the ongoing debate regarding youth capacity to consent to hormone therapy, concerns are raised about youth maturity to make decisions and susceptibility to peer pressure; these are countered with evidence similar to that presented in the youth health care literature, calling attention to the type of decisions being made and research on youth capacity to make health care decisions (Shield, 2006). Giordano (2007) addresses a concern that youth might be coerced into medical intervention, stating there is no evidence of children or youth being coerced into this type of treatment. Legal requirements for parental consent to care create barriers for youth whose parents do not support their gender health goals (Romero & Reingold, 2013; Shield, 2006). In jurisdictions where there are avenues for youth to access some kinds of care without parental consent (e.g., emancipation, mature minor doctrine), some argue in favor of developing a similar exception to allow youth to access gender health care without parental consent, based on the potential consequences of being denied access to care (Huft, 2008; Shield, 2006).

Rights to confidentiality and privacy are cited as important for keeping trans youth engaged with health care providers, and while parental involvement in endocrine care is strongly encouraged in practice standards, it is recognized by some authors that this may not always be in a youth's best interests (Bernal & Coolhart, 2012; Giordano, 2007; Holman & Goldberg, 2006; Swann & Herbert, 2000). While some types of health care may be delivered without parental knowledge (e.g., contraception), maintaining privacy around provision of gender health care is complicated by the obvious physical manifestations of hormone therapy, which limit the possibility of providing this care surreptitiously (Shield, 2006). However, respect for autonomy arguably requires that youth be reassured their medical information will be kept private by health care providers, and only shared with their permission or according to legal requirements (Holman & Goldberg, 2006).

2.6.2 Benefits and Risks

Weighing benefits and risks in consideration of the best interests of trans youth is central to gender health care. Much of the scholarly literature on youth gender health care supports endocrine interventions based on documented benefits (e.g. relieving psychological suffering, preventing development of unwanted secondary sex characteristics), the low risk of physiological harms associated with treatment, and the established risks of withholding care (e.g. suicidality, harassment, violence, lost connection with care providers, use of non-prescribed hormones) (Antommara, 2014; Baltieri et al., 2009; Giordano, 2007, 2008; Holman & Goldberg, 2006; Stein, 2012; Vrouenraets et al., 2015). Clinicians have reached agreement that withholding care is not a neutral option and that conversion therapy is harmful and unethical (Baltieri et al., 2009; Bernal & Coolhart, 2012; Giordano, 2007, 2013b).

Despite relative consensus regarding the benefits of hormone therapy, clinicians and ethicists raise unresolved ethical issues around the potential risks of providing this care. Some question whether informed consent is possible, given the largely unknown long-term implications of hormone therapy related to the mental health, physical health, bone density, and fertility of trans youth (Antommara, 2014; Bernal & Coolhart, 2012; Khatchadourian et al., 2014; Swann & Herbert, 2000). One response to this is an argument that if unknown risks were grounds for not allowing someone to consent to a health care intervention, then many medical interventions could no longer be offered (Giordano, 2007). Lack of consensus about the nature of gender is also cited as an ethical issue, with some positing that the interruption of development with pubertal suppression could prevent a natural ‘crisis of gender’ that might have led to resolution of gender dysphoria (Vrouenraets et al., 2015). This idea is refuted by Giordano (2007) who argues that evidence clearly shows adolescents with gender dysphoria will continue to identify as trans in adulthood, and withholding care is more likely to cause harm than good.

Finally, at the root of many ethical concerns is what is in the best interest of youth. Here, a desire to avoid future regret is raised. While regret is mostly discussed in relation to gender affirming surgery, it underlies discourses around youth capacity to make decisions about hormone therapy and risks of unknown future fertility implications (Milrod, 2014; Murphy, 2012; Unger, 2014). Of importance to this discussion is existing longitudinal research documenting that trans youth who accessed pubertal suppression, hormone therapy, and gender affirming surgery did not experience regret about their medical decisions (de Vries et al., 2014). Absent from this discourse is examination of regret experienced by youth who were unable to access care. While this is acknowledged in discussions of harm related to development of

unwanted secondary sex characteristics, this is not accounted for in relationship to the potential harms of regret.

2.6.3 Justice

Issues of justice in youth gender health care include the need for consistency in how treatment is provided, in particular related to systemic barriers that prevent equal and non-discriminatory access to care (Giordano, 2007). These barriers include cost, lack of insurance coverage, lack of family support, health care providers who are not knowledgeable about gender health care, and geographic areas without services making extensive travel necessary to obtain care (Cavanaugh et al., 2016; Clark et al., 2017; Rosenthal, 2014). Health care provider education is cited as a key factor for improving access to culturally competent health care for trans youth, through increasing understanding of both health outcomes and care needs of trans youth and of the sociocultural context in which they live (Clark, 2017; Clark et al., 2017).

Ethical dilemmas also arise when belief systems of health care providers, parents, and youth conflict (Romero & Reingold, 2013; Swann & Herbert, 2000). Taking a queer bioethics perspective, Roen (2016) discusses the impacts of cisgenderism, and how assumptions about gender normativity disempower trans people by perpetuating conceptualizations of gender non-conformity as problematic. This issue is brought to light in a different manner by Antommara (2014), who analyses the right of health care providers to refuse to provide pubertal suppression on the basis of conscientious objection to supporting trans youth. While scholars have ultimately concluded that refusal to treat would likely be discriminatory, and possibly carry ethical and legal implications, the existing right of health care providers to conscientiously object to providing care highlights the potential role of health care provider values in creating barriers to

youth gender health care (Antommara, 2014; Cohen-Kettenis, Delemarre-van de Waal, & Gooren, 2008). Finally, Stein (2012) reflects on how assumptions that gender is binary may “reproduce social prejudices and stereotypes and...fail to acknowledge and embrace the multiple pathways for expressing one’s gender”, calling attention to the need to promote autonomy, beneficence, nonmaleficence, and justice through treatment centered around individualized gender health goals.

In recommendations on ways to address current ethical concerns in youth gender health care, clinicians and ethicists focus on conceptualizations of gender, bioethics principles, and the need for long-term data to inform evidence-based practices. Emphasis is placed on recognizing the multitude of healthy ways that gender may manifest and in supporting these diverse possibilities (Roen, 2016; Stein, 2012). Autonomy may be supported through an informed consent model of gender health care and other health care decision-making processes in which benefits and risks are carefully weighed in order to serve the best interests of individual youth (Cavanaugh et al., 2016; Giordano, 2007, 2013a, 2013b; Stein, 2012; Vrouenraets et al., 2015). Confidentiality and privacy should be respected, and while family involvement is ideal, it should be recognized that this can be harmful in some circumstances (Giordano, 2007, 2013b; Holman & Goldberg, 2006). Finally, justice can be addressed through the development and delivery of equitable health care services, for example individualized care without arbitrary age requirements and ensuring providers are trained and accessible outside of large urban centers (Clark et al., 2017; Giordano, 2007, 2013a, 2013b).

This review has revealed several unresolved ethical issues within the youth gender health care literature, surrounding the nature of gender, capacity to consent, parental role in decision-making, harms of providing and withholding treatment, potential for regret, and inequitable

access to care. Many of these issues have been addressed in scholarly literature on gender, health care decision-making, ethical decision-making, and ethics in youth health care, however there is a disconnect between this work and the youth gender health care literature, particularly in the areas of capacity, regret, and equitable access to care. Furthermore, the available research focuses primarily on clinician perspectives, with rare representation of youth and parent perspectives. While many ethical frameworks have been developed to support health care providers in practice, there is very limited exploration of clinical ethical decision-making within the youth gender health care literature. Overall, research on health care and ethical decision-making in youth gender health care is lacking, particularly in the Canadian context, however the broader extant literature provides a strong foundation for exploration of individual health care decision-making, shared decision-making, and ethical decision-making with trans youth, parents/caregivers, and health care providers.

Chapter 3: Methods

3.1 Overview of Methodology

A qualitative, constructivist grounded theory approach was undertaken to generate new understandings of how trans youth, parents/caregivers, and health care providers engaged in ethical and health care decision-making related to hormone therapy initiation. Constructivist grounded theory, as established by Charmaz (2014), emphasizes both actions and processes to answer questions about social processes and social psychological processes. This method centers perspectives, meanings, and experiences of research participants within their social contexts (Charmaz, 2014). Therefore, this method was selected as appropriate to generate new knowledge about decision-making processes within and among the three salient participant groups.

A North American bioethics framework was employed to support analysis of clinical ethical issues emerging over the course of the study. The strength of this framework lies in the attempts to integrate multiple ethical theories in a way that is relevant to health care; however, critique includes concern that the principles are difficult to apply in practice and that insufficient attention is given to factors such as relationship and social justice (Holm, 1995; Marway & Widdows, 2015). While many ethical frameworks and theories could be applied in analysis of this data (e.g., relational, queer bioethics, justice doing), a North American bioethics framework was the approach consistently applied by health care provider participants (Bergum, 2013; Reynolds, 2011; Roen, 2016). Given that one goal of this research was to support evidence-based practices in youth gender health care, it was decided that using a framework that was familiar and accessible to the intended audience of these research findings was most appropriate.

Understandings of a broad range of ethical theories and approaches to health care decision-making remained sensitizing concepts throughout the analysis.

3.2 Research Paradigm and Theoretical Grounding

The research paradigm for this study can be described as critical realism, wherein a constructivist understanding of concepts central to the project was maintained, alongside belief that there is “a real world that exists independently of our perceptions and theories” (Maxwell, 2013, p. 43). For example, sex and gender were viewed as social constructs, however some physiological processes were considered independent realities (e.g. testosterone stimulates facial hair growth). The present study fit within this framework, with an overarching purpose of understanding how people made health care decisions within their socially constructed realities. This research was also approached from a critical theory perspective, aligning with researcher values of challenging oppression and working toward social change through research (Thomas, 2009). Values and beliefs fundamental to the current study were: (1) gender is self-determined; (2) hormone therapy is medically necessary for some individuals; and (3) all trans people should have access to gender affirming health care. Finally, this research was theoretically grounded in the gender affirmative model of care (Ehrensaft, 2016; Hidalgo et al., 2013). This model is built on six premises, all of which were central to this dissertation:

(a) gender variations are not disorders; (b) gender presentations are diverse and varied across cultures, therefore requiring our cultural sensitivity; (c) to the best of our knowledge at present, gender involves an interweaving of biology, development and socialization, and culture and context, with all three bearing on any individual’s gender self; (d) gender may be fluid, and is not binary, both at a particular time and if and when it changes within an individual across time; (e) if there is pathology, it more often stems from cultural reactions (e.g., transphobia, homophobia, sexism) rather than from within the child. (Hidalgo et al., 2013).

3.3 Research Questions

The initial research questions for this study were designed to address multiple decision-making processes, both independent and social (e.g., collaborative, shared) and to understand, from participants' perspectives, how they could be better supported in these processes. For example, questions about how trans youth make decisions about hormone therapy and how youth, parents, and health care providers engage in shared decision-making processes were posed (see Chapter 1 for complete list). In accordance with Charmaz's (2014) approach to grounded theory, flexibility allowed for incorporation of research questions that emerged over the course of data collection and analysis. In this study, it became clear that youth experiences of barriers and facilitators to enacting their decisions regarding hormone therapy initiation and of health care provider approaches to hormone therapy readiness assessment/care planning were significant, and should therefore be addressed through emergent research questions.

3.4 Setting, Recruitment, Sampling

This research took place in British Columbia, Canada. Data collection was undertaken in four of the province's five geographic health regions. Participants were recruited through organizations that explicitly served trans youth, parents/caregivers of trans youth, and/or health care providers. Youth and parents/caregivers were recruited through community support groups, community events, and clinics providing gender health services. Health care provider recruitment was facilitated by a partner organization, Trans Care BC, through a letter of invitation distributed to professionals providing gender health care in British Columbia.

Purposive sampling was undertaken to ensure representation of the populations of interest. Demographic characteristics deemed relevant for this study included diverse ages,

genders, ethnicities, geographies, and hormone therapy statuses (i.e., on hormone therapy, still deciding about hormone therapy, experiencing barriers to hormone therapy, decided not to access hormone therapy). The approach primarily took the form of expert sampling, to elicit data from those who had relevant personal and professional experiences, with snowball sampling employed as needed. Health care provider recruitment began first, in order to obtain information about what health care providers would like to know about youth and parent experiences. This information was sought early on so that it could be integrated into youth and parent interviews. This was followed by initiation of recruitment of youth who were not connected with gender health clinics, to support representation of this subpopulation. Finally, recruitment of youth and parents was started through organizations that provided gender health care. Recruitment efforts were overlapping and ongoing. Recruitment for each participant group was closed when participants with the relevant characteristics had completed interviews and theoretical sufficiency had been achieved (Dey, 1999). All participants who made contact with the researcher during the recruitment period were provided with the opportunity to complete an interview.

3.5 Participants

Trans youth, their parents/caregivers, and their health care providers are primary participants in hormone therapy initiation decision-making processes, and were therefore the three groups of interest in this study. Eligible youth participants were aged 14 through 18 years ($n=21$), resided in British Columbia, Canada, self-identified as trans, were able to give informed consent in English, and met one of these four hormone therapy status criteria: (1) had initiated hormone therapy within the last two years, (2) were considering whether or not to access hormone therapy, (3) had decided not to access hormone therapy, or (4) were experiencing a

barrier to accessing hormone therapy. Parents/caregivers ($n=15$) of any youth who met the above criteria, who resided in British Columbia, Canada, and who were able to provide informed consent in English were the second group eligible group. The third cohort of participants comprised credentialed health care providers ($n=11$) who were offering hormone therapy readiness assessment/care planning services for youth in British Columbia, Canada and able to provide informed consent in English. Parents/caregivers did not need to have a youth enrolled in the study in order to participate; likewise, youth could participate without their parents/caregivers taking part. Participants were informed that no data would be linked if a youth and a parent/caregiver from the same family participated.

The twenty-one youth who participated in the study lived in four of British Columbia's five health regions. Ten youth stated they were exclusively white, 7 were people of color, and 4 did not share their ethnicity. Two youth identified themselves as Indigenous and one as a newcomer to Canada. Ages ranged from 14 through 18, with a mean of 16.4 years (median = 17). Youth genders were diverse, but dispersed fairly equally across three broad categories: female or transfeminine ($n=8$); male or transmasculine ($n=8$); or non-binary or genderfluid ($n=5$). The majority of youth ($n=14$) were on hormones, one was in the process of starting hormone therapy, three were undecided, and three were experiencing barriers to care.

Parent/caregiver participants included 12 mothers and three fathers, evenly distributed across four of BC's five health regions. Because all participants in this group identified themselves as parents, this descriptor will be used (in place of parents/caregivers) for the remainder of this dissertation. The ages of their trans children ranged from 14 through 18, with a mean age of 16.1 years (median = 16). Parents understood their child's gender to be: female or transfeminine ($n=7$); male or transmasculine ($n=6$); or non-binary ($n=2$). The majority of their

children were taking hormones or had taken them previously on a planned short-term basis; one was in the process of starting hormones at the time of the interview.

Health care providers represented a range of disciplines and worked in three of the province's health regions, with the majority concentrated urban areas. Six of the health care providers had been providing hormone therapy readiness assessment/care planning services for trans youth for four years or less, two for 5-9 years, and three for ten or more years. More specific demographic information, such as the number of health care providers practicing in specific disciplines, has not been reported in order to avoid disclosure of potentially identifying information.

3.6 Data Collection

Individuals who expressed interest in study participation were screened by phone or e-mail and sent a copy of the appropriate consent form (see Appendices A, B, and C) at least 24 hours before the scheduled interview time. Each interview was scheduled in a private location selected by the participant, such as the participant's home, school, or office, or a local health clinic, library, or community centre. Interviews were scheduled at a time convenient to the participant, within parameters of researcher availability within each geographic health region. On the day of the interview, the researcher reviewed the consent form with the participant and ensured all questions were answered. Capacity to provide informed consent was evaluated through discussion-based evaluation of participant understanding of procedures, risks, and benefits of study participation. Once the criteria for informed consent were met, the researcher invited the participant to sign the consent form and offered to provide the participant with a

copy. Each participant completed a semi-structured interview of approximately one hour in length, which was recorded using a digital audio recorder.

In keeping with constructivist grounded theory, those invited to participate had first-hand experience with decision-making related to youth hormone therapy initiation. The interview guide was designed to allow for exploration of participant experiences and perspectives, employing open-ended questions to elicit detailed responses (Charmaz, 2014). Questions were asked to clarify information and to follow up on responses; however, care was taken to avoid questions that would be overly intrusive or beyond the bounds of the study as it had been explained to participants (Charmaz, 2014).

Youth and parents were asked to describe how decisions were made about hormone therapy initiation, what issues needed to be resolved as part of the decision-making process, what supports had been available to them, and how decisions were shared among youth, parents, and health care providers (see Appendices D and E). Lifeline drawings were also generated to document how these processes unfolded over time (Berends, 2011; Davies, 1996; Pirskanen, Jokinen, Kallinen, Harju-Veijola, & Rautakorpi, 2015; Sheridan, Chamberlain, & Dupuis, 2011). Using a large piece of paper, the participant and the interviewer collaboratively mapped out key events in the decision-making journey, elicited in response to interview guide and clarifying questions (see Appendix F). This technique was used to stimulate recall, to organize narratives, and to create temporal representations of decision-making processes to augment the interview transcripts.

Health care provider interviews addressed ethical dilemmas encountered in practice, approaches to ethical decision-making, and shared decision making-practices. A hypothetical practice scenario developed as part of the interview guide was presented to health care providers,

followed by an invitation to identify salient ethical issues and to describe what their clinical approach would be in addressing these concerns (see Appendix G). This elicitation device was employed to gather additional data on ethical decision-making processes. These processes could be observed in the moment, rather than solely depending on recall of past ethical decision-making. This process was designed as a means to learn more about participants' initial responses to a common scenario, an important aspect of the ethical decision-making process as this represents a time when a judgment as to whether an ethical dilemma exists may first be formulated. Similar to elicited documents, by looking at a common hypothetical scenario and predicted actions the intent was to generate data illustrating the "conditions under which specific actions, intentions, and processes emerge or are muted" (Charmaz, 2014, p. 35), in order to compare decision-making processes across this group of participants.

At the conclusion of each interview, participants were given the website address for the University of British Columbia Stigma and Resilience Among Vulnerable Youth Centre, where research reports would later be posted or linked. They were also offered the opportunity to share their e-mail address and/or phone number with the interviewer in order to receive information about future knowledge translation activities and publications. Nearly half of the participants expressed interest in member checking their transcribed interviews for accuracy, with the opportunity to redact any information they later decided they did not want shared. De-identified transcripts were shared with their participants either by e-mail or in person, per individual preference.

3.7 Data Analysis

Data for grounded theory analysis included interview transcripts and lifeline drawings. Analysis was completed with the assistance of NVIVO 11 Pro software. Analysis began following the first interview, such that analysis for all three participant groups was occurring simultaneously. Response to the invitations to participate in the research was rapid and completing interviews when participants were interested and available was prioritized. This resulted in a temporary backlog of transcripts for analysis at some points in time.

Memos were written immediately following each interview to document initial themes, connections among interviews, and relationship of data to sensitizing concepts. Sensitizing concepts in this analysis included North American bioethics principles, other ethical frameworks, and knowledge of the medical, psychosocial, and systems aspects of youth gender health care in the literature and in the province of British Columbia. Memo writing continued to be used throughout the research process to better understand connections within the data and to move analysis forward through exploration of theoretical ideas. All codes were inductively developed and grounded in the data gathered from participants.

Data from each interview transcript were coded line-by-line, and then data from lifeline drawings were coded phrase-by-phrase, using constant comparative methods. Staying close to the data, simple inductive codes (e.g., “unable to provide needed care”, “difficulty accessing information”) were developed to describe processes, actions, feelings, and consequences of the processes; in vivo codes (e.g., “I have my rights”, “the only path I can really go down”) were frequently used to preserve the language of participants (Charmaz, 2014). Initial coding was followed by focused coding, through which patterns were identified and parent codes were developed to encompass related in vivo codes (e.g., “it was confusing”, “nightmares”, and

“frustrated, angry” were grouped together under the parent code “emotional impact”). Finally, theoretical coding was employed to relate codes to one another in ways that addressed the initial research questions and illuminated emergent research questions. Diagramming to create visual representations of the data and relationships among concepts was central to this analysis, and was conducted primarily by hand. During theoretical coding, lifeline drawings were integral to analyzing and generating models representative of the temporal aspects of health care decision-making experiences among youth and parent participants.

Ultimately, several models were developed to address research questions regarding various aspects of health care and ethical decision-making. North American bioethics principles of autonomy, beneficence, nonmaleficence, and justice informed the analysis of ethical issues arising in health care practices with trans youth, as this bioethics framework was consistently applied by health care providers during interviews (Beauchamp & Childress, 2013).

3.8 Rigor and Reflexivity

Several steps were taken to promote rigor within this research. First, rich data were collected through both interviews and lifeline drawings. Second, respondents were given opportunities to verify their contributions through member checking of transcripts, supporting accurate transcription and communication of ideas. Rigor was bolstered through triangulation of interview data and emergent themes from members of three distinct, but interrelated participant groups. The researcher engaged in reflexive practices throughout the research process, including peer supervision, consultation, and writing memos following each interview and throughout the analysis process.

3.9 Research Ethics

This research was covered by certificates from the following research ethics boards and committees: University of British Columbia (UBC) Behavioural Research Ethics Board, the University of British Columbia Children's and Women's Health Centre of British Columbia Research Ethics Board, the Vancouver Coastal Health Research Institute, and the Northern Health Research Review Committee.

It was recognized that some participants might experience transient emotional risk of becoming upset surrounding disclosure of personal information during an interview or later decide that they did not wish to have personal information shared. The following procedures were put in place to address this risk: (1) if a participant showed signs of discomfort during an interview, the interviewer would remind the participant that they could withdraw from the study and ask the participant to reconfirm their consent; (2) the interviewer would ask participants to reconfirm their consent if they chose to share highly personal information; (3) all participants were invited to member check transcripts and to redact any information they not want included in the study. Additionally, all participants were provided with contact information for the Transgender Health Information Program, a service that offered referrals for gender-affirming supports within communities across British Columbia, in the event that a participant wanted to access supports or resources following an interview.

Risks associated with confidentiality of data and privacy of personal information were addressed in multiple ways. As face-to-face interviews were conducted, anonymity could not be achieved; however, confidentiality was maintained by assigning each participant a unique study identifier. Lifeline drawings were stored securely, then digitized and anonymized prior to data analysis. Following each interview, the digital recording was labeled with the study identifier

and later transcribed via an external transcription company. Privacy was protected via a confidentiality agreement with the company and use of an encrypted server for transfer of all study files. Throughout the study, all files were uploaded onto an encrypted server using password protected computers. Transcripts were accuracy checked and identifying information (e.g., individual names, health clinics) removed. If youth and parents from the same family participated in the study, their data were not to be linked. Due to the small number of eligible individuals and enrolled participants, limited demographic information is reported.

Benefits of study participation included the opportunity for participants to share their stories and have them validated by the researcher, to contribute to improved systems of care for themselves/their children/others, and to be connected with supportive resources. All participants received a \$25 honorarium for their travel expenses, time, and expertise. Participants acknowledged that this research had the potential to positively impact trans communities, health care professionals, and health care systems in ways that could provide direct benefit or help others who would later seek to access or provide gender health care.

Chapter 4: Hormone Therapy Initiation Decision-making

4.1 “That’s Their Choice, Not Mine”: Decisions About Hormone Therapy for Trans Youth

Health disparities of transgender (trans) youth are well-documented, and both parent support and access to gender affirming health care are factors that influence health outcomes in this population (Clark, Veale, Greyson, & Saewyc, 2017; Delemarre-van de Waal & Cohen-Kettenis, 2006; Khatchadourian et al., 2014; Olson J et al., 2011; Ryan et al., 2010). Many trans youth and their parents make decisions about initiating hormone therapy when youth are ages 14-18, and they may seek the support of health care providers as part of this process. While there is research documenting the benefits of hormone therapy for this population, and programs in many parts of the world offering this care (de Vries et al., 2011; Delemarre-van de Waal & Cohen-Kettenis, 2006; Edwards-Leeper & Spack, 2012; Khatchadourian et al., 2014), the topic of how youth and parents make and enact decisions related to hormone therapy initiation has gone largely unexamined.

Within the gender health care literature, youth perspectives are generally underrepresented and frequently limited to those who have already accessed care. Parent voices are rarely included, even though parents are frequently involved in youth health care decision-making. There exists a gap between practices described in the literature and the lived health care experiences of trans youth and their parents, calling into question how well current approaches to care are meeting the needs of this population. Therefore, the goal of this study was inform evidence-based practices for youth gender health care through exploration of the decision-

making processes and experiences of trans youth and their parents around initiation of hormone therapy, as well as facilitators and barriers to enactment of these decisions.

4.1.1 Background

Trans youth have an experience of gender that differs from the sex assigned to them at birth (Frohard-Dourlent et al., 2016). Within the gender affirmative model of care, these genders are considered to be a natural part of human diversity, and the ability to live freely in the gender that feels most real and/or comfortable for a person is termed gender health (Ehrensaft, 2016; Hidalgo et al., 2013). For some trans youth, medical intervention is necessary to support positive gender health and mental health outcomes. For example, hormone therapy may be needed to facilitate development of secondary sex characteristics that align one's body with one's gender (Connolly et al., 2016; de Vries et al., 2014; Khatchadourian et al., 2014; Mallon, 2009; Wylie et al., 2016).

Access to health care and parental support are established as two important factors in the health of trans youth (Connolly et al., 2016; de Vries et al., 2014; Khatchadourian et al., 2014; Travers et al., 2012). Strong parental support is correlated with higher self-reported mental health, self-esteem, and life satisfaction outcomes; youth who encounter barriers to hormone therapy report poorer mental health, self-harm, and suicidality outcomes than those who are able to access this care (Olson J et al., 2011; Olson et al., 2016; Raj, 2008; Travers et al., 2012; Veale et al., 2015; Wallace & Russell, 2013). Several studies have documented positive results related to professional support interventions with parents of trans youth, such as reduced conflict and increased acceptance, however research in this area is limited (Malpas, 2011; Menvielle & Hill, 2010; Menvielle & Rodnan, 2011). Barriers to needed gender health care take many forms. For

trans youth, these include lack of trained providers; inconsistently applied protocols; use of incorrect names and/or pronouns; gatekeeping; lack of care coordination; delayed and limited access to hormone therapy; and insurance exclusions (Gridley et al., 2016). Gender health and cultural competency training for health care providers, delivering care through primary care settings, creating safer clinic spaces, and implementing evidence-based policies and practices are strategies cited by researchers as potential avenues for addressing these health care access issues (Clark et al., 2017, 2018; Gridley et al., 2016; Sherer et al., 2015; Stoddard et al., 2011; Vance et al., 2014).

Parents are typically involved in their children's health care, and their engagement in decision-making about hormone therapy is encouraged (and sometimes required) by health care providers. It is understood, however, that involving parents may not always be in a youth's best interests, for example, if such involvement would place a youth at significant risk of serious harm (Bernal & Coolhart, 2012; Giordano, 2007; Holman & Goldberg, 2006; Swann & Herbert, 2000). In some jurisdictions, parental consent is required for a youth to start hormone therapy, but when parents are unwilling or unable to do this, it leaves youth unable to access needed care (Romero & Reingold, 2013; Shield, 2006). Furthermore, in youth health care, maintenance of confidentiality is important when dealing with sensitive health care issues and in work with marginalized populations (English, 2005; Morreale et al., 2005; Parker, 2011). The legislation governing youth consent to health care in British Columbia is similar to other Canadian legislation, giving youth the authority to consent to their own health care, provided their health care provider determines they have the capacity to do so and that the care is in their best interests (Canadian Paediatric Society, 2004; Infants Act, 1996). This contrasts with consent laws in many parts of the world, which establish minimum ages of consent (e.g., 16 or 18) for health care.

While the law supports youth authority to consent for their own health care, the capacity to make a particular health care decision is determined by the health care provider working with the youth. The capacity to consent to a specific health care intervention is evaluated based on: understanding of the intervention, including the risks, benefits, and alternatives; ability to ask relevant questions; and ability to make a decision consistent with one's values (Cummings & Mercurio, 2010). Health care consent must also be informed and voluntary (Unguru, 2011). The capacity of youth to consent to health care is an area of ongoing debate within pediatric bioethics. Authority to consent varies according to legislation across jurisdictions; however, researchers have established age 14 as the point at which youth typically develop health care decision-making capacity (American Academy of Pediatrics, 1995; Canadian Paediatric Society, 2004; Coleman & Rosoff, 2013; Salter, 2017; Tillett, 2005; Weithorn & Campbell, 1982). In clinical practice, it is appropriate to use a sliding scale, which requires youth to have a greater degree of capacity to make health care decisions with more significant potential consequences (Canadian Paediatric Society, 2004). Benefits of involvement in health care decision-making for youth include a greater sense of control, ownership over health care choices, and long-term decision satisfaction (Jeremic et al., 2016; Tillett, 2005; Unguru, 2011)

Before starting hormone therapy, trans youth must engage with a health care provider around hormone therapy readiness assessment/care planning (Trans Care BC, 2017b). Health care providers offering this service come from various disciplines (e.g., psychiatry, psychology, family practice), and while there are general guidelines for assessing hormone therapy readiness, individual approaches to providing this care vary. Elements that may be incorporated include gender self-determination, medical screening, standardized psychological measures, and family involvement (Cavanaugh et al., 2016; Chen et al., 2016; Coolhart et al., 2013; Edwards-Leeper et

al., 2016; Edwards-Leeper & Spack, 2012; Gridley et al., 2016; Leibowitz & de Vries, 2016).

This process typically involves health care provider evaluation of whether hormone therapy is in the best interests of a youth, along with generation of a care plan to address youth needs (Trans Care BC, 2017a, 2017b).

Individual health care decision-making is influenced by many factors. Health behavior models have been developed to explain and predict individual health behavior. For example, the Health Belief Model takes a linear approach, wherein modifying factors (e.g., age, gender, ethnicity, personality, socioeconomics, knowledge), influence individual beliefs, which then influence action (Skinner et al., 2015). In a similar approach, the Integrated Behavior Model draws on constructs from the Theory of Reasoned Action/Theory of Planned Behavior models, centering intention as the primary driver of health behavior (Montaño & Kasprzyk, 2015). In this model, attitude toward a particular health behavior, perceived norms, and personal agency all contribute to intention to enact that health behavior, while other direct influences on behavior include knowledge, skills, salience of the behavior, environmental constraints (i.e., barriers to care), and habit (Montaño & Kasprzyk, 2015). Finally, Anderson's (1995) Behavioral Model of Health Services Use focuses on health outcomes rather than solely on health behaviors. Outcomes are influenced by four interacting constructs: environment (e.g., health care system), population characteristics (e.g., need), health behavior (e.g., use of health services), and outcomes (perceived health status).

In recent empirical studies examining youth and parent health care decision-making, researchers have identified constructs salient to youth health care decision-making that are reflective of these three models (e.g., demographics, socioeconomics, beliefs, and social norms). In one study, personal/parental beliefs were found to be the primary influence on parental

decision-making (Sturm et al., 2005). These beliefs were influenced by social/environmental factors (e.g., media), interface with health care (e.g., provider attitudes), and institutional factors (Sturm et al., 2005). Getrick et al. (2014) studied youth and parent human papillomavirus (HPV) vaccine decision-making, determining that socioeconomic and cultural factors played a significant role decision-making and decision confidence. These studies vary in focus and populations of interest, however constructs such as intentions, attitudes, beliefs, behaviors, agency, individual characteristics, norms, and the environment are commonly integrated into models of health behavior and decision-making to inform understanding of health behavior and health outcomes.

The sociocultural context in which health care decisions are made is important to consider when seeking to understand related decision-making processes. In dominant North American culture, cisnormativity, heteronormativity, and bionormativity promote assumptions that people are cisgender, that they are heterosexual, and that creating families via biological children is superior to other means, respectively (Baylis & McLeod, 2014; serano, 2017). These norms contribute to stigmatization of trans youth, which can be enacted as discrimination, harassment, and violence (GLAAD, 2017; Huft, 2008; James et al., 2016; Taylor & Peter, 2011; Veale et al., 2015). One framework for understanding how stigma manifests in the lives of trans people is the Gender Minority Stress model, which offers a conceptual understanding of how external stressors influence mental health (Hendricks & Testa, 2012; Testa et al., 2017). Stigma also contributes to ongoing pathologization of gender, health care systems that are not designed to meet the needs of trans youth, and lack of trans cultural competencies on the part of health care providers, factors that can create barriers to care (Clark et al., 2017, 2018; Gorton & Grubb, 2014; Gridley et al., 2016; Menvielle & Gomez-Lobo, 2011; Veale et al., 2015).

4.1.1.1 Purpose

Health care decision-making is a complex process, influenced by factors such as individual beliefs, social norms, agency, knowledge, skills, and barriers to care. While research supports hormone therapy as an effective intervention for trans youth who need this care, health care provider approaches to hormone therapy readiness/care planning are not consistent, and there are no known studies exploring youth and parent experiences with decision-making around hormone therapy. Therefore, the primary objective of this study was to explore how trans youth and parents of trans youth made decisions around hormone therapy initiation. A secondary objective that emerged during this study was to explore how youth experienced barriers and facilitators to enactment of decisions regarding hormone therapy initiation.

4.1.2 Methods

The setting for this study was British Columbia, Canada. Trans youth ($n = 21$), parents of trans youth ($n = 15$), and health care providers ($n = 11$) were recruited to participate through organizations serving these populations. Eligible youth were aged 14 through 18, and met one of the following criteria: (1) had initiated hormone therapy within the last two years, (2) were considering whether or not to access hormone therapy, (3) had decided not to access hormone therapy, or (4) were experiencing a barrier to accessing hormone therapy. Parents of trans youth who met these criteria were eligible to participate. Youth and parents from the same family were eligible (but not required) to participate; however, in order to protect privacy, the study was not designed to link data among participants. Health care providers who were currently providing hormone therapy readiness assessment/care planning for youth were eligible. All participants resided in British Columbia, Canada and were able to provide informed consent and complete

interviews in English. Purposive sampling, with additional snowball sampling as needed, was undertaken to elicit diverse perspectives.

Youth participants were aged 14 through 18 years, with a variety of genders that fit within three broad categories: female or transfeminine ($n = 8$); male or transmasculine ($n = 8$); and non-binary or genderfluid ($n = 5$). Most youth ($n = 14$) were on hormones, one was in the process of starting, three were undecided, and three were experiencing barriers to care. Parent participants had children aged 14 through 18 years, with a diversity of genders. Youth and parents lived in four of the province's five geographic health regions. Health care providers came from many disciplines, the majority from urban centers. They had been providing hormone therapy readiness assessment/care planning services, from 1 to over 10 years, within three of the five health regions.

The primary method of data collection was semi-structured interviews of one hour in length. Locations were selected by participants, and included homes, schools, health care clinics, libraries, and community centers. Interviews were digitally recorded and subsequently transcribed. In youth and parent interviews, descriptions of how decisions were made regarding initiation of hormone therapy (e.g., what was important in deciding/thinking about hormone therapy, what questions were important to have answered), who was involved in decision-making, and supports that were available or desired during these processes were elicited. Lifeline drawings were completed to create temporal illustrations of these processes, an activity that also served to stimulate recall and help participants organize their narratives (Berends, 2011; Davies, 1996; Pirskanen et al., 2015; Sheridan et al., 2011). Health care provider interviews focused on practices related to ethical dilemmas and decision-making in youth hormone therapy readiness assessment/care planning practice.

A constructivist grounded theory approach (Charmaz, 2014) was employed in the analysis of interview transcripts and lifeline drawings, to better understand the social processes involved in making decisions about hormone therapy initiation. Analysis was conducted within participant groups, then across groups. Categories of relevance to decision-making emerged through constant comparative analysis, which was followed by focused and theoretical coding. Lifeline drawings supported temporal analysis of how decision-making processes unfolded over time and generation of temporal models illustrative of participant experiences.

This study was covered by certificates from the Behavioral Research Ethics Board of the University of British Columbia, the University of British Columbia Children's and Women's Health Centre of British Columbia Research Ethics Board, the Vancouver Coastal Health Research Institute, and the Northern Health Research Review Committee.

4.1.3 Results

Decision-making processes of parents and youth are represented below through temporal models. These models were constructed primarily using data from youth and parent lifeline drawings, and augmented by interview transcript data. These models organize youth and parent narratives around the kinds of decisions made, who was involved, and how these processes unfolded. Health care providers were only involved in a portion of these hormone therapy decision-making journeys, however their roles were significant and thus explored from youth, parent, and health care provider perspectives.

4.1.3.1 Youth

Youth were asked to describe experiences with hormone therapy decision-making from the time they first started thinking about hormone therapy until the present. These experiences were organized within paper lifeline drawings, with significant decision-making moments and interactions plotted on a timeline. Tasks undertaken by youth formed three sequential phases of hormone therapy decision-making: discovery, (inter)action, and reflection (Figure 4.1). The majority of youth ($n = 14$) had reached the reflection phase at the time of the interview; others were still in the discovery phase ($n = 3$) or the (inter)action phase ($n = 4$).

4.1.3.1.1 Discovery

During the discovery phase, youth first became aware of hormone therapy as an option, often as they were developing awareness of trans experiences and finding language to describe their own gender and experience. A cycle of growing awareness was supported by research—primarily conducted independently and online—focused on accurate medical information and personal narratives. “One thing that I really did find helpful was on YouTube they actually have trans people who will go on and talk about their own experiences.” Youth engaged in covert information-seeking, a receptive approach to acquiring understandings of gender and self necessary for articulating one’s gender in relation to others’ experiences. Fear of parental reaction to this information-seeking was present in many interviews. For example, “I didn’t want my parents to find out I was looking up these things.” When asked if they posted their own questions in online forums, one youth responded, “I lurked. That was way beyond me.”

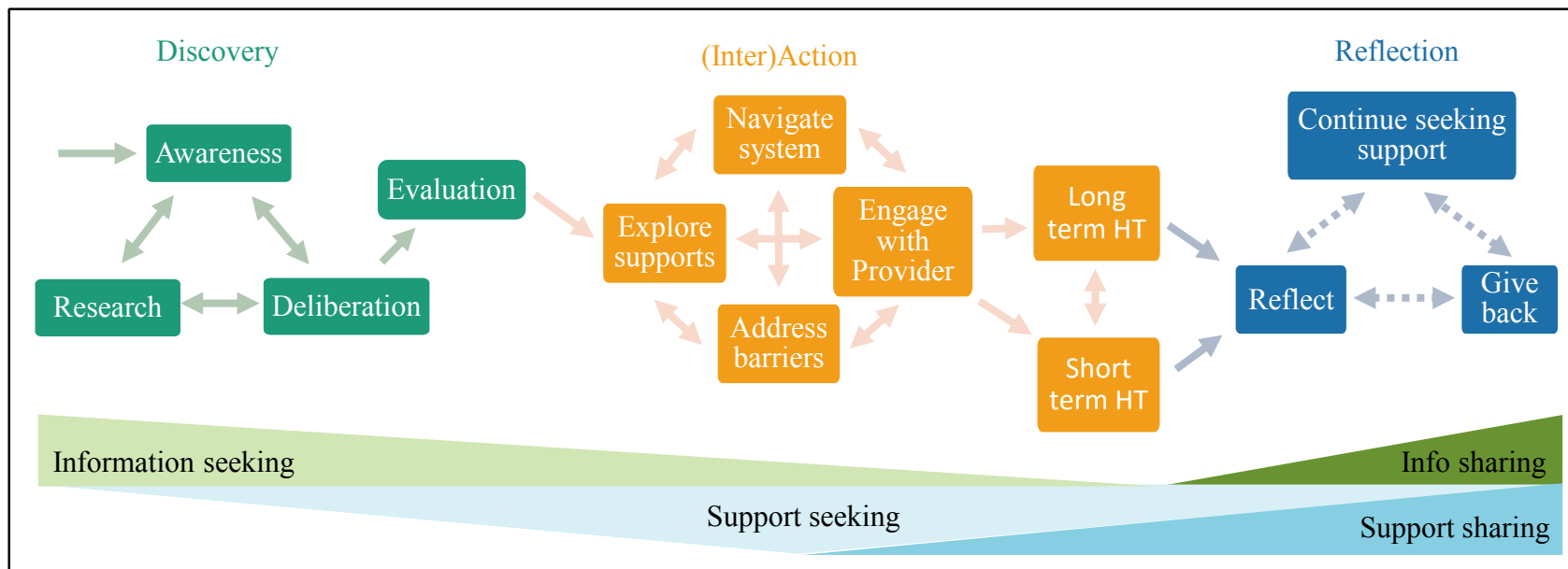


Figure 4.1 Trans Youth Hormone Therapy Decision-making Model

The other component of this cycle was deliberation about gender goals. “I knew I wanted to have the body of a woman, and that wasn’t what was my reality at the time.” Over time, youth discovered that there were steps they could take to address their gender-related distress (e.g., hormone therapy), and began to see themselves as a member of one or more trans communities. “I search for just transgender and then I find out that there is this big community and it is possible.” For some, this process took years of deliberation and evaluation before taking action, for others the timeframe was weeks or months. Articulation of gender and decision-making about gender health needs were viewed as highly individual processes. “So, I had to come to this decision by myself alone. I wasn’t out to anyone. I didn’t feel comfortable speaking to anyone about it.” The discovery phase culminated with evaluation of steps necessary for realization of gender goals, leading out of an internal discovery phase, into one involving action and interaction with others (e.g., parents, health care providers).

Safety and societal stigma—ranging from internalized stigma, to cues from parents about gender acceptance, to fear surrounding the treatment of trans people in public spaces—were important themes in participants’ process of discovery. Fear; perceptions of support within families, communities, and society; and intensity of distress about their bodies contributed to youth feeling that they needed to either wait to disclose their gender at a later time or that coming out and seeking hormone therapy was more urgently necessary for them. A youth in the process of starting hormone therapy offered this description: “The dysphoria is getting so bad that I feel self-conscious all the time... I’m graduating in a year and a half, and I’ve realized I can’t be in this same position... I needed to sort of fix that problem in my head before it was too late to the point where I was back in that dark spot and I didn’t know how to get out.”

4.1.3.1.2 (Inter)Action

The first task of the (inter)action phase was to explore available supports. The parenthetical “(inter)” represents the sometimes-present process of collaborative decision-making, while the “action” indicates that youth were proceeding with seeking care either with, or in the absence of, support from others. Youth-parent relationships and communication affected both decision-making and care seeking. Those who came out to parents and declared their need for hormone therapy encountered a range of supportive and unsupportive reactions related to gender health goals. This led to a cycle of exploring supports more broadly, navigating systems of care, addressing barriers, and engaging with health care providers, either alone or with support from their parents. Interactions with peer support groups, youth workers, social workers, health care providers, and parents were integral to youth determinations of how to access hormone therapy—some primarily taking action to seek care alone and others interacting with parents, other adults, or peers in shared system navigation and/or collaborative decision-making.

Most youth participants felt safe enough to come out at home and subsequently continued to be supported by their parents in areas of life outside of gender health goals (e.g., emotional support, necessities of life). Parent reactions and approaches to gender health goals varied. Some youth stated that they were fully supported by their parents in making decisions and seeking care related to gender health goals. Both youth and parents also described situations where parents gradually became supportive. Many youth and parent participants reported maintaining strong relationships and communication despite some degree of strain related to disagreement about hormone therapy initiation. “Me and my mom had a lot of tension between us and both of us were really frustrated with each other because neither of us was really seeing eye-to-eye about anything, including the trans stuff.” Some youth reported that their parents refused to

acknowledge their gender health goals or sought to undermine access to hormone therapy.

Statements such as this led to youth doubting their decision to access hormone therapy, “My dad was, like, ‘Oh, so why do you want to disfigure your body like that? Why would you do that to yourself? You’re such a pretty girl.’” It is important to note, however, that both youth and parent participants described situations in which parents who were unsupportive of gender health goals remained supportive of their children in other areas of their lives.

Youth viewed health care providers as people who could offer emotional support, answers to questions, and information about the hormone therapy process. Some appreciated health care provider assistance in helping parents to understand youth gender health needs, while others found requirements to involve parents problematic. Other challenges in youth relationships with health care providers involved assumptions about what care a youth would need (e.g. unwanted pressure to pursue genital surgery), disrespectful and condescending communication, and inaccurate information.

In addition to experiences of parental discouragement and challenging health care provider interactions, the mismatch between how youth were perceived in the world and their internal experience of gender at times contributed to a sense of hopelessness about ever being able to live in their authentic gender. However, youth participants demonstrated high levels of resilience in their ability to independently overcome both internalized stigma and a range of external barriers. “It just makes you feel terrible, the way they look at you, like, oh, that person’s just a man in a dress. And I didn’t want to be that man in a dress. So that really stopped me and set me back in the whole transitioning thing, but I got over it. I’m over it now.”

4.1.3.1.3 Reflection

Youth in the reflection phase were looking back on, and making sense of, their hormone therapy journeys. “I feel a lot happier in general, and that’s a lot to do with emotional growth, but also I feel to do with hormones because I feel a lot more comfortable with things that are happening in my body.” All youth who had progressed to this phase ($n = 14$) declared that hormone therapy was the right decision for them, and expressed gratitude for support they had received from family, peers, and health care providers. None shared regrets about the decision to start hormone therapy, though some wished the process had unfolded differently, in particular youth who had been denied puberty blockers and developed unwanted secondary sex characteristics while waiting for care. One youth described the experience of waiting for care this way:

It’s like being stuck in a wet, cold, sandy, uncomfortable swimsuit that is too tight, and everybody else is wearing warm, dry clothes...and somebody not letting you have [warm dry clothes] until you prove [your gender]. It’s rather irritating and uncomfortable and angry-making and depressing and all that other evil, nasty stuff.

Additionally, two youth had been connected with gender health care providers after seeking support around physical assault and sexual assault. In the words of a youth, “After I got sexually assaulted, I had to go to get tested for STDs and STIs...then they also referred me to trans health care services...so I was able to get connected with a doctor.” In these situations, participants made sense of tragic circumstances as a gateway to needed gender health care.

Youth who accessed hormone therapy while residing at home and without their parents’ support for gender health goals described maintaining relationships with their parents and retaining support in other areas of their lives (e.g., housing). One youth reflected on her living situation with her parents this way: “They’re coming around. They’re still kind of uncomfortable with the whole ‘me transitioning thing’, but slowly I kind of added some girl clothes to my

wardrobe until now, where I just completely present as female.” Another youth said, “I am so grateful for [starting hormone therapy at 16], but at the same time, I feel really guilty for being grateful about it, the expense that it’s had on mine and my mom’s relationship, although at the same time, we’re a lot stronger now than we were before.” Experiences of parental and societal support were summarized by one youth this way, “I think that if my parents were more supportive, and if society was more understanding, then I’d live much more comfortably. I’d be so much happier. I would have been so much happier. I wouldn’t have been so confused, and I wouldn’t have hated myself so much.”

In reflecting on their journeys, youth frequently described having a sense of accomplishment, pride, or satisfaction with their ability to ultimately access the care they needed. This contrasted with the frustration characteristic in narratives of participants who had not been able to access hormone therapy. During this phase, many youth also engaged in ongoing support seeking and found ways to give back to trans communities. “In the last two or three years, I’ve been in a magazine, I’ve spoken at a conference...I’ve tried to sort of offer support to other kids who are going through it now because I just remember how alone I was, and I don’t want anybody else to have to feel that too.” These actions allowed youth to share the wellbeing and happiness that resulted from accessing hormone therapy and to find their place in the world and within specific communities as a trans or non-binary person.

4.1.3.1.4 Trans Youth Hormone Therapy Decision-making Model

The tasks and phases described are illustrated in Figure 4.1. Across the entire process, information seeking was most intensive during the discovery phase and diminished over time. Youth sought diverse information about hormone therapy, for example: what it was; what it

could and could not do; associated health risks; personal experiences of other trans and non-binary people; how to access care and supports; and what their rights were in terms of accessing care. Support seeking related to hormone therapy—from peers, family, and professionals—peaked during the (inter)action phase and reduced as youth initiated hormone therapy and moved on to reflection. During this final phase, information sharing and support sharing expanded, as some youth gave back to their communities after receiving support needed to achieve their own gender goals.

4.1.3.2 Parents

Parent participants were also asked to respond to questions about hormone therapy decision-making processes and to complete lifeline drawings in interviews that paralleled those asked of youth participants. Data indicated that parents engaged in similar tasks to youth, but in a somewhat different sequence. A parent typically began this journey as their child entered the (inter)action phase, came out to them, and requested support in seeking hormone therapy. As a result, the parent discovery process was interrupted in order to take action in response to their child's often urgent need for gender health care. Thus, parents engaged simultaneously in discovery and (inter)action tasks, as illustrated in Figure 4.2.

4.1.3.2.1 Discovery and (Inter)Action

The hormone therapy decision-making journey began with awareness. Usually parents became aware of their child's gender when their child came out to them in the teen years, though a few parents were aware of their child's gender or gender non-conformity earlier on. Awareness of their child's need for hormone therapy usually occurred soon after coming out, leading to initial

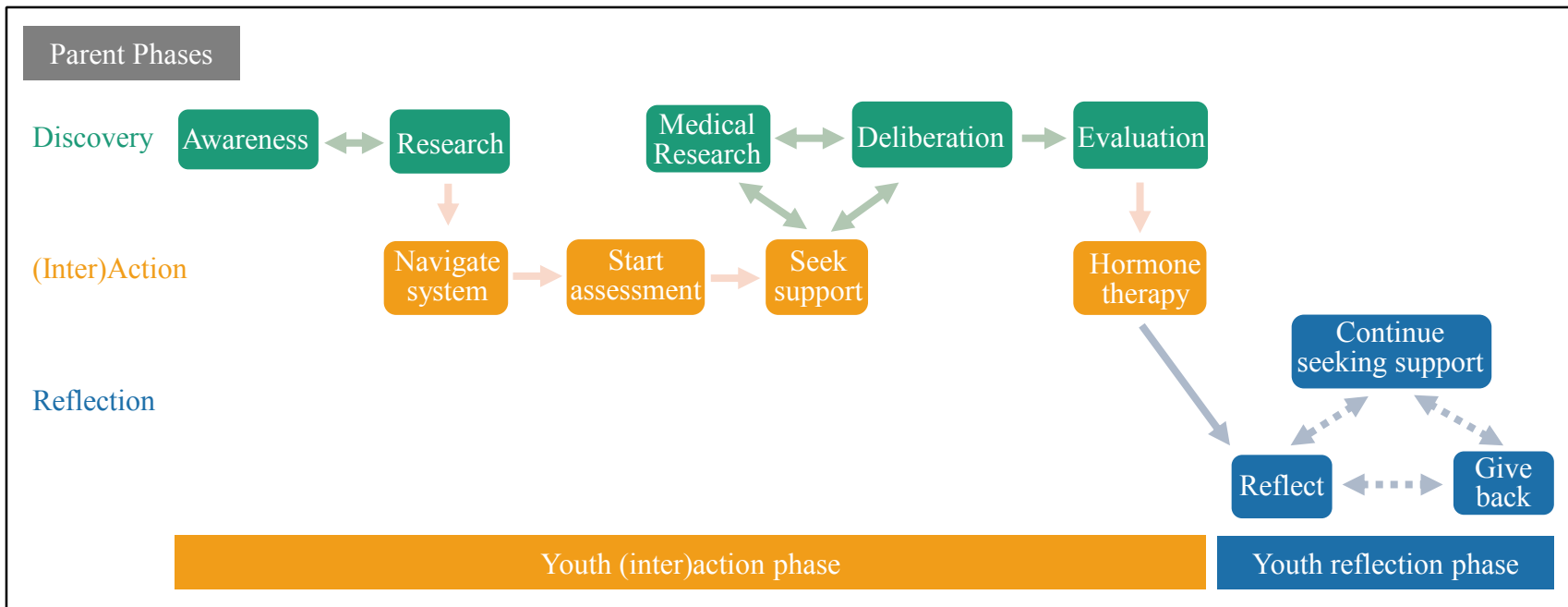


Figure 4.2 Parents of Trans Youth Hormone Therapy Decision-making Model

research about gender, transition, and medical interventions, including hormone therapy. Not surprisingly, the majority of parents interviewed were supportive of their children accessing hormone therapy early on and assisted with system navigation. As one parent framed it, “She’s a woman, so she needs all the tools to be a woman.” After their child’s immediate needs were addressed, parents engaged in a cycle of medical research, support seeking, and deliberation that led to an evaluation of options before their child initiated hormone therapy. “I was still feeling very overwhelmed and kind of upset about all this, and it really helped, talking to other parents about what they were going through.”

Communicating with health care providers and with other parents (in-person and online) helped parent participants make sense of the situation and their role. Parents identified emotional support, answers to questions, and information about the hormone therapy initiation process as components of positive health care provider interactions. One parent felt reassured after meeting with her child’s health care provider: “[it] kind of made me feel like, okay, I’m not so much in quicksand.” Another discussed the importance of clear communication about medical information: “The health care provider was very good at giving us all the information...letting us know what the next steps were.” Some parents felt shut out of decision-making processes and others described problematic parent-health care provider miscommunication, in one case so severe that it resulted in a youth being denied timely access to needed care. Overall, parent experiences were mixed, resulting in views of the health care provider as either a source of support or as a gatekeeper whose role was to check the boxes necessary to access hormone therapy.

Parents’ strong relationships and communication with their children were invaluable in facilitating decision-making and care seeking processes. “Knowing my child and knowing our

relationship and being able to communicate and go through things together, I think was the most helpful.” Some parents who were reluctant to support their child’s goal of accessing hormone therapy took a lesser role in system navigation, but still sought out support and engaged with health care providers. Parent participants who described initially feeling reluctant either: (1) gradually came on board with the plan to initiate hormone therapy or (2) maintained a belief that hormone therapy was not a healthy intervention while simultaneously supporting their child’s autonomy and right to make their own decisions. “I support my child in being who they want to be, but I do not support putting a chemical in their body... it doesn’t mean that I don’t love them and support them in their choices, but that’s their choice, not mine.” In this situation, the parent and their child shared in, and supported one another through, complex decision-making processes, wherein consensus about hormone therapy initiation was not achieved, but they did agree that it was appropriate for the youth to autonomously consent to hormone therapy.

4.1.3.2.2 Reflection

The reflection phase was similar in parent narratives as in interviews conducted with youth. Parents looked back on their decisions, continued seeking support, gave back to the communities, and generally expressed resolve that the decision to start hormone therapy had been the right one for their child. “I could see changes that were incredible, psychologically and then physically as well.” In contrast to youth participants, some parent participants held concern that their child might someday change their mind or regret their decision to start hormone therapy. Many parents were distressed about the barriers encountered in care seeking and the life-long implications associated with their child’s potential emotional suffering due to delay of treatment and development of unwanted secondary sex characteristics. “That’s unfortunate

because [waiting due to a limited number of qualified health care providers] continues that dysphoria and anxiety for that much longer, and people shouldn't have to live like that, you know? Especially our kids.” This parent's reflection was characteristic of many participants' sentiments about decision-making processes: “But I have to always go back to, you make the best decision you can with the information you have at the time, with as pure a heart as you can.”

4.1.3.2.3 Parents of Trans Youth Hormone Therapy Decision-making Model

Throughout all phases, parent participants focused on promoting their child's wellbeing, through direct communication, emotional support, and connecting with health care providers. This process was driven by parental duty to protect and nurture their child. Fear was a common theme among parents, though it manifested in diverse ways. For example, some parents discouraged their children from accessing hormone therapy when this intervention was perceived as dangerous. Others became strong advocates and took responsibility for navigating systems in response to their child's need for gender health care. Many parents discussed taking steps to ensure transition would be safe for their child, whether through researching side effects of hormone therapy or working with their child's school to put a transition plan in place. While the tasks and processes of all parent participants fit within this decision-making model, parent decisions, actions, and interactions with their children and with health care providers varied. The experiences described here may not be representative of all parents, due to bias in who volunteered to be part of the study and in what information they elected to share when interviewed.

4.1.3.3 Supporting Decision-making Processes

An additional research objective emerged during the course of this study: to explore facilitators and barriers to youth enacting decisions about hormone therapy initiation. Thus far, the decision-making journeys of youth and parents have been explored from when they first began thinking about hormone therapy until the time of the interview. In the final section, health care provider perceptions of their role in the decision-making process, types of decisions made by all parties, and the ways in which parent and health care provider approaches facilitated or impeded youth access to care are examined.

4.1.3.3.1 Health Care Provider Role

Health care providers took on roles of protector, collaborator, facilitator, and gatekeeper. Some providers took an approach to assessment that included a fairly standardized psychological evaluation (e.g., screening for specific mental health concerns, comprehensive childhood gender history), leading to a diagnosis of gender dysphoria and then approval of hormone therapy. Many health care providers expressed fear that harm would befall the youth, whether they facilitated access to hormone therapy (e.g., damage to the youth-parent relationship, parental rejection, foreclosure of fertility options, future regret of starting hormone therapy) or not (e.g., youth self-harm, suicide). While some saw their primary role as evaluating gender dysphoria, while others described a collaborative process of determining when (not if) youth would move forward with hormone therapy following confirmation of meeting established hormone therapy criteria. One health care provider described an interaction with a youth this way, “I said, ‘Look, we’re here. We’re on board. It’s just a matter of when.’ And, so, it’s often a matter of when. Not a matter of if. It’s pretty clear.” These health care providers often described their role as facilitators of

patient-centered care, wherein they assisted youth in making plans for safer hormone therapy initiation, including evaluation of medical safety, mental health, and support systems, as well as youth capacity to give consent for hormone therapy.

All providers sought to involve parents in decision-making; some required parental involvement, while others allowed youth to decide how parents would be included in their care. When parents were unable or unwilling to support their children's gender health goals, some health care providers worked with the youth to build up other support networks. One health care provider described working to evaluate and mitigate risks in this way: "What are the risks and how do I help minimize those risks as much as possible or help to build up a safety network for this young person?" Health care provider narratives generally focused on the importance of their communication and relationships with youth and parents, as well as with other health care providers. Some discussed a sense of isolation in their practice, while others were grateful for being networked with peers through supervision groups or working as part of a team.

4.1.3.3.2 Decisions

Key decisions made during each phase of the hormone therapy decision-making journey are highlighted in Table 4.1. Youth made many different decisions over the course of these journeys. Some made a clear choice that hormone therapy was right for them, while others described being pre-decided about this and discovering hormone therapy as the means to realize the gender health goals they already had (e.g., physiological changes to live more fully in their gender). Youth decisions occurring across the three phases included decisions to learn more about hormone therapy, to work to bring their parents on board, to initiate hormone therapy, and

Youth	Parents	Health care providers
Discovery		
I am trans I need to learn more about hormones I need support deciding about hormone therapy This is my decision to make I need hormones Transition is not possible right now		
(Inter)action	Discovery/(Inter)action	(Inter)action
Come out to family, others	I have to support my child	Plan collaboratively with youth
Work to bring parents on board	Positives outweigh negatives	If youth has capacity to consent
Move out of unsafe situations	Alternative (suicide) is unacceptable	Conduct psychological evaluation
When to access hormone therapy	Trust my child to know who they are	If youth meets hormone therapy criteria
Access hormone therapy without parent support	It's my child's decision	If youth is likely to regret hormone therapy
Have a hormone therapy readiness assessment	Seek care immediately	Whether to require parental support
Find alternatives to prescribed hormone therapy	Advocate for needed care	If it is safe to move ahead with hormone therapy
	Support hormone therapy	
	Seek support (or not)	
Reflection	Reflection	
Use experience to help others	We made the right decision	
Participate in research	Offer support to new parents	
Attend support groups		

Table 4.1 Decisions Made by Youth, Parents, and Health Care Providers

to use their experience to help others. Parents also had many decisions to make, for example, to support their child in seeking hormone therapy, to trust their child to know who they were, that their child should make their own health care decisions, and to advocate for needed care.

Meanwhile, health care provider decisions focused on evaluating several things: capacity; whether the youth met criteria to initiate hormone therapy; whether it was safe to move ahead with hormone therapy; the likelihood of youth regretting hormone therapy; and whether to require parental support prior to hormone therapy initiation.

4.1.3.3.3 Barriers to Enacting Decisions

Barriers to youth accessing gender health care included lack of parental support for gender health goals and challenges navigating system of care. System barriers were present for most youth, though the impacts were mitigated in some cases by parent support around system navigation. In addition to cost, travel, and other typical system-based impediments, requirement of parental support for gender health goals also functioned as a barrier to hormone therapy initiation for some youth.

All health care providers preferred having parents on board regarding decisions about initiating hormone therapy, but their approaches to requiring, persuading, or asking youth to engage parents varied. Health care providers expressed hesitancy to initiate hormone therapy without parental approval, as they felt it might cause youth to lose support of their parents beyond the current lack of support for gender health goals. These participants cited research indicating that youth with parental support have better health outcomes, and expressed fear that hormone therapy initiation without parent support could cause harm (e.g., distress related to parental rejection, harm to youth-parent relationship, housing insecurity).

However, data from both youth and parent interviews indicated that even when youth pursued hormone therapy against parent wishes, parents generally continuously provided other kinds of support (e.g., housing, financial, education, inclusion in family, support for autonomous decision-making). Consistent with these findings were perspectives of some health care providers, specifically those who had facilitated hormone therapy initiation for youth (or young adults) without parental support for this intervention, indicating positive outcomes for these young people. “It doesn’t always play out in the way that you’re fearing.”

Another health care provider reflecting on current practice articulated, “it’s unfair treatment when you look at it. If I had a 15-year old who came, loving parents, super supportive, everybody’s happy, then it could happen really quick, versus the youth that comes in who doesn’t have a supportive family, then all of a sudden, it’s going to take way longer.” Overall, health care provider narratives gave scant attention to how health care provider-imposed delays compound the experiences of lack of parental support, system navigation, and other barriers to care. One participant did ponder the potential harm of delaying access to hormone therapy, stating, “that, ethically, is also a bit of a dilemma. Why am I dragging this out? Why am I taking all of this extra time? Is it right to do that? Am I putting this person at risk?”

The experience of health care provider-imposed delays to bring parents on board is also represented in the narratives of youth. “I wasn’t able to [involve my parents in the assessment process], and that was largely why the assessment actually halted, because that was the main thing that I couldn’t do that the doctor did want.” The more resistant parents were to supporting youth gender health goals, the more insurmountable barriers became, resulting in greater challenges for the youth with the lowest levels of parental support (figure 4.3). In Figure 4.3, the imposition of health care provider delays related to parental involvement is included as a system

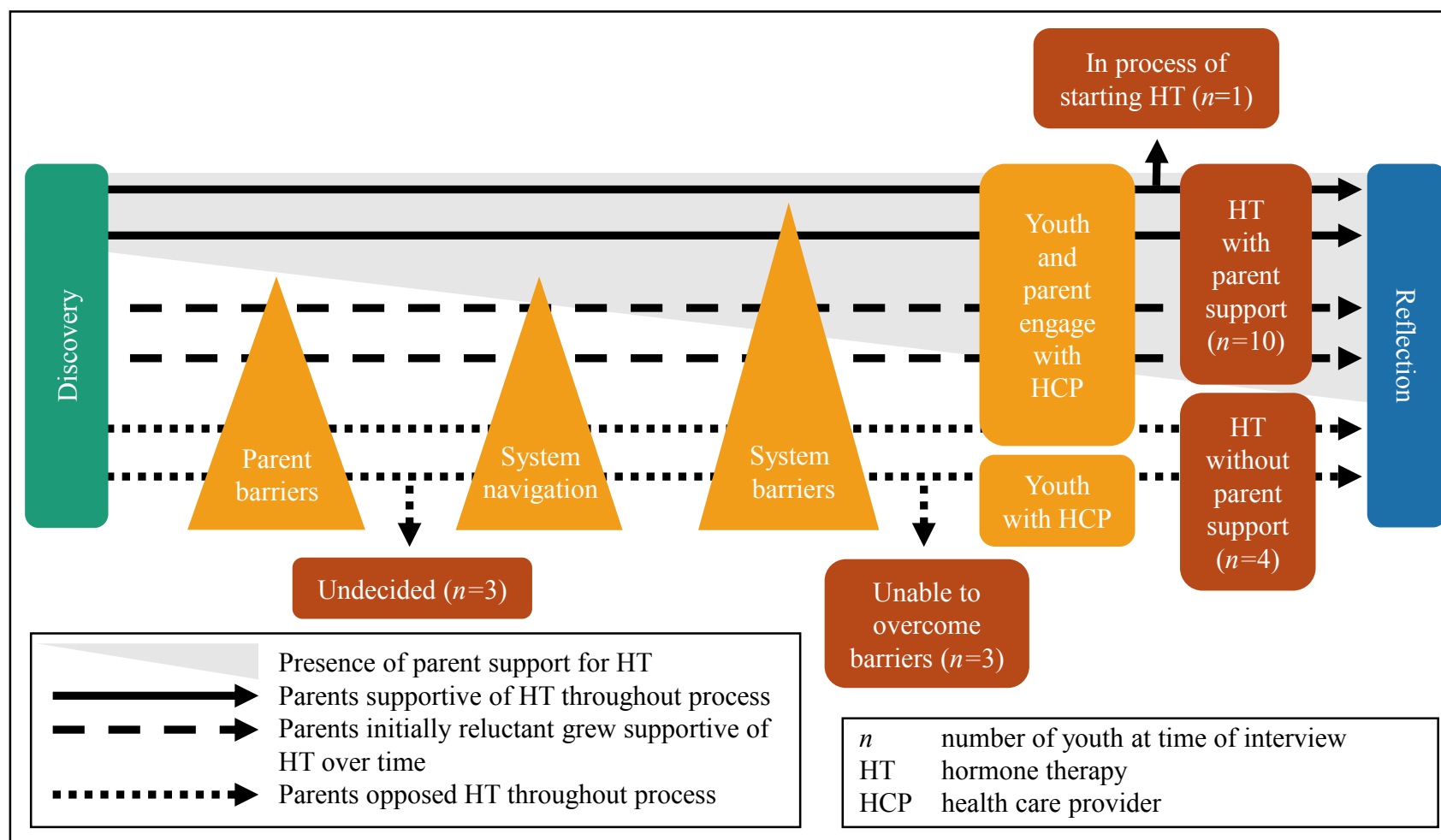


Figure 4.3 Parental Support and Barriers to Hormone Therapy Experienced by Trans Youth

barrier. Youth with the lowest levels of overall support (e.g., for gender health goals, for decision-making processes, in accessing care) had often not been able to make decisions about hormone therapy ($n = 3$) or were unable to access needed hormone therapy ($n = 3$). Those who had accessed hormone therapy without parental support for gender health goals ($n = 4$) had often done so aided by a surrogate support person (e.g., youth worker), while youth who described stronger parental support for gender health goals ($n = 11$) encountered markedly fewer barriers to accessing care (Table 4.2).

Youth-reported parent support	Hormone therapy status
Supportive of hormone therapy throughout process ($n = 8$)	Accessed hormone therapy (or in process of starting) with parent support ($n = 8$)
Initially reluctant, grew supportive of hormone therapy over time ($n = 3$)	Accessed hormone therapy with parent support ($n = 3$)
Opposed to hormone therapy throughout process ($n = 10$)	Accessed hormone therapy without parent support ($n = 4$)
	Unable to overcome barriers to hormone therapy ($n = 3$)
	Undecided about hormone therapy ($n = 3$)

Table 4.2 Youth-reported Parent Support and Hormone Therapy Status

4.1.4 Discussion

Findings from this grounded theory study with trans youth, parents of trans youth, and health care providers offering hormone therapy readiness assessment/care planning services provide several points for discussion. The primary objective of this research was to explore how youth and parents made and enacted decisions about hormone therapy initiation. Youth and parents were found to have similar decision-making processes involving three phases: discovery, (inter)action, and reflection. The temporal models generated illustrate this process in a novel way. This contribution may assist health care providers in gaining further understanding of the

extensive processes youth and parents undergo prior to, during, and after their interactions with the health care system. Youth frequently engaged in independent research, deliberation, and decision-making prior to discussing hormone therapy with anyone else in their lives; for many youth, this included making the decision—or developing an awareness—that they needed to start hormone therapy. Most youth sought parental support for their gender health goals prior to accessing care. For some, this process of deliberation and parental support seeking took years and for others it was much shorter.

Regardless of the length of time youth had waited prior to engaging with health care providers (either by their own choice or due to parent or system navigation barriers), those who sought hormone therapy were clear about their need for this intervention. Youth who requested hormone therapy without parental support for this intervention described the urgency of their need for hormone therapy outweighing the benefits of working to bring their parents on board at that time. Some youth appreciated having health care provider assistance in helping their parents understand their need for hormone therapy, while others experienced attempts or requirements on the part of health care providers to engage their parents as a barrier to care. Youth who were not sure about their need for hormone therapy, and those who felt it was presently more important for them to bring their parents on board than to immediately access care, had not sought hormone therapy from a health care provider.

The findings of this study also align with facets of health behavior models in the literature, especially around the roles barriers play in health behaviors and outcomes. For example, perceived benefits and barriers are important constructs in the Health Belief Model (Skinner et al., 2015), and were two factors consistently weighed by participants in determining what steps to take. The Integrated Behavior Model accounts for external factors differently,

acknowledging environmental constraints, as well as knowledge and skills, as factors influencing behavior (Montaño & Kasprzyk, 2015). Within the discovery phase, youth were exploring what could be framed as attitudes (i.e., response to the idea of starting hormone therapy), perceived norms (i.e., pressure from others, actions of peers), and personal agency (i.e., sense of control and self-efficacy to access health care), factors that can lead to an intention to seek health care. However, in many cases, this was followed by encounters with other direct influences on health behaviors that resulted in barriers, such as lack of knowledge and skill to navigate systems and environmental constraints. The Behavioral Model of Health Services Use places the environment first in a linear understanding of the four main constructs: environment, population characteristics, behavior, and outcomes (Andersen, 1995), which fits with youth narratives detailing repeated encounters with barriers to care within their environments preventing enactment of health care decisions. These three models align in various ways with the youth and parent journeys detailed in the current investigation, however none capture the full spectrum of introspective and interactive aspects of the health care decision-making and enactment experiences of trans youth and their parents illustrated in the models emerging from this study.

The secondary objective of this study focused on facilitators and barriers to decision enactment by youth participants. Overall, most barriers to care identified by youth and parents were consistent with those documented in the literature, for example, delayed access to care and negative experiences with health care providers (Clark et al., 2017, 2018; Gridley et al., 2016). An additional barrier of health care provider-imposed delays, in order to bring parents on board with gender health goals, was identified in this study. One point of divergence among participant perspectives was around when and how to involve parents in decision-making. Parent support and access to gender health care are both important factors in trans youth wellbeing (Connolly et

al., 2016; de Vries et al., 2014; Khatchadourian et al., 2014; Travers et al., 2012) and youth who have lower levels of parent support for their gender health goals experience poorer health outcomes than their peers with stronger support (Ryan et al., 2010; Travers et al., 2012; Veale et al., 2015). While health care providers in the present study cited this extant literature in defense of including parents in hormone therapy decision-making, there was also acknowledgment by some health care providers that youth were treated differently (i.e., length of time to access to care) based on level of parent support. This was viewed as problematic in that it could have significant implications for emotional distress, unwanted irreversible pubertal changes, and compromised safety in the community.

The benefits of parent support are uncontested, however there is currently no empirical evidence that requiring parental support for gender health goals prior to initiating hormone therapy for capable youth is beneficial. In this study, youth seeking support in bringing their parents on board with their gender health goals benefited from health care provider intervention. Additionally, parents seeking support appreciated the information offered by their child's health care providers. This was consistent with positive outcomes of professionally-facilitated parent support initiatives in the literature (Malpas, 2011; Menvielle & Hill, 2010; Menvielle & Rodnan, 2011). However, for youth whose need to access hormone therapy was urgent and/or whose parents were highly resistant to this idea, health care provider-imposed delays and refusals to support hormone therapy initiation without parental support served as a double barrier to care. Conversely, capable youth who were able to confidentially access hormone therapy without parental involvement expressed satisfaction with this care. Overall, youth with the lowest levels of parental support experienced the greatest challenges with system navigation and provider barriers. While it might be imperfect to proceed with hormone therapy without parent support,

some youth could not wait, and when able to access hormone therapy without parental support for this, positive outcomes were reported. This suggests that it may be more harmful than beneficial to impose requirements for parental support of gender health goals prior to hormone therapy initiation for youth who are capable of consenting to this health care intervention. However, this needs to be evaluated on an individual basis, and parental support made available for those wish to access this service.

Consistent with previous research, the accounts of participants in this study supported conventional wisdom that youth developmentally have capacity to make health care decisions around age 14 (Canadian Paediatric Society, 2004; Weithorn & Campbell, 1982). Youth, or parents of youth, who made decisions about puberty blockers or hormone therapy younger than age 14 discussed the need for parental involvement in decision-making and for parents to provide consent to initiate treatment, alongside youth assent. Youth who were currently making decisions, as well as youth who had decided about hormone therapy at age 14 or older, consistently demonstrated the core elements of capacity: understanding of the nature of hormone therapy, the risks, the benefits, and the alternatives; formulating and seeking answers to relevant questions; and making decisions that were in line with their values and consistent over time (Cummings & Mercurio, 2010). Additionally, while parent participants were engaged in decision-making to different degrees, they typically viewed their children (age 14-18) as capable of making this health care decision and were aware that youth had legal authority to do so.

Finally, the context in which youth and parents were making decisions about hormone therapy is worthy of attention. Stigma, harassment, and discrimination faced by trans youth stem from the same social norms that influence hormone therapy decision-making on the part of youth, parents, and health care providers (Clark et al., 2018; Gridley et al., 2016). Youth in this

study described being concerned about safety and stigma, which, during the discovery phase, influenced decisions to either delay disclosure or to move forward with accessing hormone therapy to increase the level of safety in the community. Enacted stigma during the (inter)action phase was experienced by some as discouraging, leading to a hopelessness about being able to live comfortably in their gender, consistent with gender minority stress theory (Hendricks & Testa, 2012; Testa et al., 2017). Health care providers have an important role to play in reducing the impacts of stigma through providing culturally competent gender health care, and developing systems of care that address stigma-based barriers for trans youth.

4.1.4.1 Limitations

There is limited extant gender health literature in which to contextualize these findings, therefore, the literature review and discussion draw on sources from other fields of study. These findings are also limited by the method of data collection, which did not allow for direct observation of interactions among participants and only occurred at one time point. It may be challenging to transfer some of the findings outside of the Canadian context due to differences in legal context, though setting the study in this location allowed for exploration of decision-making experiences that were less constrained by limitations on youth consent to care. Bias may be present in who elected to participate and what information they chose to share, however rigor was enhanced through triangulation of youth, parent, and health care provider data and clarifying recall of experiences through completion of lifeline drawings.

4.1.4.2 Recommendations

This is the first known study to explore hormone therapy decision-making processes in the field of youth gender health care. The processes undergone and barriers faced by trans youth and their parents highlight a need for increased supports in several areas. One opportunity for intervention is making accessible and accurate gender health information available online for youth and parents during the discovery phase. Topics of interest to youth included information about gender, trans communities, medical transition options, health care system navigation, and personal stories of trans people. Parents were interested in similar topics, as well as ways to connect with other parents. When parents had access to online or community-based peer support, it was generally viewed as helpful; some cited this type of support as an unmet need. Scarcity of providers and delays in accessing care are issues that need to be addressed, in order to facilitate timely access to needed care closer to home. Training of health care providers in settings where youth are already served (e.g., youth clinics, family practice) is recommended to address the disparities in access across the province as well as the overall resource scarcity.

The final clinical recommendation relates to the issue of health care provider-imposed requirements for parental involvement or support prior to hormone therapy initiation. Evidence in this study suggests that imposing a requirement for parental support prior to hormone therapy initiation may, in some cases, be harmful. When youth with unavailable or unsupportive parents are legally and developmentally capable of making their own health care decisions, it is recommended that a parallel process be considered. “Parallel process hormone therapy initiation” would involve a health care provider working with a capable youth to make a plan for safer hormone therapy initiation, while concurrently offering support to parents (with youth consent), with a goal of bringing them to a supportive stance as soon as possible. Offering support to

parents who have been informed that their child is making their own health care decisions is likely to create a dynamic different from the practices commonly found in this study, wherein parents were given the opportunity to prevent their child from accessing care by withholding support or refusing to engage with health care providers. Youth and health care providers in this study reported positive hormone therapy-related outcomes, even when the youth was living at home with parents who did not approve of this intervention. One possible explanation for this is that parents grew more understanding of their child's gender health needs and increasingly accepting of their decision to take hormone therapy as they witnessed the positive effects hormone therapy had for their child. Parallel process hormone therapy initiation is an area of interest for future clinical practice in youth gender health care.

Research recommendations are threefold. First, there is need for development, pilot implementation, and evaluation of parent support initiatives based on needs identified in this research. Second, increased health care provider training is recommended to make gender health care more accessible and to reduce wait times, accompanied by evaluation of trainings to ascertain what approaches are effective in building trans cultural competencies and addressing current health care system deficiencies. Finally, the idea of parallel process hormone therapy initiation is worthy of further study. This may hold potential for increasing access to care, reducing inequities, improving health outcomes, and supporting parents; however, evaluation of this approach is recommended to build on the preliminary results emerging from this study and to support development of evidence-based practice guidelines for working with parents who are resistant to supporting their child's gender health goals.

4.2 “You’re the Expert of You”: Shared Decision-making in Youth Gender Health Care

In light of documented health care access and health equity challenges of transgender (trans) youth, and the important role access to health care plays in overall wellbeing, exploration of trans youth experiences engaging with health care providers is warranted (Clark et al., 2017; Olson-Kennedy et al., 2016). Current research indicates trans youth experience barriers to necessary health care including hormone therapy, a medically necessary intervention for some youth (Clark et al., 2017; Gridley et al., 2016). However, little attention is given to the decision-making processes that unfold among youth, parents, and health care providers when determining whether to initiate hormone therapy. Greater understanding of how individual and shared decision-making processes unfold within current systems of care is needed to inform design and delivery of services to improve health equity and to better support trans youth, their parents, and their health care providers.

4.2.1 Background

The term trans is used in this study to describe an experience of gender that differs from sex assigned at birth (Frohard-Dourlent et al., 2016). A non-pathologizing stance is taken, consistent with the gender affirmative model of care, wherein all genders are viewed as natural parts of human diversity (Ehrensaft, 2016; Hidalgo et al., 2013). It is important for trans youth to be able to live freely in the gender that feels most real and/or comfortable, an aspect of wellbeing known as gender health (Ehrensaft, 2016; Hidalgo et al., 2013). In order to support optimal gender health, some youth require hormone therapy, in order to develop secondary sex characteristics consistent with gender (Connolly et al., 2016; de Vries et al., 2014; Khatchadourian et al., 2014; Mallon, 2009; Wylie et al., 2016).

Access to gender health care (e.g., hormone therapy) and parental support have been identified as two key factors in overall wellness of trans youth, correlated with mental health, self-esteem, and life satisfaction outcomes (Clark et al., 2017, 2018; Olson J et al., 2011; Olson et al., 2016; Raj, 2008; Travers et al., 2012; Veale et al., 2015; Wallace & Russell, 2013). Health care systems are not necessarily designed to meet the needs of trans youth, as evidenced by the ongoing barriers to care, such as: delayed and limited access to pubertal suppression and hormone therapy; gatekeeping and insufficient care coordination; incorrect name and pronoun use; and an overall lack of trans cultural competencies on the part of health care providers resulting in negative health care experiences, (Clark et al., 2017, 2018; Corliss et al., 2008; Gorton & Grubb, 2014; Gridley et al., 2016; Menvielle & Gomez-Lobo, 2011). When trans youth seek access to hormone therapy, they enter a process of hormone therapy readiness assessment/care planning with a health care provider (Trans Care BC, 2017b). Approaches to this process of evaluating whether hormone therapy is indicated are varied, and can include elements such as gender self-determination, medical screening, standardized psychological measures, and family involvement (Cavanaugh et al., 2016; Chen et al., 2016; Coolhart et al., 2013; Edwards-Leeper et al., 2016; Edwards-Leeper & Spack, 2012; Gridley et al., 2016; Leibowitz & de Vries, 2016). Parental involvement in hormone therapy readiness assessment/care planning is generally encouraged, although in cases where parents are not supportive of their child's gender and health care goals, it is recognized that involving parents may not be in a youth's best interests (Bernal & Coolhart, 2012; Giordano, 2007; Holman & Goldberg, 2006; Swann & Herbert, 2000).

In all areas of youth health care, health care providers are obligated to act in the best interests of the youth. Best interests may be understood as acting to ensure, "to the greatest

extent possible, the child's physical, psychological and emotional safety, security and wellbeing" (Family Law Act, 2011). In British Columbia, Canada, the *Infants Act* establishes no minimum age for consent, therefore youth in this province are legally able to consent to care that their health care provider deems to be in their best interests and that they have the capacity to do so (Infants Act, 1996). Capacity to consent to a specific health care intervention is based on the ability to: understand the intervention, including the risks, benefits, and alternatives; to ask relevant questions; and to make a decision consistent with one's values (Cummings & Mercurio, 2010). For youth who lack capacity to consent to a specific health care intervention, parents are typically the legal proxy decision-makers involved in their care.

In practice, approaches to health care decision-making vary and are largely influenced by the approach of the health care provider. Paternalistic and informed choice models situate the health care provider as the expert knowledge-holder, but differ in terms of who is responsible for making decisions (Charles et al., 1997; Makoul & Clayman, 2006). Either can be problematic, as patients may feel disempowered if providers make decisions for them or overburdened if given full responsibility for decisions (Elwyn et al., 2000). Shared decision-making is a collaborative, relationship-centered approach in which the decision-making responsibilities of health care providers and patients/clients are balanced and the values and expertise of patients/clients are considered alongside health care provider knowledge and empirical medical information (Crickard et al., 2010; Hetrick et al., 2008; Langer & Jensen-Doss, 2016; Makoul & Clayman, 2006; O'Brien et al., 2011). While there is no single definitive model, shared decision-making approaches share common characteristics. Charles et al (1997) propose four key components: (1) minimum of two participants are involved; (2) medical information and patient values are shared; (3) both (or all) parties actively participate; and (4) a mutual treatment decision is made.

Elements identified by other scholars include: the need to have more than one viable treatment option about which to decide; all parties should agree to an agenda; relationship and trust are central to the process; and shared decision-making processes must be allowed to unfold over time (Elwyn et al., 2000; Murray et al., 2006). Researchers note that health care providers need to take patient/client preferences into account in their approach to care, as patient/client autonomy could be violated by imposing an unwanted paternalistic, informed choice, or shared decision-making approach (Murray et al., 2006).

Shared decision-making is being used in youth care, with several identified benefits for this population: meaningful integration of youth and parent perspectives; youth motivation, empowerment, and healthy development; patient satisfaction and treatment plan adherence; and more culturally competent care (Coyne et al., 2014; Crickard et al., 2010; David et al., 2017; Edbrooke-Childs et al., 2016; Hetrick et al., 2008; Langer & Jensen-Doss, 2016; O'Brien et al., 2011). For example, Crickard et al (2010) have developed a three-step model for shared decision-making with youth, which includes three functional areas: setting the stage, facilitating, and supporting youth decision-making. Langer et al. (2016) also identify shared decision-making as a helpful framework for addressing disagreement among decision-makers and accommodating a range of developmental levels of youth. Shared-decision making with marginalized populations is an area of practice that has recently been addressed in the literature, with several studies addressing lack of access to shared decision-making experienced by racial, ethnic, sexual, and gender minorities, a disparity linked to challenges around communication, relationship, trust, and unconscious bias, microaggressions, and health care provider cultural competencies (DeMeester et al., 2016; Foglia & Fredriksen-Goldsen, 2014; Peek et al., 2010, 2016). Conceptual frameworks have been developed by Peek et al. (2016) and DeMeester et al (2016) to

contextualize shared decision-making processes and account for the effects of race, culture, intersectionality, normative beliefs, cultural competencies, and trust on health outcomes. No such models have been identified that directly address youth gender health care.

4.2.1.1 Purpose

The goal of youth gender health care, as with any youth health care, is to promote the best interests of the youth; however, there are no established frameworks for engaging in health care decision-making about hormone therapy initiation with trans youth and their parents. While shared decision-making may be effective in addressing challenges commonly encountered in practice with trans youth and their parents (e.g., integration of youth and parent perspectives, culturally competent care), this approach has yet to be studied within youth gender health care. The purpose of this study was therefore to explore: (1) how trans youth, parents, and health care providers engaged or did not engage in shared decision-making practices around hormone therapy initiation; and (2) how trans youth, parents, and health care providers could be better supported in shared decision-making.

4.2.2 Methods

Social processes involved in making decisions around hormone therapy initiation were explored using a constructivist grounded theory approach (Charmaz, 2014). This research was conducted in British Columbia, Canada, and the study was covered by certificates from the Behavioural Research Ethics Board of the University of British Columbia, the University of British Columbia Children's and Women's Health Centre of British Columbia Research Ethics

Board, the Vancouver Coastal Health Research Institute, and the Northern Health Research Review Committee.

Study participants included trans youth ($n = 21$), parents of trans youth ($n = 15$), and health care providers ($n = 11$). Youth aged 14 through 18 who met one of the following criteria were eligible for participation: (1) had initiated hormone therapy within the last two years, (2) were considering whether to access hormone therapy, (3) had decided not to access hormone therapy, or (4) were experiencing a barrier to accessing hormone therapy. Parents of any youth who met the above criteria were eligible for the study. Youth and parents from the same family could participate, however, any such data were not to be linked, in order to maintain participant confidentiality. Eligible health care providers were those currently providing hormone therapy readiness assessment/care planning for youth. All participants were required to live in British Columbia, Canada and to both provide informed consent and be interviewed in English. All youth, parents, and health care providers who responded to recruitment were provided the opportunity to interview.

Purposive and snowball sampling were used to recruit participants with diverse backgrounds and perspectives. Youth ages spanned 14 through 18, and they described their genders in ways that could be categorized as: female or transfeminine ($n = 8$); male or transmasculine ($n = 8$); and non-binary or genderfluid ($n = 5$). The hormone therapy statuses of the youth fell into four categories: on hormones ($n = 14$), in the process of starting ($n = 1$), undecided ($n = 3$), and experiencing barriers to care ($n = 3$). Parent participants had trans children who were aged 14 through 18, with a similar diversity of genders to the youth cohort. Youth and parent participants resided in four of the province's five health regions and health care providers practiced in three of these regions, mostly concentrated in urban centers. Health care

providers represented many disciplines and the length of time they had been providing hormone therapy readiness assessments for youth ranged from 1 to over 10 years.

Data were collected primarily through one-hour semi-structured interviews. Participants selected interview locations, such as homes, schools, health care clinics, libraries, and community centers. Interviews were recorded digitally and later transcribed. Youth and parent interviews were focused on three topics: how decisions were made regarding hormone therapy initiation (e.g., what was important in deciding/thinking about hormone therapy; what questions were important to have answered), who was involved in decision-making, and supports that were available or desired during these processes. Lifeline drawings were also generated during interviews to illustrate and organize these narratives (Berends, 2011; Davies, 1996; Pirskanen et al., 2015; Sheridan et al., 2011). Interviews with health care providers centered around ethical dilemmas and decision-making in hormone therapy readiness assessment/care planning practice with trans youth and parents. Data were analyzed using a constructivist grounded theory approach (Charmaz, 2014). Categories relevant to shared decision-making processes emerged through application of constant comparative analysis and focused coding methods.

4.2.3 Results

Youth, parent, and health care provider participants described many different decision-making processes, some inclusive of shared decision-making characteristics. The following section briefly explores the decision-making interactions of youth, parents, and health care providers surrounding youth hormone therapy initiation. This is followed by a description of five conditions that emerged through grounded theory analysis as fundamental to supporting shared decision-making with this population.

4.2.3.1 Decision-making Interactions

The decision-making journeys of youth and parents are explored in greater depth in section 4.1 of this dissertation. Central to this paper is how youth, parents, and health care providers worked together (or not) to make decisions about hormone therapy initiation. While participants generally did not use shared decision-making language, terms such as collaboration and patient-centered care were employed in describing interactions that were consistent with many elements of shared decision-making models. The following pairs of quotations contrast how shared decision-making characteristics were unsupported (in the first quotation) or supported (in the second quotation of each pair) in interactions among youth, parents, and health care providers.

4.2.3.1.1 Youth and Parent Interactions

These quotations described different approaches to communication between youth and parents that could serve to either weaken or strengthen relationship and trust. In the first quote, the parent is described as actively opposing the youth's gender, prior to any discussion of hormone therapy.

And then it just kind of escalated from there. And I just remember [my mother] yelling at me, and I just remember her this close to my face, yelling in my face. 'You're always my little girl. You're always going to be my little girl.' And I just left...because I felt like we weren't going to get anywhere productive. And then we didn't kind of talk for a few days. Things were really uncomfortable around the house. (youth)

In the second quote, a parent describes engagement in a supportive discussion around identifying and enacting gender health goals.

So then we all sat down and had a chat, and it was just like, ‘Okay, well, how long have you been feeling like this?’ And he said, ‘As long as I can remember,’ and we said, ‘Why,’ you know, ‘why did you wait so long?’ And he said, ‘Because I didn’t think anyone would believe me, and I didn’t think that anyone would think that this was true,’ and he said, ‘I don’t know how to do this.’ And I said, ‘Okay, well, that’s why we’re all here together, you know?’ I said, ‘We’ll figure this out.’ (parent)

4.2.3.1.2 Youth and Health Care Provider Interactions

The following youth and health care provider interactions call attention to how events unfolded differently when participants were or were not in agreement about the agenda for the decision-making process. First, a youth was not comfortable answering invasive questions and did not understand how the questions asked were pertinent to assessment of readiness to start hormone therapy.

That [health care provider] asked me way more personal, invasive ones, I would say. Like, in ways that didn’t really seem medically relevant. Of course, sometimes doctors ask you questions that could be invasive, like are you sexually active or do you smoke or something like that, which, I’m sure, lots of people would not be comfortable asking. But this went above and beyond that. (youth)

In the second example, the youth received the assurance they were seeking from the health care provider about their gender health goals, after previous encounters with other adults who were largely unsupportive.

[The hormone readiness assessment] was helpful. This whole time I was like, this is it, I’m trans, I’m going to transition, I’m going to get on hormones, so on, but when I talked to the [health care provider], I was like, should I get on hormones? And is this right for me? Was I just going into this too fast and I was rushing things? And you know, [the health care provider] took a look at me and [the health care provider] was like, ‘Yeah, I’ve been doing this for a really long time, and I know that you’re trans. And I know that this is probably the right decision for you, and I think that it will benefit you.’ And it just gave me that assurance. (youth)

4.2.3.1.3 Health Care Provider Role

These scenarios are focused on health care provider roles and highlight differences in levels of active participation and collaborative decision-making. The first scenario involved a family (parents and youth) in agreement that hormone therapy was necessary prior to interacting with a health care provider. The parent described having to adjust expectations regarding the role of the health care provider conducting their child's hormone therapy readiness assessment after determining that seeking support from this person could be counterproductive.

We sort of realized in the last little while [the health care provider is] not really that much in the way of support. It's more we need to be just reporting to [the health care provider] how well [my child's] doing to get a check mark... This is not someone who you go, 'I'm having a really bad week. I don't want to get out of bed. Help me. What should I do?' Who will give you a pep talk and help you get ready and say, 'You know, this is your goal. Work towards it.' This isn't the person to do that. This is the person that you go and say, 'Okay, what is it you need from me to be able to write that referral?' And you make that check list and you check it off until you have it filled up. (parent)

In this situation, a health care provider described a collaborative process, rejecting a paternalistic approach to approving or rejecting youth for hormone therapy.

I don't say, 'I've decided that you can take hormones.' I mean, that's not how it is. I go, 'What do you want to do now? And why do you want to do it?' And then we talk about, you know, what are the implications of that, and how will they manage certain aspects of that? And we talk about that. So, it's really a collaborative decision. I'm not on high going, next. You can go. You can't. It's a collaboration. (health care provider)

4.2.3.1.4 Enacting Gender Health Goals

In the final pair of quotations, approaches to decision-making impacted whether care was focused on patient values and enactment of youth gender health goals. In the first, the youth described a frustrating experience, being unable to find any health care provider to support access to pubertal suppression and going through unwanted pubertal changes. Then, during the long-awaited assessment, the youth felt compelled to provide a narrative that fit the health care

provider's binary gender expectations in order to receive approval for hormone therapy; this youth was very concerned that other youth would not be able to navigate this process to gain access to the care they needed.

It's a system which I think does a lot of damage to the youth participating in it...with the assessment, I was already in a state of, [pubertal changes] are happening faster than I like. And it felt like I had to fit into a cisgender woman's box as to what categorized me as transgender to apply to actually receive hormones. And I fit into that box fairly well on my own, but feeling like I had to fit into that box was really hard...I said that I'd been experiencing [gender dysphoria] since I was seven or eight because that's what she wanted to hear. And I think that a lot of kids might not make it through that sort of gauntlet of assessment and analysis to the other side. And that's a really distressing thought to me. (youth)

Lastly, this health care provider discussed safely facilitating a youth's gender health goals.

So the medical onus lies on me. I need to make sure it's safe, I need to make sure you're not having any contraindications...But if someone's got a clear presentation—for the most part that's what we see—and has clear goals in mind, I'm there to facilitate them safely. So, it's shared. It's very shared. But that's again being patient-centered, right? It's like, I'm the expert. You're the expert of you. I'm the expert of how to get you the stuff you want, but you're the expert of you. (health care provider)

These quotes highlight three main points. First, that participant experiences around decision-making were diverse and reflected qualitatively different youth-parent interactions and experiences with health care providers. Second, not all situations described were conducive to engagement in productive shared decision-making processes. Third, many elements of shared decision-making models were identifiable, even though no participants were using a formal shared decision-making model.

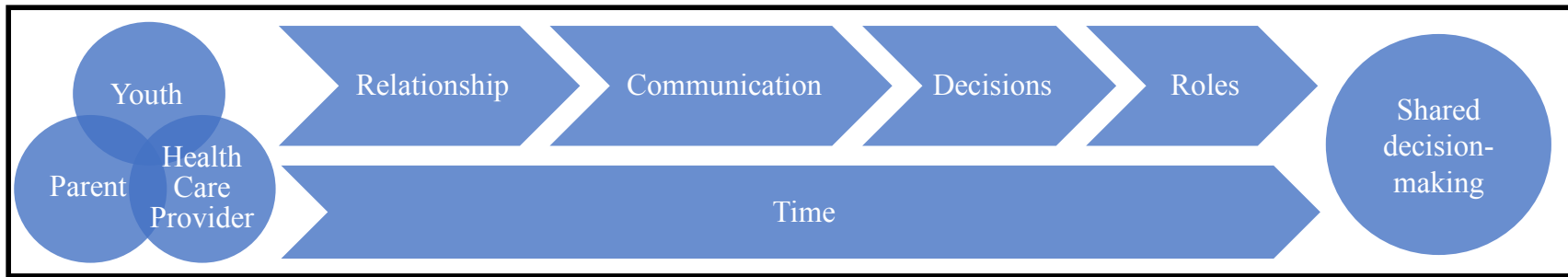


Figure 4.4 Shared Decision-making Conditions

4.2.3.2 Conditions for Shared Decision-making

Through constant comparative analysis of youth, parent, and health care provider interview transcripts, five conditions emerged as necessary to support shared decision-making processes: strong relationships; strong communication; decision agreement; role agreement; and adequate time for decision-making processes to unfold. Figure 4.4 illustrates the conditions necessary for shared decision-making approaches to appropriately and productively be integrated into gender health care for youth and their families. The following section contains detailed exploration of these conditions.

4.2.3.2.1 Relationship

Descriptions of relationships among youth, parents, and health care providers varied widely. One key to the ways in which decision-making processes unfolded was the strength of pre-existing relationship between youth and parent. In the words of one youth: “We both just wanted the exact same thing. We both just wanted to have a relationship that is actually going to last when I’m older, and when I’m eventually coming home for Christmas and stuff like that, that we can actually be in the same room with each other.” However, when relationships were previously strained (e.g. by factors that led to placement in the care of social services), a foundation for engagement in shared decision-making was often lacking.

Youth described relationships with health care providers in ways that were sometimes indicative of a lack of trust. For example, “I just don’t feel like she believed me.” Description of very positive relationships between youth and health care providers that supported collaborative processes were also present. It is important to note that previous negative experiences with health care providers impacted current relationships. As one youth described, “I’ve had a lot of bad

experiences with [health care providers] who really mistreated me when I was a child, so it was difficult for me to communicate with these [health care providers].”

4.2.3.2.2 Communication

Youth and parent participants leveraged strong communication skills in coming to shared understandings about how to proceed with hormone therapy decision-making (e.g., agreed to proceed with hormone therapy; agreed to allow youth to make their own decision about initiating hormone therapy). While relationship and communication are often intertwined, these two constructs were not always interdependent. For example, some parent and youth participants described taking part in difficult discussions when a parent was not supportive of hormone therapy initiation, all the while staying committed to maintaining the parent-child relationship. According to one parent: “[My son] and I have a very good communication, so we never, like, don’t talk to each other. We can always just talk to each other about whatever that comes up, and the only saving grace from all of it was our communication.” Communication challenges (e.g., disparaging statements about hormone therapy by a parent, parent screaming at a child, parent refusal to discuss hormone therapy) created barriers to shared decision-making process. While there was evidence of open communication among youth, parents, and health care providers in some instances, parents also expressed concern about the impact of poor youth-health care provider communication on the care received. “If [my child] has any doubts, I don’t think she would have spoken them here...if she was already worried that she wouldn’t get a referral to get [hormone therapy], she would have lied and hidden things if she needed to, to jump through these hoops. So how is that helpful?”

4.2.3.2.3 Decisions

Some decisions made by youth were not considered appropriate for shared decision-making. For example, youth decisions to identify themselves as trans, to come out to others, or to transition to, or live in, their affirmed gender were ones that they needed to make independently. In response to a question about who was involved in making the decision to initiate hormone therapy, one youth replied, “Me, myself and I. It’s a very personal decision. It’s very good to let your parents know, but it’s a very personal decision.” After youth came out and involved others in their hormone therapy journeys, opportunities for shared decision-making often emerged, particularly around working together to create safer plans for hormone therapy initiation. One youth framed decisions to be made in this way: “It’s what thing is being decided. Like, what are parents deciding, and what are healthcare providers deciding? And what you’re deciding is not *if*, you’re just deciding *when*.” Individuals could only share in decision-making when they agreed on the decision or decisions that were to be made collectively versus individually. For example, if one party felt a decision should be made by a particular individual while another thought this decision should be shared (e.g., when to initiate hormone therapy), it did not create conditions necessary for shared decision-making.

4.2.3.2.4 Roles

“It’s my decision.” The majority of youth declared they had made the decision to start hormone therapy on their own. “I have to make that decision...this is something that I’m going to have to do for the rest of my life.” Many youth made a clear decision that they needed to access hormone therapy, while for others, discovery of language to describe their gender, along with knowledge acquired about hormone therapy, allowed them to articulate something that was

pre-decided. This was described by one youth in this way: “I felt like I’d already made the decision before I knew it was an option. It was something that I wanted, and I just didn’t have the medical terms to really think about it.” Likewise, many parents said their children had made hormone therapy decisions independently and discussed trusting their children to make good decisions. One parent stated: “It’s not my decision. I’m along for the ride.” This health care provider described supporting youth to set the agenda for decision making: “I said, ‘You know, this is your health care, so you decide. I have no agenda. I’m here for you.’ And that was very relieving for them as well. And that’s really how I approach everything. I don’t have an agenda besides care.”

Parents were often actively involved in their children’s care, especially for younger youth. Health care providers spoke of advantages of working with parents who understood that capable youth had the right to make their own health care decisions. For example:

‘This is my kid’s decision, not mine. I’m here to support’, and I love it when I hear parents say that, and ultimately it’s true, but not every parent sees it that way, and it’s really nice when they do. And I also have parents who come in have lots of questions and aren’t necessarily on board but still say, ‘I know this is their decision. I know that I cannot stop this. These are the reasons why I’m worried about it.’

Youth were respectful of their parents’ need to do their own research and appreciated the concern for their safety as they collaboratively made plans to seek care. In the words of one youth: “[My mom] did a lot of research first and stuff, and researched obviously all the harmful things that it could do because she cares about me, you know? She just wanted what’s best for me. She was like, ‘Okay, if you want to do this, we can totally do this.’” Parents also emphasized their role in ensuring their children were making a well-informed decision. This parent took an active role in supporting her daughter’s decision-making process: “She can go and do the research, but then we can talk about it, and I can ask questions that might be a little bit hard that

she might not want to look at or things. I think because that's important too. I don't want to be blind support because that's not helpful." Many youth and parent participants were able to collaboratively make decisions when they accepted the roles that each would play in the process.

Some youth described their parents as directly oppositional to their gender health goals specifically around hormone therapy. For instance:

My parents are just trying really hard to stop me, but I live in Canada, I have my rights, I will do what I want. I'm not doing anything illegal, I'm not harming anyone, so I will continue down this path and go where I want to go...ultimately, I'm the one who's making this decision, and I'm the one who has to sit down and think about this.

As these parents were actively opposing access to hormone therapy, the youth was not able to engage with them in a shared decision-making process, but was able to work with health care providers to gain access to hormone therapy. One parent described being supportive of her child, but not of the decision to initiate hormone therapy. However, she and her child reached an agreement that the youth was capable of making their own decision and could therefore give consent themselves. In the parent's words: "If you are telling me that they are mature enough and responsible enough to be making this life decision, then they need to be the one signing off on it...I am not signing off on that." Unfortunately, conflict emerged when health care providers would not accept the roles to which the youth and parent had agreed.

Health care provider roles varied from paternalistic to collaborative. Youth described a range of paternalistic situations, from the health care provider making a determination of readiness, "the psychologist made the final decision about whether I was ready or not," to having to complete required tasks or answer health care provider questions correctly to pass the assessment process, "your fate has been decided." No parents indicated that the decision to start hormone therapy fell solely to a health care provider, but they did discuss access to hormone therapy hinging on a health care provider diagnosis of gender dysphoria. Some health care

providers embraced a paternalistic, gatekeeping role; others saw themselves more as collaborators in making decisions about care, but acknowledged that ultimately, they did make decisions about recommending or prescribing hormone therapy. As one provider conceded, “I suppose, bottom line, if I’m the one writing the prescription, then it falls to the prescriber...I think that must be hard as a person coming in and knowing that—feeling like you have to jump through these hoops to get that person to do what you want them to do.”

While health care providers ultimately had the role and responsibility of ensuring access to hormone therapy was safe, many worked to structure decision-making as a collaborative, patient-centered process. One described the process this way: “I always start any visit with a new trans assessment with, ‘I’m here to facilitate your care. I’m not here to put a barrier between you and your care. Let’s chat about you.’” Many parents expressed appreciation for the support they had received from health care providers, for instance, provision of accurate medical information, direct support for their child, and guidance in navigating systems of care. Youth who were seeking help in bringing their parents on board with their gender health goals also expressed gratitude for health care providers support with this. In the words of one youth:

[My health care provider] ended up having a couple appointments with my mom and me in the same room, and those appointments did so much... [the health care provider] put it in words that my mom actually got and helped her somewhat come to terms with, and deal with it, and understand my need for [hormone therapy].

The role assumed by the health care provider facilitating the decision-making process, and its alignment with the needs and expectations of the youth and parents, was a crucial factor in creating conditions necessary for shared decision-making.

It is also important to place the decision-making roles of youth, parents, and health care providers within the context of British Columbia legislation. The British Columbia *Infants Act* (1996) gives health care decision-making authority to youth who are capable of making a

particular decision, provided the care is in their best interests. Parent participants generally recognized the right and developmental capacity of their children to make these decisions. Data from youth and health care provider interviews confirmed this to be the case with many parents, but also revealed that some parents asserted or perceived that they had full health care decision-making authority until their child turned 18 (despite the age of majority being 19 in British Columbia). The roles of youth and health care providers came into conflict when capable youth wanted to exercise what they understood to be their right to access hormone therapy and the health care provider felt that best interests would not be served without having their parents on board.

4.2.3.2.5 Time

Time was a consideration in shared decision-making engagement. The time it takes for shared decision-making processes to unfold is variable and dependent on individual circumstances. Youth with high levels of distress and urgent need for hormone therapy had limited time to access care. One youth reflecting on her parents taking a supportive role in immediately helping her access care said, “If they straight up said you can’t transition, I probably wouldn’t be alive right now. I was in a really bad place before I transitioned.” Other youth had a desire to preserve strong relationships with their parents that outweighed the need to immediately start hormone therapy, and consequently the youth delayed accessing this care. Health care providers discussed the importance of evaluating youth level of distress when deciding if, how, and when to involve parents in decision-making processes. Some youth participants were unable to wait until their parents were ready to participate in this process. According to one youth: “My

parents were very iffy about the idea of me being trans, and didn't want me to even think about transitioning until I was at least 18 or 19 and living on my own. And I can't do that."

4.2.4 Discussion

The first research question addressed the how participants did or did not engage in shared decision-making processes around hormone therapy initiation. The decision-making interaction quotes provided context for this discussion, highlighting situations in which shared-decision making may have occurred or been possible as well as scenarios that were not conducive to such a process. Consistent with the extant literature, interactions among youth and parents drew attention to the need for strong communication, relationships, trust, and willingness to actively participate, while youth interactions with health care providers highlighted how degree of agreement on the agenda for decision-making influenced the process (Charles et al., 1997; Murray et al., 2006). When families were seeking shared decision-making but health care providers approached care paternalistically, the decisional roles were not balanced in terms of valuing the expertise and input of youth and families (Crickard et al., 2010; DeMeester et al., 2016). Finally, some youth experienced delays to care and lengthy standardized assessment processes as barriers to addressing urgent needs. In contrast, health care provider descriptions of processes that focused on youth goals and values, balanced with medical information and safety, were aligned with established shared decision-making characteristics (Charles et al., 1997; Murray et al., 2006).

What this study adds is an exploration of conditions necessary to engage in shared decision-making. This is consistent with the literature on honoring patient autonomy through selecting a decision-making process that meets the patient needs and preferences (Murray et al.,

2006). Strong pre-existing relationships and communication between youth and parents, in addition to development of relationship and communication among youth, parents, and health care providers were important conditions for supporting for inclusion of parents in shared decision-making processes. Youth and parents, in particular, emphasized that some decisions could be shared, while others belonged to youth. This aligns with previous findings that all parties need to agree that there are multiple options in order to collectively engage around a particular decision (Elwyn et al., 2000). Consistent with the literature, youth wanted to take an active role in decision-making about their own care (Coyne et al., 2014). Unwanted paternalistic approaches represented a missed opportunity to meet some families where they were at in terms of their already-established collaborative decision-making processes, and in other situations, to productively engage with families who were experiencing conflict (Langer & Jensen-Doss, 2016). There is a general acknowledgment in the literature that time is needed for shared decision-making processes to unfold (Murray et al., 2006). Time considerations specific to youth gender health care included: parent willingness to engage within a reasonable time frame; youth level of distress and risk of self-harm; and ongoing secondary sex characteristic development.

Overall, agreement regarding participant roles in shared decision-making processes emerged as one of the most important pieces of this puzzle. Presumably related to the *Infants Act* (1996) and evaluation of decision-making capacity, youth were frequently centered as the primary decision-maker, both by themselves and by the adults supporting them. Parent involvement in decision-making was frequently present and consistently encouraged by health care providers, as would be expected from the review of literature (Bernal & Coolhart, 2012; Giordano, 2007; Holman & Goldberg, 2006; Swann & Herbert, 2000). Some parents were immediately supportive of their child's gender health goals. Others never became supportive of

hormone therapy, but maintained strong relationships, good communication, and provided support in other ways. There were parents who consistently worked to undermine their child's access to hormone therapy; however, many parents grew more supportive of hormone therapy over time, in some cases seemingly in part due to seeing positive changes in their child following hormone therapy initiation. At a minimum, a youth and a health care provider must be involved for shared decision-making to occur; parent involvement is dependent on many factors, but central to their integration is mutual agreement regarding participant roles.

The second research question addressed ways to better support youth, parents, and health care providers in shared decision-making. If the identified five conditions are met, implementation of a shared decision-making approach with trans youth and parents has the potential to yield several benefits. Drawing on the results of this study and the extant literature, it is proposed that shared decision-making can support emerging autonomy, facilitate development of health care decision-making skills, foster ongoing engagement with the health care system, strengthen youth-parent relationships and communication, and empower youth as they move forward in their lives (Crickard et al., 2010; David et al., 2017; Edbrooke-Childs et al., 2016; Hetrick et al., 2008; Langer & Jensen-Doss, 2016; O'Brien et al., 2011). Specific clinical and research recommendations are included in a subsequent section.

As a final point of discussion, it was noted that youth in this study reported being invited by health care providers to share their goals of care, but it was unclear if discussion of their values, as they related to hormone therapy, was also undertaken. This component of shared decision-making is necessary to aid health care providers in developing greater understanding of a youth's worldview. Trans youth face distinct barriers to accessing needed health care, specifically: gatekeeping, delayed or limited access to care, lack of care coordination, lack of

health care providers with strong trans cultural competencies (Clark et al., 2017; Gridley et al., 2016). Therefore, application of cultural shared decision-making frameworks may be useful in supporting critical thinking about normative beliefs, intersectionality, trans culture, and the lived experiences of trans youth in relationship to how health care decisions are made (DeMeester et al., 2016; Foglia & Fredriksen-Goldsen, 2014; Peek et al., 2010, 2016).

4.2.4.1 Limitations

This study is the first known to explore shared decision-making experiences within youth gender health care, and consequently could not be contextualized within a directly related body of research. The data collection method did not include observation of interactions among participants, which would be of benefit in future studies examining shared decision-making processes. Despite recruitment targeting youth experiencing barriers to care, it is not possible to know how representative this sample is of the population. As expected, parents who elected to participate reported generally being more supportive of their children than the average level of support reflected within the youth and health care provider narratives. Health care provider bias in decision-making is an area relevant to shared decision-making with trans youth that was not fully explored and would be a key area to address in future studies with more in depth data collection (e.g., multiple interviews with each health care provider participant).

4.2.4.2 Recommendations

The following recommendations address both clinical application of shared decision-making approaches and areas for future research. As outlined here, health care providers should evaluate the five conditions to determine when shared-decision making may be viable.

Pre-existing youth-parent relationships and communication should be taken into account in determining who is appropriate to involve in shared decision-making (e.g., youth and health care provider only; parent inclusion). Health care providers should work to establish trusting relationships and open patterns of communication with youth, which can be supported through honoring preferences and maintaining confidentiality. Within the current health care system, health care providers are gatekeepers of hormone therapy and have significant power in relation to trans youth. Communication by health care providers can exacerbate or minimize this power differential. They should be aware of the power they possess as gatekeepers, and ensure that language used to invite or persuade youth to involve their parents is not viewed as an ultimatum or experienced as coercion. Development of trans cultural competencies is necessary for health care providers striving to develop and maintain strong relationships with trans youth.

Health care providers should be transparent about their duties, respect decisions already made by a youth, and reach an agreement about which decisions will be made collaboratively and which will be made individually. In accordance with the gender affirmative model of care, some decisions are not appropriate for shared decision-making (e.g., what a youth's gender is). Within existing shared decision-making frameworks, appropriate decisions to be shared are those with multiple viable options (Elwyn et al., 2000). It is therefore important that health care providers ensure various parties are in agreement about the decision(s) being made and that all parties are open to multiple outcomes.

Parties may take up different roles within the shared decision-making process. For example, the health care provider can contribute medical expertise, the youth likely knows best what they need to live comfortably in their gender, and parents may offer perspective on family, school, and community factors. Some youth (typically older) may want to assume a very active

role in the decision-making process, while others (often younger and with emerging capacity) may look to their parents to take a more significant role. To the extent possible, youth preferences regarding involvement of other parties should be honored. However, it is recognized that laws in specific jurisdictions may constrain the roles that these parties are able to play in shared decision-making.

Chosen family members often play a significant role in the lives of trans youth, as do professional surrogate supports (e.g., youth worker, social worker); it may be appropriate to involve these support people in shared decision-making with permission of the youth. A decision to not include parents in a shared decision-making process for a capable youth does not preclude the health care provider from simultaneously offering support to parents, with consent of the youth (see parallel process hormone therapy initiation description in section 4.1). Parent or other proxy decision-maker involvement may be necessary if an individual youth does not have the capacity to make their own decision about hormone therapy initiation. However, if a health care provider determines that the actions or omissions of a parent constitute an immediate and significant risk of serious and preventable harm to a youth, it is incumbent upon the health care provider to seek intervention to protect the safety and wellbeing of the youth.

The amount of time necessary for shared decision-making processes to unfold can vary considerably. Health care providers should evaluate how much time can reasonably be taken without resulting in harm. Some youth urgently require hormone therapy, have made numerous unsuccessful attempts to bring their parents on board, and need to access care quickly due to the development of unwanted pubertal changes, self-harm, and/or suicidality. In other situations, youth request, or are accepting of, assistance from health care providers in working with their parents, placing the need to develop stronger parent support above the need to immediately

initiate hormone therapy. Health care providers should consider who can be productively included in decision-making processes, within the time that is available.

The following areas hold potential for future research related to shared decision-making in youth gender health care. Development of a shared decision-making model tailored to youth hormone therapy decision-making within the British Columbia context (and other specific contexts) would be an important step forward in providing the foundation necessary to integrate this potentially beneficial practice into youth gender health care. Elements of youth and cultural shared decision-making models, along with the five conditions presented here, should be incorporated into such a model to address the specific needs of this population. Outcomes of interest may include: ease of application of such a tool, impact on barriers to care, effects on youth-parent relationships, decision satisfaction, and cultural safety.

Chapter 5: Ethical Decision-making

5.1 Belief-Dilemma-Action Model: Construction of Ethical Dilemmas Among Health Care Providers Assessing Transgender Youth Readiness for Hormone Therapy

Many transgender (trans) youth require hormone therapy to align their bodies with their gender. Ethical issues arising for health care providers involved in providing this care have been documented in many countries, however much of this literature comes from jurisdictions where there is a minimum age for consent to care (e.g., The Netherlands, United States). In British Columbia, Canada, youth are able to consent to health care deemed by their health care provider to be in their best interests based on capacity rather than age (Infants Act, 1996). This study explores the ethical dilemmas encountered by health care providers providing hormone therapy readiness assessment/care planning in British Columbia and presents a theoretical model illustrating factors that influence the construction and resolution of ethical dilemmas in this area of youth gender health care.

5.1.1 Background

The following review of literature addresses four topics: ethics in youth health care, gender health, sociocultural context, and ethics in youth gender health care.

5.1.1.1 Ethics in Youth Health Care

Ethical issues arising in health care services for youth are diverse, complex, and influenced by multiple factors. The ways in which ethical issues manifest specifically within youth gender health care have received increasing attention in recent years. Many ethical

approaches hold potential for examining salient issues in youth gender health care, such as relational ethics, queer bioethics, and justice-doing (Bergum, 2013; Reynolds, 2011; Roen, 2016). However, the framework that dominates the literature is a North American bioethics framework—centering the principles of autonomy, beneficence, nonmaleficence, justice (Beauchamp & Childress, 2013). This approach draws on multiple ethical theories in providing a framework specific to health care, but it is important to recognize that critique has been rendered regarding both the utility of the principles in practice and the lack of focus on relationship and social justice (Holm, 1995; Marway & Widdows, 2015). However, given its pervasiveness in the literature and in health care provider participant descriptions of ethical decision-making in this study, this bioethics approach is used in structuring the following review of literature surrounding ethical issues of relevance to youth health care practices.

Autonomy, or respect for persons, is an ethical principle supporting the right of people to make choices and take actions that are grounded in their values and beliefs (Beauchamp & Childress, 2013). With respect to youth, issues of autonomy are frequently raised in discussions of capacity to consent to health care and the right to confidentiality. Parents are typically the health care decision-makers for their children, as they are usually best positioned to understand their child's needs (Unguru, 2011). As youth develop, they are progressively able to assume more decision-making responsibility (i.e., emerging capacity) and should be involved to the extent possible in decisions concerning their health care (Canadian Paediatric Society, 2004; Diekema et al., 2011). Determining whether a youth has the capacity to consent to a specific health care intervention involves evaluation of: understanding of the intervention, including risks, benefits and alternatives; ability to ask relevant questions; appreciation of the nature and consequences of treatment and refusal of treatment; and ability to make decisions consistent with

personal values (College of Physicians and Surgeons of British Columbia, 2015; Cummings & Mercurio, 2010). Concern may be raised that youth are susceptible to making decisions impulsively, however, the time and support provided to make decisions generally mitigates such issues in health care contexts (Grootens-Wiegers et al., 2017). While laws dictate legal authority to consent to care in specific jurisdictions, capacity to consent for many health care interventions is developmentally typical of youth aged 14 and older (Weithorn & Campbell, 1982). Issues of confidentiality can be complex due to the role parents typically play in youth health care. However, maintaining confidentiality around sensitive issues (e.g., mental health, pregnancy) is recognized an important part of youth health care. Young people may be at risk of harm if certain health-related information is disclosed to their parents and more generally at risk of becoming disconnected from the health care system if they distrust their health care providers (Canadian Paediatric Society, 2004; English, 2005; Jones & Boonstra, 2004; Morreale et al., 2005; Parker, 2011).

The ethical principle of nonmaleficence requires that health care providers strive to do no harm, while beneficence describes the obligation to act in ways that benefit those in one's care (Beauchamp & Childress, 2013). In the pediatric context, both parents and health care providers are tasked with acting in the best interests of a child. The best interests standard is subjective and without a universal definition, but it generally refers to protecting a child's physical, psychological, and emotions safety and wellbeing (Family Law Act, 2011). When someone does not have capacity to make health care decisions, a proxy decision-maker is charged with determining what is in that person's best interests, based on the worldview of that person (Diekema et al., 2011; Jonsen et al., 2015; Rhodes & Holzman, 2014; Salter, 2017). Parents typically act as decision-makers for their children, as it is commonly assumed that parents want

what is best for their children and know them best; however, there are times when parents may refuse treatment that health care providers feel is in the best interests of the child (Diekema, 2005; Diekema et al., 2011; King, 2013; Okninski, 2016; Pinnock & Crosthwaite, 2005). Health care providers may be legally and ethically compelled to intervene in such situations, for example, if the care refused is likely to have significant benefits for the child and protect them from harm (Rhodes & Holzman, 2014). A standard that can be used to determine when such intervention is needed is the harm principle. Decisions that pose an immediate and significant risk of serious, preventable harm warrant intervention to protect the best interests of a child or youth (Diekema, 2004). Additionally, in keeping with the principles of both non-maleficence and autonomy, health care providers are not compelled to provide treatment they do not feel would be in a patients' best interests (Canadian Medical Association, 2004; Savulescu & Schuklenk, 2017).

In terms of justice, youth have established rights to fair and equitable treatment and access to health care. Such rights are addressed in several human rights agreements to which Canada is a signatory, for example, the United Nations Convention on the Rights of the Child and the Constitution of the World Health Organization (United Nations, 1989; World Health Organization, 2006). These declarations focus on non-discrimination, having a youth's best interests given primary consideration, healthy development, involvement in decision-making, freedom of expression, privacy, access to health care, and the right to the highest possible standard of health (United Nations, 1989; World Health Organization, 2006). In these documents, specific attention is given to youth rights to mental, sexual, and reproductive health care and access to accurate health information (Office of the United Nations High Commissioner for Human Rights, 2008; United Nations, 1989).

Clinical ethical dilemmas can emerge when the principles of bioethics come into conflict and the available options in a given scenario all have significant downsides. After identification of such a dilemma, “the ethical decision-making process begins when a person or group assumes the responsibility for resolving [the] problem” (Bosek & Savage, 2000, p. 113). Several factors may affect this process. In identifying options and making treatment recommendations, health care providers are influenced by their personal and professional values, as well as organizational culture (Bosek & Savage, 2000; Smith et al., 1991). One’s cultural awareness and identity can impact whether ethical conflicts are perceived in different clinical situations (Garcia et al., 2003). Furthermore, researchers have demonstrated that even when health care providers are aware of how to apply professional ethical codes and laws to ethical dilemmas determining how they *should* act, they base predictions about how they *would* act on their values and practical considerations (Smith et al., 1991). In light of these findings, further research into ethical decision-making of health care providers, which takes into account the role of personal and professional values as well as organizational culture, is warranted (Ametrano, 2014).

Many ethical decision-making frameworks have been developed to support health care providers in working through ethical dilemmas, though it is unclear to what extent they are utilized in practice. These include process/rational models built on principles, reflective models, and cultural models (McAuliffe & Chenoweth, 2008). For example, the four topics approach was developed to operationalize the principles of bioethics (Beauchamp & Childress, 2013) through a framework that aids health care providers in gathering salient information about medical indications, patient preferences, quality of life, and contextual features in order to identify ethically acceptable courses of action in a given situation (Jonsen et al., 2015). Cultural models—which focus on accountability, critical reflection, cultural sensitivity, and

consultation—have been developed to support culturally-informed ethical decision-making with queer and racialized populations (Garcia et al., 2003; McAuliffe & Chenoweth, 2008; Wiggins & Williams, 2005). However, scholars have critiqued existing models for their lack of attention to the unique context of pediatric care (Friedman Ross, 2016). While some efforts have been made to address this through development of pediatric-specific models, variations in health care consent law make it difficult to develop models that can be universally applied (Friedman Ross, 2016; Manley et al., 2001). Greater insight into the ethical decision-making processes of youth gender health care providers is necessary to identify or develop appropriate frameworks to support this area of practice.

5.1.1.2 Gender Health

Gender health is the state of living freely in one's gender, in a way that feels most real and/or comfortable (Ehrensaft, 2016). This paper is grounded in the gender affirmative model of care, which guides health care providers to support youth in achieving the highest levels of physical, emotional, social, and gender health possible (Ehrensaft, 2016; Hidalgo et al., 2013). Ehrensaft (2016) proposes that gender is a three-dimensional web—based on nature, nurture, and culture—that each person begins to weave for themselves in early childhood. Recommendation given for determining a child's gender within this model is as follows: “If you want to know a child's gender, listen to the child and the child will tell you” (Ehrensaft, 2016, p. 47). New research indicates that young trans or gender creative children demonstrate similar understandings as cisgender children of their own genders, as well as consistencies in gender stereotypic preferences, gender stereotyping, and gender constancy (Olson & Gülgöz, 2017), supporting the idea that young children can be relied upon to know their own gender.

Trans youth may or may not require medical intervention to support their gender health, however many access hormone therapy in order to develop secondary sex characteristics that align the body with gender (Mallon, 2009; Wylie et al., 2016). Hormone therapy benefits are well-documented and associated physiological risks can be well-managed (Antommaria, 2014; Coolhart et al., 2013; Dahl et al., 2015; de Vries et al., 2014; Delemarre-van de Waal & Cohen-Kettenis, 2006; Vrouenraets et al., 2015). Hormone therapy readiness assessment/care planning is a process through which youth, health care providers, and sometime parents, are involved in determining youth readiness to initiate hormone therapy (Trans Care BC, 2017b). Approaches to this process vary, incorporating such elements as gender self-determination, medical screening, standardized psychological measures, and family involvement (Cavanaugh et al., 2016; Chen et al., 2016; Coolhart et al., 2013; Edwards-Leeper et al., 2016; Edwards-Leeper & Spack, 2012; Gridley et al., 2016; Leibowitz & de Vries, 2016).

Access to culturally safer gender health care is an important factor in trans youth wellbeing, as are parent and family support (Bernal & Coolhart, 2012; Cavanaugh et al., 2016; Clark et al., 2017; Gridley et al., 2016; Olson J et al., 2011; Olson et al., 2016; Travers et al., 2012). In the absence of gender-affirming health care and parental support, trans youth report difficulties with mental health, suicidality, self-esteem, and other measures of wellbeing, while those with better access to care and support report higher levels of wellbeing (Clark et al., 2017; Delemarre-van de Waal & Cohen-Kettenis, 2006; Khatchadourian et al., 2014; Olson J et al., 2011; Ryan et al., 2010; Travers et al., 2012; Veale et al., 2015). In response to family rejection and lower likelihood of having children, one longstanding support strategy taken up within queer and trans communities is building chosen families, or creating family structures among non-related queer and trans individuals (Knauer, 2016). Creative choices about how to create families

allow queer and trans individuals “to build community and provide support and solidarity” (Knauer, 2016, p. 159).

5.1.1.3 Sociocultural Context

Youth gender health care is unique in terms of the sociocultural context in which care is currently being delivered. Mainstream health care approaches are shifting away from pathologizing trans people, to gender affirmative frameworks in which diverse genders are considered a natural part of human diversity (Corliss et al., 2008; Erickson-Schroth & Boylan, 2014b; Menvielle & Gomez-Lobo, 2011; Reisner, Bradford, et al., 2015b). However, the longstanding history of pathologization is entwined with cultural norms that create gender-related stigma on an ongoing basis. For example, cisnormativity and heteronormativity are biases based on assumptions that people are cisgender and heterosexual, respectively, while bionormativity describes bias in favor of creating families via biological children (Baylis & McLeod, 2014; serano, 2017). Such biases fuel gender-based stigma, which can be enacted through discrimination, harassment, and violence, impacting all areas life, from family to school, and from community to health care (Clark et al., 2017; GLAAD, 2017; Huft, 2008; James et al., 2016; Taylor & Peter, 2011; Veale et al., 2015). Compromised health outcomes experienced by trans youth can be explained, using the gender minority stress model, as a product of the stress and distress associated with gender-based rejection, victimization, and negative expectations (Brill & Kenney, 2016; Erickson-Schroth & Boylan, 2014b; Hendricks & Testa, 2012; Keo-Meier & Fitzgerald, 2017; I. H. Meyer, 2003; Testa et al., 2017).

5.1.1.4 Ethics in Youth Gender Health Care

Ethical issues arising in youth gender health care are reflective of those found in the general youth health ethics literature, including discussion of capacity, consent, confidentiality, best interests, and equitable access to care. While the extant literature is primarily informed by North American bioethics principles, as Vrouenraets et al (2015) note, these principles are frequently applied to the same issue in contrasting ways by different health care providers.

Youth capacity to provide informed consent, coercion, parental involvement, confidentiality, and legal constraints on decision-making are autonomy-related issues arising in the youth gender health ethics literature (Giordano, 2007, 2013b; Stein, 2012; Vrouenraets et al., 2015). Concerns exist surrounding youth autonomy, specifically, youth capacity to consent to health care interventions, susceptibility to peer pressure, and potential for coercion. However, it is argued that health care decisions are inherently deliberative and therefore not highly vulnerable to impulsivity or coercion; such arguments are bolstered by evidence that youth are typically developmentally capable of making many health care decisions during the teen years (e.g., abortion, cancer treatment) (Giordano, 2007; Shield, 2006). Maintenance of confidentiality and privacy of health information involves competing issues of: the rights of youth to access care; the impossibility of providing hormone therapy surreptitiously due to physical effects; the benefits of parental involvement; and recognition that disclosure to parents may place some youth at risk of harm (Bernal & Coolhart, 2012; Giordano, 2007; Holman & Goldberg, 2006; Shield, 2006; Swann & Herbert, 2000). However, Holman and Goldberg (2006), writing from a Canadian perspective, argue that respect for persons requires that youth medical information be kept private and only shared with permission or when required by law.

Issues of law intersect with clinical practice in ways that can create ethical dilemmas for health care providers. For example, legislation in some jurisdictions requires parental consent for health care until age 18, leaving some youth whose parents are unsupportive of their gender health goals without access to needed hormone therapy (Romero & Reingold, 2013; Shield, 2006). This raises issues of respect for persons, harm, and equity. Some scholars argue that exceptions should be made to allow youth to access gender health care without parental consent, in light of possible negative outcomes of being denied access, similar to mental health, sexual and reproductive health, and substance use treatment exceptions currently in place in parts of the United States (Huft, 2008; Shield, 2006). However, across much of Canada, many youth already have authority to consent for health care prior to the age of 18, based on laws that allow consent to health care based on capacity. In British Columbia, the *Infants Act* (Infants Act, 1996) supports youth consent to health care interventions, provided their health care provider deems the intervention to be in their best interests. Ethical issues arising in youth gender health care within a Canadian legal and clinical context have yet to be addressed in depth in the literature.

In making health care decisions, health care providers and parents are responsible for acting in the best interests of a child. These interests of a child are often determined by weighing the risks and benefits of potential courses of action. The literature provides ample evidence supporting hormone therapy as an effective intervention to support the gender health of trans youth, and current research indicates low risks of known harms (Antommara, 2014; Baltieri et al., 2009; Giordano, 2007, 2008; Holman & Goldberg, 2006; Stein, 2012; Vrouenraets et al., 2015). However, ethical concerns persist surrounding unknown long-term risks of hormone therapy for trans youth (e.g., mental health, physical health, bone density, regret, and future fertility implications) and concern that the nature of gender is not adequately understood by

health care providers (Antommaria, 2014; Bernal & Coolhart, 2012; Giordano, 2007; Khatchadourian et al., 2014; Murphy, 2012; Swann & Herbert, 2000; Unger, 2014; Vrouenraets et al., 2015). However, there is evidence that youth do not experience regret about their gender health-related medical decisions (de Vries et al., 2014), and consensus within the field that withholding hormone therapy is more likely harmful than beneficial, and that therapies aimed at changing a youth's gender are both harmful and unethical (Baltieri et al., 2009; Bernal & Coolhart, 2012; Giordano, 2007, 2013b; Vrouenraets et al., 2015).

Finally, systemic inequities and barriers to gender health care are issues of justice raised in the literature (Giordano, 2007). Cost, lack of insurance coverage (e.g., hormone therapy readiness assessment/care planning, medications), lack of family support, health care providers who are uninformed about gender health care, and geographic barriers all impact equity, and play out differently according to health care system and insurance structures in different locations (Cavanaugh et al., 2016; Clark et al., 2017; Rosenthal, 2014). Capacity-building within existing systems of care is needed to address such structural issues, however insufficient resources have historically been allocated to this work (Clark, 2017; Clark et al., 2017). Conflicting values of youth, parents, and health care providers can also give rise to ethical dilemmas and potentially result in barriers to care (Antommaria, 2014; Cohen-Kettenis et al., 2008; Romero & Reingold, 2013; Swann & Herbert, 2000).

5.1.1.5 Purpose

Unique issues arise in youth gender health care, and tools have yet to be developed to assist health care providers in navigating ethically complex clinical situations within this field. The ways in which sociocultural factors and health care provider values impact delivery of youth

gender health care have also been given little attention. There is little available ethics scholarship related to youth gender health care, and even less that attends to ethical decision-making in contexts in which youth are able to consent to health care based on capacity rather than age. The current study explored ethical decision-making processes of health care providers engaged in hormone therapy readiness assessment/care planning for trans youth in order to address these questions: (1) what ethical issues do health care providers find challenging in hormone therapy readiness assessment/care planning practice with trans youth; (2) how do health care providers construct and resolve ethical dilemmas that emerge in hormone therapy readiness assessment/care planning practice with trans youth; and (3) how can health care providers be better supported in ethical decision-making processes related to hormone therapy initiation?

5.1.2 Methods

This research was undertaken in the province of British Columbia, Canada, as part of a study on youth hormone therapy decision-making. The University of British Columbia Behavioural Research Ethics Board, University of British Columbia Children's and Women's Health Centre of British Columbia Research Ethics Board, the Vancouver Coastal Health Research Institute, and the Northern Health Research Review Committee approved this study.

Health care providers were recruited with the assistance of a partner organization, Trans Care BC, that distributed a letter of invitation to those currently offering hormone therapy readiness assessment/care planning for youth. Interested health care providers contacted the researcher directly to express interest and arrange an interview at their clinic or office. Participants ($n = 11$) represented a range of health care disciplines and had been involved in this type of care from one year to over 10 years. They practiced in rural and urban settings and

represented three of the five regional health authorities in the province. Due to the small number of health care providers engaged in this practice in British Columbia, further demographic information was not collected in order to protect the identities of the participants.

Interviews were semi-structured, one-hour in length, and digitally recorded for later transcription. Participants were given the opportunity to member-check their transcripts. The interview questions of relevance to this paper focused on ethical dilemmas that health care providers faced in practice with trans youth and approaches they took in resolving these dilemmas. Data were analyzed via constant comparative methods, using a constructivist grounded theory approach, to examine the processes underlying ethical decision-making. The model resulting from these analyses offers: (1) a way to understand ethical decision-making processes of health care providers providing hormone therapy readiness assessment services for trans youth; and (2) a framework for approaching health care provider education that may enhance ethical decision-making.

5.1.3 Results

Participants were asked to talk about ethical dilemmas they had encountered when providing hormone therapy readiness assessment/care planning for youth. While many topics were consistent across interviews, health care providers approached them differently, both in terms of how they constructed dilemmas and the actions they took to address them. Additionally, differences were noted in beliefs about key concepts (e.g., gender, capacity) that arose in these discussions. Core constructs involved in the ethical decision-making processes were identified as beliefs, dilemmas, and actions. Further analysis explored how these constructs interacted within health care practices with trans youth and their families.

Figure 5.1 illustrates the three core constructs of beliefs, dilemmas, and actions. Experiences of providing care—past, present, and future—are captured in the centre, as the decision-making processes examined took place in the context of health care relationships. The ring surrounding the model represents sociocultural influences, serving as a reminder that all health care and ethical decision making is acted out within, and influenced by, sociocultural factors, such as bias, cultural gender norms, religion, law, colonization, pathologization, and western medicine. In the following section, contrasting beliefs, dilemmas, and actions are described, followed by an analysis of how these constructs interact.

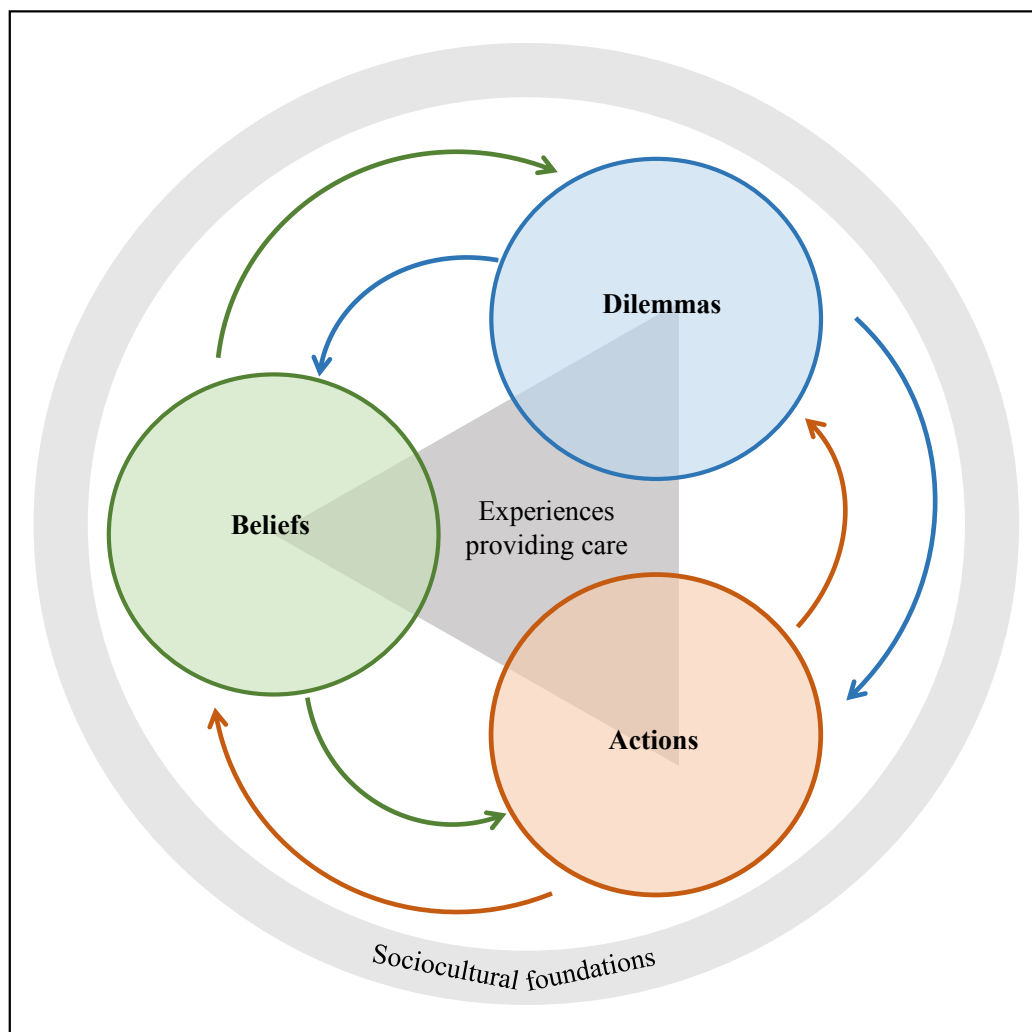


Figure 5.1 Belief-Dilemma-Action Model of Ethical Decision-Making

5.1.3.1 Beliefs

Health care provider responses to questions about ethical dilemmas and moral distress revealed many beliefs relevant to the care of trans youth and their families. Six categories of beliefs emerged through coding of the data as having theoretical significance: youth ability to know their gender, health care provider role, family, rights, capacity, and best interests. Specific beliefs within these categories were central to health care provider ethical decision-making processes, and are described within this section. It should be noted that there were values that were universally held by health care providers (e.g., do no harm, act to benefit youth,), and while such values influence ethical decision-making, it is areas of divergence in beliefs that were of primary interest in understanding how ethical decision-making processes unfolded differently among health care providers.

5.1.3.1.1 Gender

Beliefs about youth ability to know their own gender formed one of the clearest points of divergence among health care providers. In an early interview, a health care provider introduced the idea that assessing the needs of trans youth is challenging due to a lack of health care provider understanding about the phenomenon of gender. In the health care provider's words, "So, there's an ethical quandary, when you can't even trust your own perceptions of the issue that you're trying to assess." This response highlighted the potential for lack of health care provider understanding of gender to influence how care was provided to trans youth. Therefore, in subsequent interviews, health care providers were asked to comment on the need to understand the nature of gender in order to assess youth readiness for hormone therapy.

A small number of participants expressed concern regarding youth capacity in general to consent to hormone therapy based on a belief that individuals may not know their own gender or that gender is not stable in adolescence. For example, “You can’t just rely on the principle that people should trust their own inclinations.” Adolescence was viewed as a time of life during which identity was fluid in general and when youth were still considering what their gender was. One provider believed that, “In an adolescent, identity is fluid, and the more challenging early childhood experiences have been, the more fluid identity is.” This health care provider’s assertion of gender instability was supported by a belief that youth were immature and susceptible to coercion or influence of media, peers, and others in their lives, possibly leading to false gender self-appraisal. Another participant gave this description: “‘I Googled it, I realized what I am.’ But whatever they looked at could determine what they are.” The possibility that people could be subconsciously seeking attention when attempting to access hormone therapy was also raised: “so this may not be an illness, but there is such a thing as factitious illness, but there could be factitious identity.” However, the health care provider proposing this concept indicated that such a situation had not been encountered in clinical practice.

The majority of participants shared a different view of the nature of gender and its relationship to their work. The belief that gender should be self-identified was described in this way: “I don’t think it’s for me to define. I think it’s for them to define. So, I’m quite comfortable treating their definition of what it is and their understanding and what they would like to have different”. There was also confidence among these health care providers that people do not make mistakes about their gender and that the health care provider’s role was to treat distress, rather than to make judgements about a youth’s gender.

Over the years, I've come to realize that it's not the sort of thing that people make mistakes about because usually by the time I see them they've been thinking about it for a couple of years already. And that people doubt themselves way more than I ever would, and they have doubted themselves and questioned themselves and challenged themselves and experimented as part of figuring out who they were.

5.1.3.1.2 Roles

Beliefs about the nature of gender frequently overlapped with health care provider understandings of their role. According to one participant, "It's more important to just treat the distress rather than the identity, or the gender." Many health care providers saw themselves as collaborators, facilitators, or advocates in providing care for trans youth. For example: "I'm here to facilitate your care. I'm not here to put a barrier between you and your care. I'm the care provider. I don't have an agenda besides care." Despite these views of gender and ideal role, many participants acknowledged that an aspect of their position was that of a gatekeeper to hormone therapy. "I do feel like it's a shared process and there's a lot of discussion, but I suppose ultimately it's making that decision, to prescribe or not."

Other health care providers expressed strong commitment to a gatekeeping role, framed in terms of responsibility for future youth wellbeing. "You've got the dilemma of trying to figure out the future and trying to determine whether it's likely that they will feel good about their decision, they won't regret it, they won't feel treated poorly in society. So, you've got that decision to make, which is very hard to make." Gatekeeping is a recognized function of health care providers, however within gender health care, this term arises in reference to long-standing pathologizing practices which required in-depth psychological assessment prior to accessing hormone therapy, rather than practices solely focusing on ensuring physiological safety related to prescribed medications or moderating access to scarce resources. There has been a shift away

from gatekeeping in the adult gender health realm, with the introduction of informed consent care, but these approaches are not widely accepted in youth gender health care. Variability in these approaches was reflected in the data, as some health care providers asserted a need to consistently provide in-depth psychological assessment to ensure safety of youth seeking hormone therapy, while others viewed their duty as one of facilitating transition at the right time, and using harm reduction approaches when necessary to promote safety.

5.1.3.1.3 Family

Beliefs about family were focused on: parent experiences; youth-parent relationships; and ways of creating families. Health care providers recognized that parents love their kids, were trying to promote what they perceived as their children's best interests, and at times were acting out of fear for what being trans would mean for their child. One health care provider described their view of some parental responses this way: "I understand you want the best for your kid. I understand your motives are because you love your kid. I understand that that's why you're doing this. It's not that you hate your child and you want the worst for them." While acknowledging that lack of alignment between youth and parent values can cause conflict, some health care providers felt confident that parents could be brought on board with their child's gender goals, and that generally parents would adjust over time. Most acknowledged that there were situations in which parents could not be brought on board.

Awareness that family dynamics may influence a youth's need to have their parents on board was also evident. Two types of youth-parent relationships were described. First were situations in which there were strong and highly valued relationships:

For some youth, especially if they're close to their family, if they really have a high regard for their family and usually involve their family in decisions and usually have a lot of respect for their family's opinions, it can be very hard if they anticipate that this is not going to go over well with their family.

Another health care provider described a scenario wherein youth-parent relationships were not considered healthy: "Then you get this other kind of family where the parents are really dysfunctional. The kids are usually a little bit more forceful because they're not so concerned about their relationship with their parents." Some participants believed that a youth's support system did not necessarily have to center around parents, when parents were unable or unwilling to fulfill a supportive role. In these cases, health care providers talked about extended or chosen family, involving individuals that youth found supportive, and helping youth to build networks of highly supportive people while their parents were unable to fulfill this role.

"Sometimes it's amazing how granny is the one who's super supportive. I'm always amazed...all the different people that are in town, especially, that play an important role, and then friends. Sometimes it's extended. Lots of people have tons of extended family around, so, finding out who's there to support."

Health care providers also discussed creation of families, primarily in relationship to fertility considerations and planning for future families. A minority of health care providers expressed concern that youth might regret possible foreclosure of future fertility options by initiating hormone therapy at a younger age. "I think that is probably the number one biggest concern that many providers have, that—starting this process younger and younger—potential fertility loss in the future, and how are youth understanding that and making that aspect of the decision for themselves." There was acknowledgment among some health care providers that youth were frequently well-informed about future family creation options: "A lot of the kids I've spoken to speak about adoption, which is really nice. They're already coming up with ways of making families that are not traditional, for lack of a better word." In contrast, another health

care provider felt that youth plans to adopt in the future were not well-informed: “I think [youth] also don’t understand the difference between having a biological child and an adopted child. Most people who adopt kids don’t know some of the risks of adoption.”

5.1.3.1.4 Rights

Participants reported working with parents who were of the opinion that they had a right to make all health care decisions for their children until they reached age 18. This conflicted with health care providers’ understanding of the British Columbia *Infants Act* and youth rights to consent for their own health care. Some health care providers articulated beliefs that youth had both the right to make their own health care decisions and the right (or responsibility) to live with the results of those decisions. Several participants also commented on youth rights to privacy and confidentiality within the therapeutic relationship. These beliefs were fairly consistent among health care providers who discussed them, however youth rights were not addressed by all participants.

5.1.3.1.5 Capacity

A majority of participants believed that most youth have the capacity to make decisions about their health care. For example, “Even if they’re under 18...I find most have that capacity.” Remarks such as, “they’re usually quite well informed about what they’re signing on for,” indicated a belief that youth were independently conducting thorough research on hormone therapy. Health care providers also noted a high level of deliberation on the part of youth: “We see just a breadth of introspection and reflection that is well beyond their years.” Some health care providers described youth as being different from adults in terms of brain development,

maturity, and decision-making capacity. “You see folks who, their brain is not fully developed, and so the risk/benefit weighing mechanisms are different than they’re going to be five or ten years from now.” Other statements reflected a view of capacity as an emerging construct that may develop at different rates across domains of functioning (e.g., insight, self-care).

5.1.3.1.6 Best Interests

The theme of best interests included beliefs about what youth need, parent involvement, and regret. Two of the primary needs identified were parental support and social support. All health care providers expressed beliefs that parent support is highly beneficial, when available. Some believed that parent-youth relationships should be given priority when determining best interests: “In terms of the long-term good of this person through their lifespan, I know that if you can reconnect parents and kids and teens, their overall life course is going to be better for the most part.” Other health care providers shared that, in some cases, they believed best interests are served by honoring the autonomy of capable youth to decide to initiate hormone therapy without parental support. In the words of one participant: “If a person is competent to make any particular healthcare decision, if I feel that they’re competent to do that, then they have a right to make that decision without their parents.” Some health care providers discussed a need to protect youth, either due to outside harms (e.g., medical neglect) or potential for regret in the future. The responsibility to protect the best interests of the youth was described in this way: “If a youth doesn’t have the insight yet to kind of understand regret and the potential for regret and the potential for patience as well, it can be really difficult. So, I want to be as generous in terms of what I can offer, but also protective.” This underscored how concerns about regret related to health care provider beliefs about the best interests of youth.

5.1.3.2 Dilemmas

At the beginning of the interview, each health care provider was asked to describe one or two ethical dilemmas they had encountered in practice. The initial dilemma described by most providers involved how to proceed when parents did not support their child's decision to initiate hormone therapy. Other ethical issues frequently raised included: challenges arising in evaluating youth capacity to consent to care; concern about the potential harm of regret—in particular, regret of potential future fertility implications of hormone therapy; and dilemmas of how to proceed when encountering resource scarcity that has the potential to create harm. Specific dilemmas are described to illustrate the diverse ways participants framed ethical issues within each category.

5.1.3.2.1 Family Conflict

Conflict between youth gender health goals and parent views was raised as an ethical dilemma by all health care providers, involving ethical principles of beneficence, non-maleficence, and autonomy. In terms of balancing risks of harms, one participant stated, “it’s a really, really big struggle, the difference between harm of acting too soon versus acting too late.” Potential harms associated with initiating hormone therapy against parent wishes, included parental rejection resulting in violence, homelessness, and loss of access to education and financial support. Providers were weighing this against the harms of delaying or withholding care, which could bring about serious risk of harm in terms of mental health and suicidality.

If a youth with decision making capacity was opposed to involving their parent(s) in their care, insisting on such involvement was seen by some as being at odds with youth autonomy. The conflict between autonomy and harm was summed up in this way: “Do you insist that they

participate because of their safety? Or do you just let them make that decision and possibly suffer the consequences?” Two health care providers also addressed the dilemma of deciding when lack of support for gender health goals exceeded the harm threshold for medical neglect. “At what point is the lack of support actual neglect or harm for a youth? I guess where the line probably is where the kid starts to experience trauma as a result of it, or significant negative outcomes as a result of it.” The potential negative repercussions of reporting parents for neglect were also highlighted. “But then the flip side to that is, there’s significant harm for reporting as well, and you know, you don’t want to make things worse for that particular youth by going down that road.”

5.1.3.2.2 Consent

Autonomy was the central ethical principle involved in discussions of youth capacity to consent for hormone therapy. These issues were framed in three ways. Two health care providers discussed challenges in supporting youth in consenting to care based on what they saw as overarching limitations. For example, one questioned how to obtain informed consent for treatment at a time when cultural norms related to gender were quickly shifting: “If they’re going to change their mind and that’s going to happen in culture, then how long do they need to be exposed to different views for them to be informed consent?” The struggle evident in these discourses was around how to respect youth autonomy, with health care providers questioning if youth could give informed consent for hormone therapy and speculating on whether allowing them to exercise their autonomy in consenting to hormone therapy would ultimately be harmful. Four health care providers shared a dilemma that focused on how to assess capacity and respect autonomy, specifically with youth whose capacity was still developing (e.g., not yet attained

capacity to decide about hormone therapy) or compromised (e.g., mental health issue). These participants did not raise concern related to youth generally having capacity or consenting to health care interventions, rather this was about how to evaluate capacity when complexities arose. Finally, one provider framed the issue of youth consenting to care essentially as a non-dilemma, citing the right of capable youth to consent to care.

Ideally everybody is going to be involved in the healthcare decision, but ultimately it's the youth who has a right to decide about their own healthcare, as long as I don't have a question that they're competent to decide that, and it's very rare that I would have a question around that.

5.1.3.2.3 Regret and Fertility

Participants generally recognized the benefits of hormone therapy, however several shared concerns about balancing a multitude of potential harms. These included potential future regret of the decision to initiate hormone therapy, particularly in relationship to hormone-related fertility implications. Health care providers were not asked directly about the topic of regret, but as a follow-up to fertility discussions in early interviews, most health care providers were invited to share their thoughts on how fertility is taken into account in their work with trans youth. Four participants described their ethical deliberation on this topic involving fear that an individual would regret their decision to start hormone therapy later in life due to impacts on fertility, indicating that they would have failed in their duty to do no harm. One described fear persisting despite evidence of the magnitude of risk: "I know that the likelihood and the rates of that regret, whether it's post-hormone or post-op, are very, very small. But, yeah, that's one of the big fears—first, do no harm." This sentiment was echoed by a participant who also acknowledged the research does not indicate that regret is a problem, but stated, "I do worry about regret. And maybe we just haven't seen that population yet who have regretted."

Of the remaining participants, three shared thoughts on regret in general and three others talked specifically about fertility-related regret, all without framing these issues as ethical dilemmas. Speaking generally about decisional regret, one provider stated, “I also believe that people can make a decision and then live with the decision.” Another participant challenged an assumption underlying most discussions of fertility regret, that infertility is fundamentally problematic. In the health care provider’s words, “why is everybody so tragic about bypassing fertility? People make all kinds of choices where they plug things off...I mean, I will never be a concert pianist, but nobody ever got really tragic about that. But they all get tragic about not being able to reproduce, which is interesting.”

5.1.3.2.4 Resource Scarcity

Mitigating harms stemming from resource scarcity was a topic addressed by the majority of participants. Harm to youth wellbeing resulted from delays in access to care (e.g., mental health services), geographic barriers (e.g., services being concentrated in urban areas), and a complete lack of some needed resources (e.g., parenting support). One participant described the impact of lack of parent support resources this way: “That resource is just not there...ethically coming back to justice, when the resources are...really not there...I find that really, really difficult.” Health care providers also discussed experiencing barriers to improving the services they were offering: “The other problem is that we don’t have a lot of training or a lot of resources on how to do family counselling, family mediation, or how to bring parents onboard.”

Several participants took the discussion of justice and resource scarcity a step further, questioning how to effectively mitigate the harm being caused by the lack of needed resources. This involved dilemmas about operating within scope of practice and navigating challenging

dynamics within the youth gender health field. For example: “Some of the ethical issues I’ve struggled with are even beyond the one-on-one encounters... disagreement between care providers around how we should manage youth, for example. Who should be able to provide care and at what age?” One participant articulated apprehension about service provision this way: “I’m very concerned about there being other young people...who are getting seen in clinics which maybe don’t have as much psychiatric knowledge or in-depth assessment, who may get hormones”. Health care provider descriptions of unresolved dilemmas related to justice and resource allocation indicated the presence of ongoing moral distress surrounding not being able to provide the care that was needed by youth and families.

5.1.3.3 Actions

The final construct involved the actions health care providers took in response to the dilemmas they encountered. The first three actions—assessment, consultation, and deliberation—were taken prior to making a decision about whether to support hormone therapy initiation for a particular youth. These are followed by: decisions about hormone therapy initiation and the actions flowing directly from them; care provided; and evaluation of approaches taken.

5.1.3.3.1 Assessment

The word assessment held different meanings among participants. Some focused on assessing core gender identity, favoring a more paternalistic approach and providing in-depth assessments to differentiate gender concerns from mental health or developmental issues. Others were focused on assessing readiness to initiate hormone therapy. This involved taking a ‘how

and when, not if”, approach, and “trying to establish where they are mental health-wise, to make sure that things were relatively stable to embark on [hormone therapy].” Exploration of risks and possibilities included accounting for safety in terms of parental support, housing, distress, and time, for example, “what is a bearable amount of time or not, and also getting a real sense for their distress.” Finally, all participants preferred to engage with parents during the assessment process. “I really encourage the family to be involved as much as absolutely possible, and really try and help the family to be there, because I think that the youth will – if possible, will benefit from a supportive family.”

5.1.3.3.2 Consultation

Consultation with colleagues was undertaken in response to being unsure of how to proceed with a particular youth. For example:

“I had to ask for backup from one of the more senior [health care providers] on the team because I just felt very stuck, because obviously I wanted to give trans competent care to this trans youth, but I also don’t want to harm them in any way and go too quickly for their development.”

Having trusted colleagues with similar approaches to care was cited as an asset. Consultation was also described in the larger context of collaborative care, in situations that involved working together with a youth, family, and/or other health care providers to provide the best possible care.

5.1.3.3.3 Deliberation

Deliberation on practice situations, ethical dilemmas, and one’s role in providing care were all undertaken by participants. For some, reflection on practice included reviewing empirical evidence to inform care. Another participant shared, “it’s a reflective practice, I think,

in terms of ethics, like checking in around the gut instinct with any clinical situation, and if your gut is saying pause, think, to really, really listen to that.”

5.1.3.3.4 Decisions

Descriptions of decisions about whether and when to initiate hormone therapy were complex. The simplest decision was to initiate hormone therapy when parents were supportive. When they were not supportive, decisions were made based on the age and capacity of the youth, other available supports, and the perceived potential harms (and benefits) of initiating and delaying hormone therapy. Some health care providers were very hesitant to initiate hormone therapy without parental support or a high level of mental health stability, feeling that this would not be in the best interest of a youth. For example, participants were concerned that the youth-parent relationship could be damaged by supporting youth to go against their parents’ wishes regarding hormone therapy initiation. Consequently some youth were refused hormone therapy. Many providers delayed initiation of hormone therapy, taking time to either bring parents on board or develop an alternative support system. In one participant’s words, “really feeling like it’s imperative that I do my best to ensure either that I can get the family on board or that, if I cannot get the family on board, that I feel that [initiating hormone therapy] is safe enough to do and that I have a plan for if things unravel to keep that youth safe.” Lastly, sometimes the decision was to move forward without parent support: “I felt like the youth had capacity to consent and it was the right decision to make for that youth to move forward, so we did start hormones in that situation.”

5.1.3.3.5 Care

Within the category of care, health care providers took many different actions. A patient-centered approach to care was highlighted by several participants. Reflecting on changes in health care delivery over time, one provider reflected, “Medicine has shifted quite a bit...there’s definitely more patient-centered care and more patient involvement in decision-making.”

Developing a collaborative plan and working to minimize risks were common actions taken. Some practitioners took interim measures before making a decision to initiate hormone therapy, such as offering Depo-Provera to stop monthly bleeding. Care was frequently provided to reduce distress and to support informed decision making. When necessary resources were unavailable in a given community, such as mental health support or family counselling, some health care providers sought out education and support in order to develop the competencies to offer these services themselves.

5.1.3.3.6 Evaluation

Providers spoke of the importance of evaluating the results of their approach to care to inform future practice. Reflections were shared regarding both outcomes, “I see people a year later, two years later and they’re beaming and happy and this is the best thing that ever happened to me, and my life is so much better now,” and process, “I think I feel okay that whatever youth I’m working with feels like they’re being respected and that their process is not dragging out longer than it should.”

5.1.3.4 Interactions and Influences

After the three main constructs emerged, the ways in which the constructs interacted were more fully investigated. Directional influences identified among all three constructs are described below and illustrated with arrows in Figure 5.2.

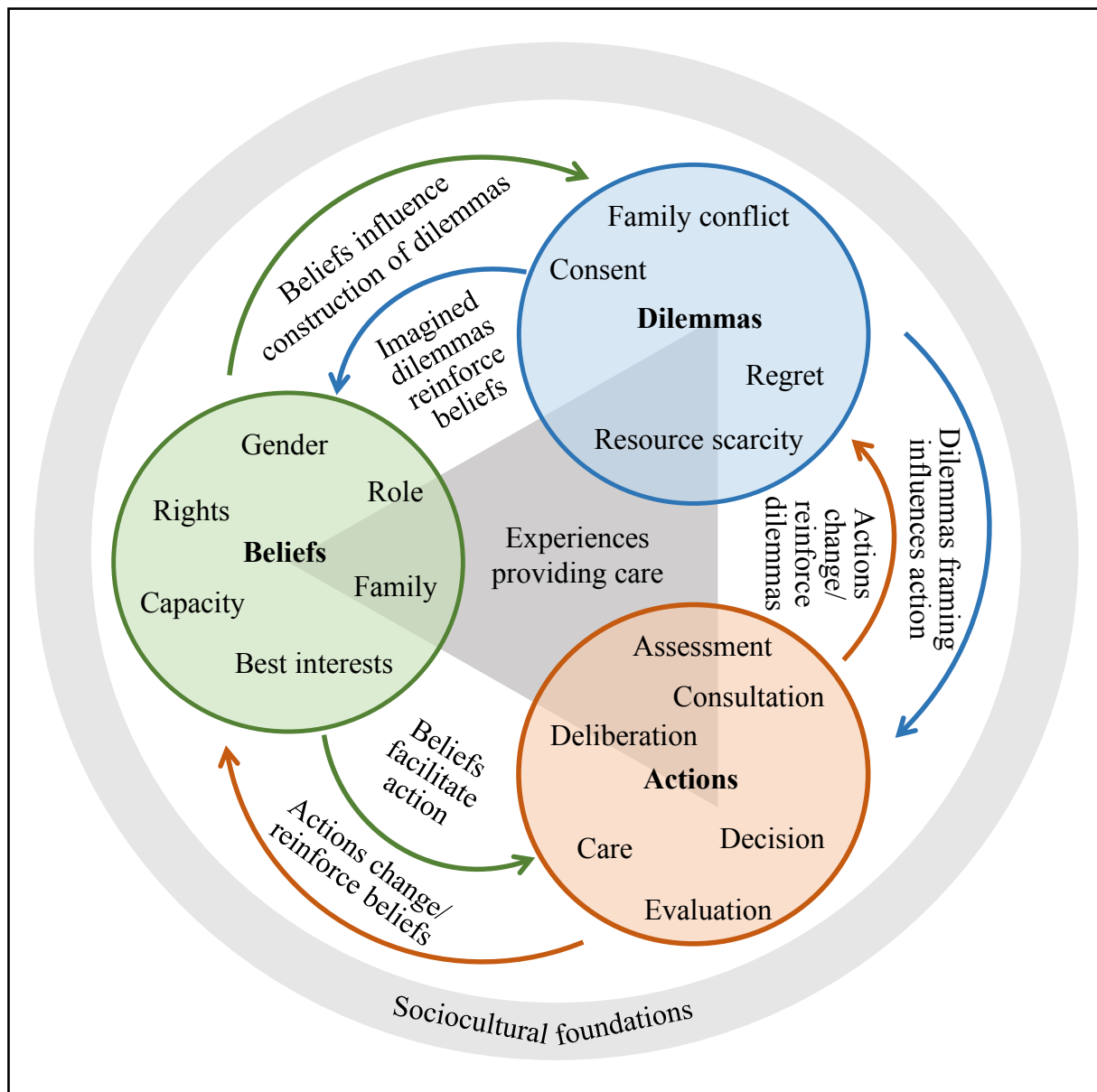


Figure 5.2 Belief-Dilemma-Action Model: Youth Gender Health Care

5.1.3.4.1 Beliefs

The following examples highlight how two differing sets of beliefs can influence the construction of different ethical dilemmas. In the first, participants questioned if the benefit of providing access for hormone therapy without in-depth psychological evaluation could outweigh potential harms. Beliefs associated with this dilemma construction involved seeing the health care provider role as that of gatekeeper, believing youth needed protection, and placing greater emphasis on the beneficence of supporting positive youth-parent relationships than on supporting youth autonomy to make decisions about initiating hormone therapy. A second dilemma was formulated around how to address the injustice and harm caused by lack of access to needed services (e.g., parent support, family mediation). Participants weighed taking on this care themselves (i.e., something is better than nothing) with the potential for minimal benefit resulting from individuals providing this care without robust training or support. These participants shared a set of beliefs including: youth having the right to access care; care should be patient-centered; and that youth benefit from strong parental support.

Not only were similar beliefs associated with similar construction of dilemmas, but tension versus congruence within a set of beliefs held by an individual was also found to be associated with differences in dilemma construction. One subgroup of participants expressed uncertainty about the nature of gender, and also held the following beliefs: youth may have capacity to give consent for care and that people don't always know what is in their own best interest. The tension between the belief that youth can have capacity to make health care decisions but that they may not know what is in their best interests is at play in the resulting dilemma: is it possible for trans youth in general to provide informed consent for hormone therapy? Conversely, health care providers who framed capacity-related dilemmas in terms of

providing care for an individual youth whose capacity was in question—rather than trans youth in general—held a set of beliefs with greater internal congruence: care should be patient-centered and depathologizing; youth can have capacity to consent to health care and have the right to do so; parent support is beneficial, however, the best interests of capable youth may be served by initiating hormone therapy without parent approval; and effective social supports do not have to revolve around parents.

When health care providers viewed a situation as a non-dilemma (as seen with multiple providers in discussion of the role fertility plays in decision-making) health care providers' beliefs facilitated action. For example, beliefs that youth could make informed decisions about fertility and that biological families should not be privileged over other ways of creating families were associated with an absence of fertility-related dilemmas. This allowed health care providers to provide care without taking time to address an ethical dilemma.

5.1.3.4.2 Dilemmas

In general, participants reported dilemmas arising out of actual practice situations, however, some also shared concern about imagined dilemmas that they feared encountering. One example involved an imagined future encounter involving a patient returning to confront the health care provider about fertility-related regret. This fear of doing harm to patients was accompanied by minimization of available evidence and construction of this issue as a significant dilemma. Imagined dilemmas indicated that not only could beliefs shape ethical concerns, but that dilemmas—even those that were imagined rather than encountered—could influence beliefs.

Framing of ethical dilemmas also influenced action. In the case of youth seeking hormone therapy without parental support, health care providers weighed potential risks and benefits as they attempted to act in the best interests of youth. Participants universally recognized the benefit of parent support and were all inclined to bring parents on board for this reason. However, the framing of ethical dilemmas was central to the actions of health care providers, specifically their decisions about whether and when to initiate hormone therapy. Health care providers who focused on a dilemma of competing harms and benefits (e.g., initiating hormone therapy without parent support versus delaying care), carefully assessed the potential impacts of delay versus action on the individual youth. For example, “I do weigh is delaying it a little bit to get the family on board impacting the youth—what’s the harm to the youth?” Others who focused heavily on supporting the best interests of youth through promotion of healthy youth-parent relationships, generally targeted their actions at bringing parents to a supportive stance, even if this meant delaying initiation of hormone therapy.

5.1.3.4.3 Actions

Health care providers had resolved past dilemmas through various actions, leading to changes in both construction of dilemmas and in beliefs. One participant described deliberating on previous clinical work with adults who chose to cease hormone therapy, an experience that shifted perspective about the permanence of the decision to initiate hormone therapy. Framing the decision for youth to start hormone therapy as something that was not permanent, thus leaving space for future changes in the care plan, changed the health care providers’ perception of the level of risk associated with hormone therapy initiation. Another participant who had been concerned about potential loss of fertility due to hormone therapy had consulted the medical

literature and was reassured by information about positive fertility outcomes after years of hormone therapy (e.g., pregnancy, childbirth). Finally, a health care provider who shared thoughts about regret reflected on how past professional actions had changed beliefs. The shift in this health care provider's perspective over time was described as going from a fearful place, "early on that's your biggest fear, especially when you're new to it because it's, like, this is really radical...that's the fear, is regret," to one informed by years of clinical experience with no clients regretting their decisions, "I just think it's really disrespectful to even consider that they might regret their choices." These examples demonstrate that health care provider actions had influenced not only the current framing of a topic (as a dilemma or non-dilemma), but also their beliefs about best interests, gender, and provider role.

All participants reported an ongoing dilemma related to working with parents and youth who disagreed about the course of care, however, most were very committed to their approaches. Their past actions, including deliberation, reinforced their beliefs and their construction of ethical dilemmas. For example, this health care provider with extensive experience working with trans youth stated that it is almost always possible to bring parents on board, therefore the approach is to, "really encourage the family to be involved as much as absolutely possible, and really try and help the family to be there, because I think that the youth will—if possible—will benefit from a supportive family." This approach had reportedly been successful, reinforcing beliefs that parent support is important and that parents can be brought on board.

5.1.4 Discussion

The major findings of this paper centre around health care provider ethical decision-making processes within the context of youth gender health care. The constructions of beliefs,

dilemmas, and actions were found to interact in all directions. Two of the key interactions were the impact of tension or congruence within a health care provider's set of beliefs relevant to youth gender health care (i.e., gender, health care provider role, family, best interests, capacity, rights) and the function of imagined dilemmas in formulating beliefs and constructing ethical dilemmas. The ethical dilemmas identified centered around four main themes of family conflict, consent, regret, and resource scarcity. Consistent with Vrouenraets et al. (2015), bioethics principles were applied across this range of dilemmas, but done so differently by different health care providers.

In terms of health care provider ethical decision-making, no decision-making models were regularly used in clinical practice, though some providers referred to professional codes of ethics and most applied a North American bioethics framework in discussing their work. Use of other ethical approaches, such as relational ethics, was not described by participants. No participants discussed feeling pressured to provide hormone therapy as an ethical issue, though they did struggle to determine when this intervention was in a youth's best interest and how to avoid bringing about harm. It is established in the literature that personal and professional values can influence identification of options and treatment recommendations in clinical practice, and that cultural awareness and identity can impact perception of dilemmas (Bosek & Savage, 2000; Garcia et al., 2003; Smith et al., 1991). This is consistent with the influence of beliefs on actions within the Belief-Dilemma-Action Model. Understanding that the way providers predict they would act in response to an ethical dilemma may be based on values and practical considerations rather than codes and laws (Smith et al., 1991) is reflected in the way beliefs and actions reinforced one another within this model. It is important to note that many participants were open to discovering and integrating new empirical evidence into their practices to better meet the

needs of trans youth and their families, however individual health care provider appraisal of such evidence varied in both interpretation and application.

Contrasting health care provider views regarding youth autonomy indicated differing beliefs about gender and capacity that were in some cases more, and in other cases less, reflective of pathologization of trans people. What is clear is that trans youth are at risk of experiencing double stigma when seeking health care, related to both gender and age. Further complicating the issues related autonomy in this study was health care provider unfamiliarity with available guidelines for evaluating capacity to consent (College of Physicians and Surgeons of British Columbia, 2015; Cummings & Mercurio, 2010). While many health care provider beliefs were grounded in the available evidence, others failed to meet this standard, resulting in a cycle of beliefs, dilemmas, and actions that reinforced non-evidence-based practices.

Some health care providers took views of youth development that were consistent with the literature. For example, many felt that many youth in the 14-18 year old age range were deeply deliberative and could demonstrate capacity to make their own health care decisions (Weithorn & Campbell, 1982). Others expressed concern that adolescent brain development limited health care decision-making capacity and raised concerns about impulsivity and susceptibility to influence. However, as Grootens-Wiegers et al. (2017) assert, time and decisional support are integral parts of health care decision-making, making these processes fundamentally different from the types of decisions subject to impulsiveness and peer influence. Previous research indicated that health care decision-making capacity typically emerges during adolescence, and while some youth will and some will not possess capacity to make specific health care decisions, all should be supported to be involved in their care to the extent possible (Canadian Paediatric Society, 2004; Diekema et al., 2011). What was frequently missing in

participant narratives was acknowledgment that evaluation of decision-making capacity is person-specific, time-specific, and decision-specific and that health care providers have an obligation to support emerging decision-making capacity. Blanket judgments regarding the capacity of all trans youth to consent (or not) to hormone therapy are not evidence-based. When health care providers hold beliefs such as beliefs about capacity, these can shape the construction and resolution of ethical dilemmas in youth gender health care.

On a related, but distinct topic, some health care providers questioned not only youth capacity to consent for hormone therapy, but also the ability of youth to know their own gender. This is inconsistent with a gender affirmative model of care and with research that demonstrates that trans children are similar to cisgender children in their early understanding of their own gender, gender stereotypic preferences, gender stereotyping, and gender constancy (Ehrensaft, 2016; Olson & Gülgöz, 2017). When youth's ability to know their own gender is questioned or disbelieved rather than supported by health care providers, it undermines youth autonomy and likely influences perceptions of capacity to make health care decisions. Participants generally endorsed that they were providing gender-affirming care; however, there were clear differences in how this term was applied. Care should be taken to clearly define what is meant by the words "gender-affirming care", and attention paid to incongruence between this paradigm and health care provider beliefs, dilemma construction, or actions that are not supportive of youth ability to know their own gender.

Many tensions in the youth gender health care literature mirror those in this study, however some played out differently due to context. Discussions of youth capacity to consent for hormone therapy, parental involvement, and legal constraints were distinct, due to the provincial legislation (Infants Act, 1996). In this context, health care providers grappled with how to

evaluate the capacity of minors and when to involve parents, whereas in previous research conducted in places where youth lacked legal authority to consent to gender health care, health care providers struggled with the ethics of being unable to support youth decision-making due to parental consent requirements (Bernal & Coolhart, 2012; Giordano, 2007; Shield, 2006; Swann & Herbert, 2000). All participants were attempting to provide care in the best interests of youth, based on their professional judgment and available evidence. However, within this cohort of health care providers, some felt that youth best interests could not be served without obtaining parental consent for hormone therapy, while others sought to make hormone therapy accessible through bolstering alternative supports. Overall, the result of divergent beliefs about capacity, gender, and family was inconsistent access to hormone therapy, and involved variable construction of ethical dilemmas and non-dilemmas, as well as contrasting actions taken under similar circumstances.

In the youth gender health care literature, beneficence and nonmaleficence receive a great deal of attention (Baltieri et al., 2009; Holman & Goldberg, 2006; Stein, 2012; Vrouenraets et al., 2015). Participants in this study all generally supported hormone therapy as an effective intervention for addressing the needs of trans youth, but expressed concern about potential harms, most often risks associated with hormone use, impacts on youth-parent relationships, and potential regret related to fertility. These harms are worthy of further examination. First, the specific medications used for youth hormone therapy have been widely used for decades, particularly in youth contraceptive care, with largely understood risks and benefits. Studies on the longer-term effects of these medications in trans populations are available, indicating benefits for gender health and overall minimal risks that can be well-managed (Dahl et al., 2015). However, unknown long term effects of hormone therapy for trans youth provided pause for

many participants, which is consistent with clinician reticence found in the literature (Bernal & Coolhart, 2012; Khatchadourian et al., 2014; Swann & Herbert, 2000). This calls into question the extent to which this harm is evidence-based and truly about physiological risks, or whether social factors (e.g., family relationships) or cisgender bias (e.g., belief that it is better to be cisgender than trans) are at the root of these concerns about the safety of hormone therapy.

The importance of parental involvement was a prominent theme in this study, with participants citing directly from the literature to explain why obtaining parental support or consent was a priority in their work with trans youth, and framing proceeding without such support as a harm that might outweigh the benefits of hormone therapy. However, this literature was cited and taken up in practice without evidence of in depth analysis on the part of health care providers. The research is clear that youth who have parent support for their gender and gender health goals have better health outcomes than those without this support (Ryan et al., 2010; Travers et al., 2012; Veale et al., 2015), and that there are both distinct benefits of providing, and clear risks associated with withholding, hormone therapy (Antommara, 2014; Coolhart et al., 2013; de Vries et al., 2014; Delemarre-van de Waal & Cohen-Kettenis, 2006; Vrouenraets et al., 2015). While no research indicates that there are benefits to delaying hormone therapy while attempting to convince parents who are unsupportive of this intervention to move to a supportive stance, the available research on parental support seemed to be interpreted by participants in this manner.

New in this study was discussion of parental refusal to consent (or express support) for hormone therapy as medical neglect, which may be related to the rights afforded to youth in Canada, flowing from the United Nations Convention on the Rights of the Child (United Nations, 1989). Participants were uncertain of what constituted medical neglect and how reports

to appropriate authorities might be received and acted on. Legislation is clear about the need to report medical neglect, however the determination of when the harm threshold has been crossed can be challenging. In a situation where a trans youth requires hormone therapy and parents are unsupportive of this intervention, attention should be given to the capacity (and legal authority) of the youth to make their own health care decisions as well as the safety of the youth. If the youth does not have capacity and the parent is refusing consent for an intervention that is likely to have significant benefits, or if a youth with or without capacity is at significant risk of serious harm for any reason, health care providers may be compelled both legally and ethically to initiate intervention to protect the best interests of the minor (Diekema, 2004; Rhodes & Holzman, 2014).

While regret was generally raised in the context of gender affirming surgery within the literature, it was a common theme among participants in discussions related to potential hormone therapy-related fertility implications. Opinions on the significance of this potential harm were diverse and informed by a range of participant beliefs. Despite an acknowledged lack of evidence that such regret exists, some participants were concerned that this phenomenon may currently exist and later surface. Fear of doing long-term harm was expressed and manifested in the form of imagined dilemmas, which in turn influenced beliefs and actions. Bionormative assumptions regarding family creation were evident in some participant narratives. For example, uneasiness about adoption as a viable means of creating a family or the validity of deciding not to have biological children indicated potential normative biases about family creation.

Participants' connections to queer and trans communities appeared to impact their beliefs about family and their comfort with supporting diverse plans for creating their families in the future. For example, as noted in the literature, chosen families have long been an important part of queer

and trans culture, as people creatively construct non-related queer and trans families to foster community, support, and solidarity (Knauer, 2016). Greater understanding of queer and trans family creation and awareness of how bionormativity may impact provision of gender health care may be beneficial for health care providers, especially those with limited connection to queer and trans communities.

One clear issue of justice related to the aforementioned biases faced by trans youth when seeking health care. Normativities influence how health care providers view gender, sexual orientation, and family (Baylis & McLeod, 2014; serano, 2017). The impacts of societal stigma on trans youth were recognized and considered in care delivery, however participants did not focus on how normativities impacted the care they themselves provided. The shift from viewing certain genders pathologically to seeing gender diversity as a natural part of human diversity is not ubiquitous (Erickson-Schroth & Boylan, 2014b; Menvielle & Gomez-Lobo, 2011; Reisner, Bradford, et al., 2015b). It is possible that the impact of belief tension on ethical decision-making could be addressed through examination of these normativities, as locating the source of tension outside the individual health care provider may more easily facilitate examination of factors contributing to inconsistencies in practice.

In accordance with international human rights agreements, non-discrimination, giving youth best interests primary consideration, healthy development, involvement in decision-making, access to health care, and attainment of the highest possible standard of health are all rights belonging to youth (United Nations, 1989; World Health Organization, 2006). All health care provider participants were committed to ensuring access to care for trans youth, though they commonly highlighted resource scarcity issues (e.g., lack of trained providers, mental health resources, supports for parents) as factors making it difficult to provide the best possible care for

all youth. These challenges were discussed as ethical issues by some participants. While cost, lack of insurance coverage, lack of family support, uninformed health care providers, and geographic location are identified as barriers to care, these are not typically explicitly framed in terms of ethical principles in the youth gender health care literature (Clark et al., 2017; Reisner, Bradford, et al., 2015b; Rosenthal, 2014).

Issues of rights and resource scarcity may both be addressed through giving attention to the variability in service models and the evidence, beliefs, and biases on which these are built. Health care providers are the historic gatekeepers of prescribed hormone therapy, though they may have no relevant lived experience, and limited understanding of, or contact with, the worlds on the other side of this gate. Informed consent care allows trans individuals to open this gate for themselves, when they are ready, provided it is safe to do so. While longstanding pathologization of trans experiences has been addressed in part through informed consent care for adults (Cavanaugh et al., 2016), extensive psychological assessment remains part of youth gender health care in many settings. This continues within the context of ongoing youth mental health care resource scarcity challenges, coupled with a very limited supply of mental health care providers with experience working with trans youth. As seen in this study, youth gender health care, including provision of hormone therapy, is being successfully delivered in primary care settings where mental health screening is a routine part of care. Reserving specialist care for trans youth with complex mental health concerns and delivering care for youth without such challenges through primary care settings holds significant potential for alleviating system strains, increasing access (e.g., timeliness, services closer to home), and improving health outcomes. Moving forward, it will be important to ensure policy and practices are both empirically and

philosophically grounded in order to develop more just and equitable health care systems for trans youth and their families.

5.1.4.1 Limitations

Data collection in this study was limited to single, one-hour interviews with each participant, which did not allow for in-depth exploration of health care provider beliefs or changes in approach over time. The sample size did not allow for reporting according to discipline or other demographics in order to protect the privacy of participants. The model has not been tested in the field or validated with study participants. The foundation for ethical analysis is limited to a North American bioethics framework. Finally, bias is possible, related to who elected to participate and what information was shared.

5.1.4.2 Recommendations

One objective of this paper was to determine how to better support health care providers in their ethical decision-making. The Belief-Dilemma-Action model provides a foundation for development of a teaching tool and ethical decision-making framework for youth gender health care. Training to support ethical decision-making competencies should address several issues identified in this research: belief congruence and tension; the law; capacity evaluation; complex family situations; evidence-based practice; and cisnormative, heteronormative, and bionormative biases. Socioculturally-driven biases and imagined dilemmas may be addressed through integration of lived experiences of trans youth and their parents into training, alongside empirical data. Ethical decision-making in practice may also be supported through the integration of additional ethical frameworks. For example, relational ethics provides a foundation for exploring

the ways in which ethics are enacted in health care interactions (Bergum, 2013), queer bioethics examines issues particular to queer and trans populations (Roen, 2016), and justice-doing addresses ethical practices within social contexts (Reynolds, 2011). Development of practice guidelines for ethical decision-making with trans youth and parents would be of benefit; however, they must be tailored to specific legal and cultural contexts. Policy to support appropriate resource allocation, as well as consistent, empirically and ethically sound approaches to clinical practice with trans youth (e.g., those with complex family situations), may support health care providers in navigating ethically complex situations surrounding issues of justice for trans youth and their families.

In terms of research, this study confirms that longitudinal health outcomes data is needed to address health care provider concerns about long-term effects of hormone therapy for youth and potential future regret related to fertility (Vrouenraets et al., 2015). It is also recommended that the Belief-Dilemma-Action Model be tested in as an analytic tool with health care provider responses to specific scenarios within youth gender health care. It may also be extended to other areas of health care to identify beliefs, dilemmas, and actions relevant for work with other marginalized populations (e.g., medical aid in dying and transplant eligibility evaluation). Research could also aid in evaluating the effectiveness of teaching tools, ethical decision-making frameworks, or practice guidelines developed with this model as a foundation. Further investigation of the ethical issues raised by these health care providers, specifically around family conflict, consent, fertility-related regret, and justice, would enhance the small body of youth gender health ethics literature.

5.2 “The Edge of Harm and Help”: Ethics and Gender Health Care for Transgender Youth with Complex Family Situations

Transgender (trans) youth are coming out in greater numbers and at younger ages than in previous generations (Alegría, 2016; de Vries & Cohen-Kettenis, 2012; Mallon, 2009; Olson J et al., 2011; Spack et al., 2012). A growing body of evidence supports the effectiveness of hormone therapy for trans youth who require it and documents the role strong parental support can play in trans youth wellbeing (Clark, Veale, Greyson, & Saewyc, 2017; Delemarre-van de Waal & Cohen-Kettenis, 2006; Khatchadourian et al., 2014; Olson J et al., 2011; Ryan et al., 2010). Access to hormone therapy is medically necessary for many trans youth, however family dynamics surrounding gender health goals are often complex and can result in barriers to youth accessing needed health care (Romero & Reingold, 2013; Swann & Herbert, 2000). Many parents find themselves in unfamiliar territory when their child discloses that they are trans and need to start hormone therapy. Parents may feel uncertain about how best to support their child, and some refuse to endorse hormone therapy. When youth who need hormone therapy seek this care without parental support for their gender health goals, health care providers may encounter ethical dilemmas surrounding what is in the best interests of the youth. In this paper, the Belief-Dilemma-Action Model of ethical decision-making (introduced in section 5.1 of this dissertation) is used to support analysis of health care provider ethical decision-making related to a complex family scenario. This is followed by an exploration of trans youth experiences with contrasting health care provider approaches to gender health care.

5.2.1 Background

For trans youth, the experience of gender differs from the sex assigned at birth (Frohard-Dourlent et al., 2016). To support gender health—the ability to live in the gender that feels most real and/or comfortable—some youth require hormone therapy (Ehrensaft, 2016; Mallon, 2009; Wylie et al., 2016). The benefits of this intervention include the development of secondary sex characteristics that align the body with gender, as well as improved physical and psychosocial health outcomes, while the risks of withholding or delaying access to care (e.g., self-harm, suicidality, violence) can be significant (Antommaria, 2014; Coolhart et al., 2013; de Vries et al., 2011, 2014; Vrouenraets et al., 2015). There are no medical alternatives that can produce the same desired effects as hormone therapy. Strong parental support and family connection are associated with better mental health, self-esteem, and life satisfaction among trans youth (Travers et al., 2012; Veale et al., 2015), and correlations have also been documented between access to health care and stronger mental health outcomes (Clark et al., 2017). However, research has yet to address how health outcomes are impacted when parental support functions as either a facilitator or barrier to accessing needed gender health care.

In the Canadian province of British Columbia, legislation grants minors the legal authority to consent to health care when they have the capacity to do so, regardless of age, providing their health care provider deems the care to be in their best interests (Infants Act, 1996). Capacity is decision-specific, and evaluated based on a youth's ability to: understand the proposed treatment, including the risks, benefits, and alternative; ask relevant questions; and make a decision consistent with their values (Cummings & Mercurio, 2010). For health care interventions with higher potential implications, youth are required to demonstrate greater capacity (Canadian Paediatric Society, 2004). Many youth have the capacity to make specific

health care decisions, but when such capacity is not present, they require the assistance of a proxy decision-maker, a role typically fulfilled by a parent (Goodlander & Berg, 2011). Parental or surrogate support can enhance the decision-making capacity of youth and decision agreement among a youth and their parents may increase health care provider comfort with the decision being made (Goodlander & Berg, 2011; Kuther & Heights, 2003). Health care providers must act in the best interests of the youth they serve, and it is expected that parents will as well, particularly when they are making health care decisions on behalf of their child (Canadian Paediatric Society, 2004). However, ethically complex situations may emerge when there is conflict among youth, parents, and health care providers regarding the best interests of a minor (Canadian Paediatric Society, 2004).

‘Best interests’ is the standard by which health care decision are made when people lack capacity to make such decisions from themselves (Diekema, 2011; Rhodes & Holzman, 2014). The risks and benefits of treatment and non-treatment options should be weighed and a course of action selected that meets both “a minimum standard of acceptable care (Kopelman, 2007, p. 189) and protect a person’s “physical, psychological and emotional safety, security, and wellbeing (Family Law Act, 2011). The best interest standard is helpful in clinical decision making; however, is considered problematic, as it is a subjective measure and reasonable people may not agree as to what this means in a given situation (Beauchamp & Childress, 2013; Kopelman, 1997; Rhodes & Holzman, 2014). While it is generally assumed that parents want what is best for their children, it is recognized that parental involvement in health care decisions may, in some circumstances, lead to harm (Unguru, 2011). It is therefore incumbent on health care providers to intervene if parents refuse treatment that is likely to be highly beneficial, for example, life-saving cancer treatment (Rhodes & Holzman, 2014). Many approaches have been

proposed to guide health care provider decision-making when a parent refuses recommended treatment, such as allowing parents to choose only from a range of medically reasonable alternatives or the not unreasonable standard (McCullough, 2010; McDougall & Notini, 2014). A commonly used alternative to the best interests standard is the harm principle, which provides a framework for deciding when to seek intervention in response to an imminent and significant risk of serious and preventable harm (Diekema, 2004, 2011; Schoeman, 1985). However, critics of the harm principle, as well as the best interests standard, highlight the challenges to procedural justice faced by those seeking to arrive at consistent judgments in support of equitable treatment under similar circumstances (Birchley, 2016; McDougall, 2016; Powell, 2011).

Myriad issues arise in the gender health care literature regarding youth capacity to consent to care, confidentiality, benefits of parent support, harms of parental rejection, benefits of hormone therapy, harms of withholding or delaying hormone therapy, and equitable access to care (Bernal & Coolhart, 2012; Cavanaugh et al., 2016; Giordano, 2007, 2013b; Holman & Goldberg, 2006; Huft, 2008; Rosenthal, 2014; Shield, 2006; Stein, 2012; Vrouenraets et al., 2015). Many of these concerns remain unresolved in the literature, which is reflective of ongoing debate about clinical practices for youth gender health care. In practice, health care providers may encounter dilemmas when there is no course of action without significant drawbacks, as ethical principles such as autonomy, beneficence, non-maleficence, and justice come into conflict. As previously discussed in section 5.1 of this dissertation, a key ethical issue identified by youth gender health care providers in British Columbia involved providing ethically appropriate care for trans youth whose parents did not support their decision to initiate hormone therapy.

5.2.1.1 Purpose

This study addresses ethical decision-making in youth gender health care practice involving complex family situations via two research questions. First, how do health care providers construct and resolve ethical dilemmas related to complex family situations that emerge in hormone therapy readiness assessment/care planning with trans youth? Second, how are health care provider approaches to hormone therapy readiness assessment/care planning experienced by trans youth? The first question was addressed through health care provider responses to a hypothetical practice scenario and the second was explored through trans youth descriptions of their experiences with care.

5.2.2 Methods

This paper is part of a study on decision-making processes surrounding hormone therapy initiation for trans youth, utilizing a qualitative, grounded theory design. The boards granting research ethics approval for this study were the University of British Columbia Behavioural Research Ethics Board, University of British Columbia Children's and Women's Health Centre of BC Research Ethics Board, the Vancouver Coastal Health Research Institute, and the Northern Health Research Review Committee.

Data for this analysis were collected during one-hour, semi-structured interviews conducted with ten health care providers and five trans youth from British Columbia, Canada. Eligible health care provider participants were offering hormone therapy readiness assessment/care planning, either privately or publicly funded, for youth in the 14-18 year-old range (e.g., psychologist, psychiatrist, family doctor). Following discussion of ethical dilemmas encountered in clinical practice, health care provider participants reviewed and responded to a

hypothetical practice scenario involving a youth who was attempting to access hormone therapy while his mother was unsupportive of this intervention (figure 5.3). The trans youth participants were aged 16-18 and had lived experiences that were reflective of the practice scenario presented to the health care providers, in that they had both attempted to access hormone therapy and reported that their parents were not supportive of them doing so. Youth interviews centered around their experiences making and enacting decisions about initiating hormone therapy.

The hypothetical practice scenario was designed to elicit data specific to health care provider ethical decision-making processes, allowing for observation and follow-up questioning in the moment. It allowed for the development of insight into the initial responses participants had to a common scenario. This initial response is arguably an important aspect of the ethical decision-making process, as it may represent the moment when a health care provider first decides whether an ethical dilemma exists in a given situation. Consistent with the function of elicited documents in constructivist grounded theory, use of the hypothetical scenario allowed for examination of conditions connected with actions and processes, allowing for comparison of decision-making processes across this cohort of health care provider participants (Charmaz, 2014).

You receive a referral for a 15-year old youth: Aidan identifies as a transguy. He is out to close friends and family. He reports that his father is fairly supportive, but lives in another province, travels a lot for work, and does not see Aidan much. Aidan lives with his mother, who is refusing to acknowledge his gender identity, name, or pronouns, and does not support transitioning at school or starting hormone therapy. Aidan would like to start testosterone as soon as possible, and to have chest surgery in a couple of years. Aidan is clear about his identity and need for hormones. When asked about what would happen if he started hormones while living with his mother, Aidan states that he will be able to hide it from her until she comes around to the idea.

Figure 5.3 Practice Scenario

Audio-recorded interviews were transcribed, accuracy-checked, member-checked (when preferred by the participant), and analyzed with the assistance of NVIVO software. The data analysis for this paper employed a constructivist grounded theory approach (Charmaz, 2014), through which health care provider and youth data were coded using constant comparative methods. Bioethics principles of autonomy, beneficence, non-maleficence, and justice were sensitizing concepts within this analysis (Beauchamp & Childress, 2013). Finally, the Belief-Dilemma-Action Model of ethical decision-making in youth gender health care was tested as a framework to structure this analysis (figure 5.4).

The Belief-Dilemma-Action Model, introduced in section 5.1 of this dissertation, comprises three main constructs: beliefs, dilemmas, and actions, which interact as health care providers encounter ethically challenging situations in the context of youth gender health care (figure 5.4). These interactions occur within a specific sociocultural context and are influenced by previous experiences providing this care. The constructs of dilemmas and actions in this paper were analyzed through data from health care provider discussions of the given practice scenario. Beliefs expressed by these health care providers in their full interviews were analyzed in relationship to the dilemmas and actions described in their responses to the scenario.

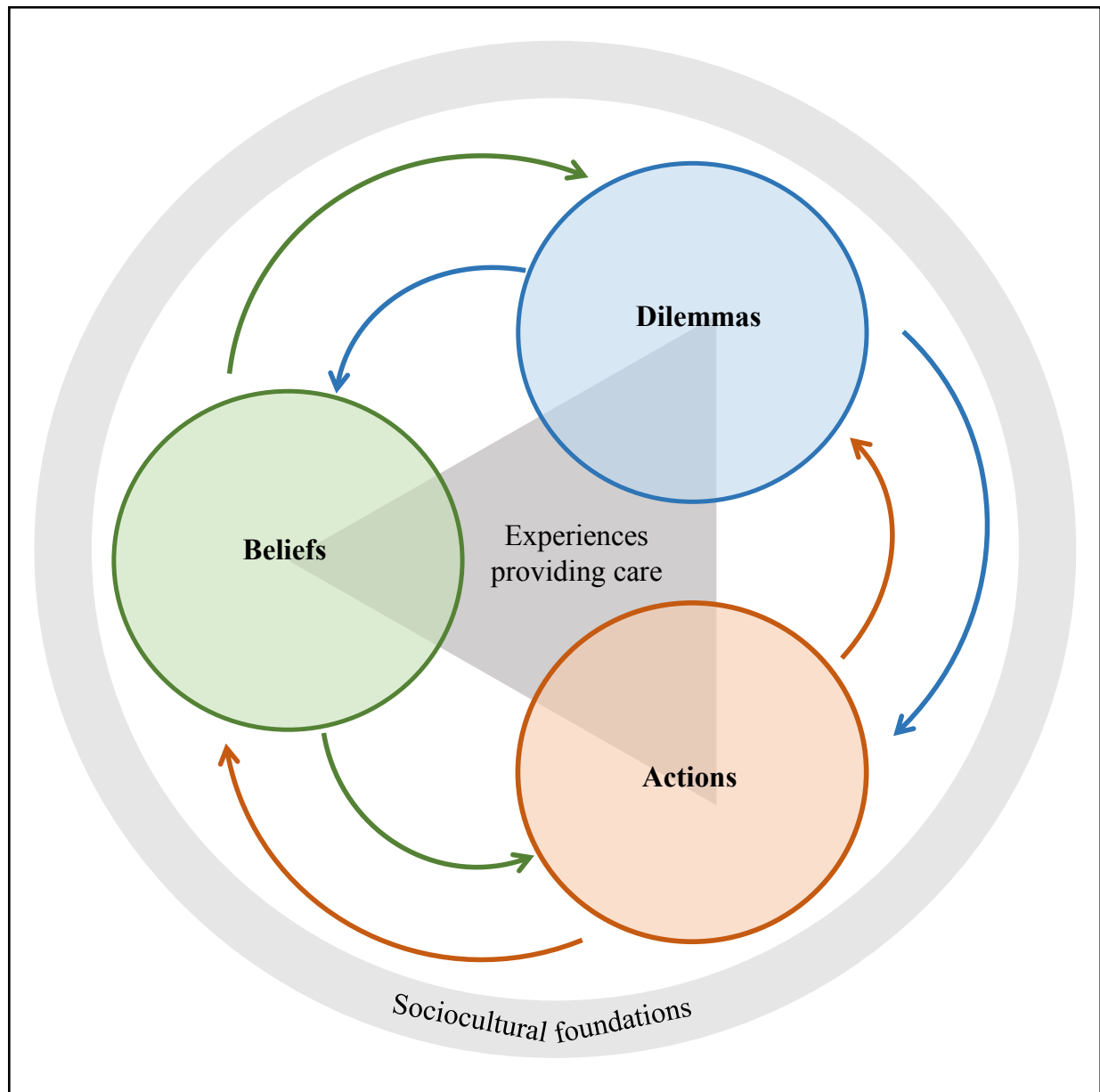


Figure 5.4 Belief-Dilemma-Action Model

5.2.3 Results

Health care providers were asked to review a practice scenario involving a complex family situation (Figure 5.3), comment on ethical issues that arose for them, and describe how they would approach the situation in their practice. Participant responses were grounded in a

North American bioethics framework, drawing on the principles of autonomy, beneficence, nonmaleficence, and justice (Beauchamp & Childress, 2013), without identification of other ethical frameworks. Therefore, the results are framed here in terms of these four principles.

5.2.3.1 Dilemmas

The ethical dilemmas identified by health care providers can be described in four ways, based on the bioethical principles at play in the construction of these dilemmas: the harm dilemma, the benefit-harm dilemma, the autonomy-benefit-harm dilemma, and the non-dilemma.

5.2.3.1.1 Harm Dilemma

One framing of this situation focused on potential harm to Aidan if he were to proceed with hormone therapy without the support of his mother. According to one health care provider, “It’s about the mother-son relationship, because he’s 15 and he’s living with Mom, I know autonomy’s in there, but this is my bias, [autonomy’s] not even on the table.” In this participant’s appraisal, Aidan’s statement about hiding hormone therapy from his mother was interpreted as evidence of incapacity to make this health care decision. Autonomy was identified as a principle, then discounted as relevant to ethical deliberation about this scenario without differentiation from decision-making capacity.

5.2.3.1.2 Benefit-Harm Dilemma

Weighing harm and benefit was another way participants approached this situation. Health care providers identified the benefits of hormone therapy and the risks of moving forward without parent support as primary issues. For example, “I think the main thing here is what’s

going to happen if he loses his mother's support...It looks like he's clear about his identity, and he's going to need care at some point." Another way of looking at the benefit-harm dilemma was to consider the benefits and harms of moving ahead with hormone therapy and the benefits and harms of delaying while attempting bring the parents to a more supportive stance. As described by one health care provider: "The dilemma for me is more the psychosocial aspect of it and how it will feel if they don't transition immediately...You know, there's a difference between would like to start as soon as possible versus is desperate to start as soon as possible and is hurt by not starting as soon as possible."

5.2.3.1.3 Autonomy-Benefit-Harm Dilemma

Autonomy was introduced into some discussions in terms of the importance of respecting Aidan's gender and need for hormones, alongside the potential benefits and harms of proceeding with hormone therapy initiation. Respecting youth autonomy and rights to access care were described this way: "If they can consent to it—and they can legally—and it's informed consent, they know they they're doing, they know what they're getting into, then I would be supporting them to do that, even if it's against their parents' wishes." In the following quote, a health care provider grappled with a potential lack of health care decision-making capacity, while wanting to find the best path forward that respected autonomy, avoided harm, and ensured benefit:

The slam dunk case of the kid who's completely aware of their gender identity, but not necessarily very good at understanding consequences...so capacity [is an issue] for sure. It's hard to name. I don't want to harm him by not starting as well, and I also don't want to harm him by starting. That's a really, really hard one. It's really the edge of harm and help.

5.2.3.1.4 The Non-dilemma

The final group of participants talked about this scenario as one they would be comfortable encountering in practice or one with which they had prior experience. While ethical principles were discussed—autonomy, beneficence, non-maleficence, and justice—the situation was not framed as a dilemma; rather a typical course of care was described. As one health care provider stated, “This would be one of those straightforward things... having to balance out the mental health of the child and what kind of effect it’s going to have if they need to wait.” Aidan was described as an appropriate candidate for hormone therapy, whose autonomy should be respected, and whose best interests needed to be addressed through care planning that accounted for potential harms that might emerge. This participant addressed autonomy, risks, benefits, as well as justice, with a focus on increasing awareness and support within the community at large, to in turn create a more supportive social context for trans youth:

In terms of ethical issues, obviously, Aidan’s autonomy. He’s very clear on what he wants to do. And I suppose part of the assessment is just to kind of figure out, is Aidan in a place where he’s able to weigh those pros and cons and make that decision, that informed consent...and maybe the justice thing...I think it’s making a difference in the people around you and trying to really increase awareness and educate.

Overall, the dilemmas described and the bioethics principles used in constructing them can be placed on a continuum, as illustrated in Figure 5.5. Non-maleficence was universally considered, as all health care providers highly valued their responsibility to ‘do no harm’. As beneficence, autonomy, and justice were factored into discussions, different framings of the scenario emerged, including viewing this situation as a non-dilemma.

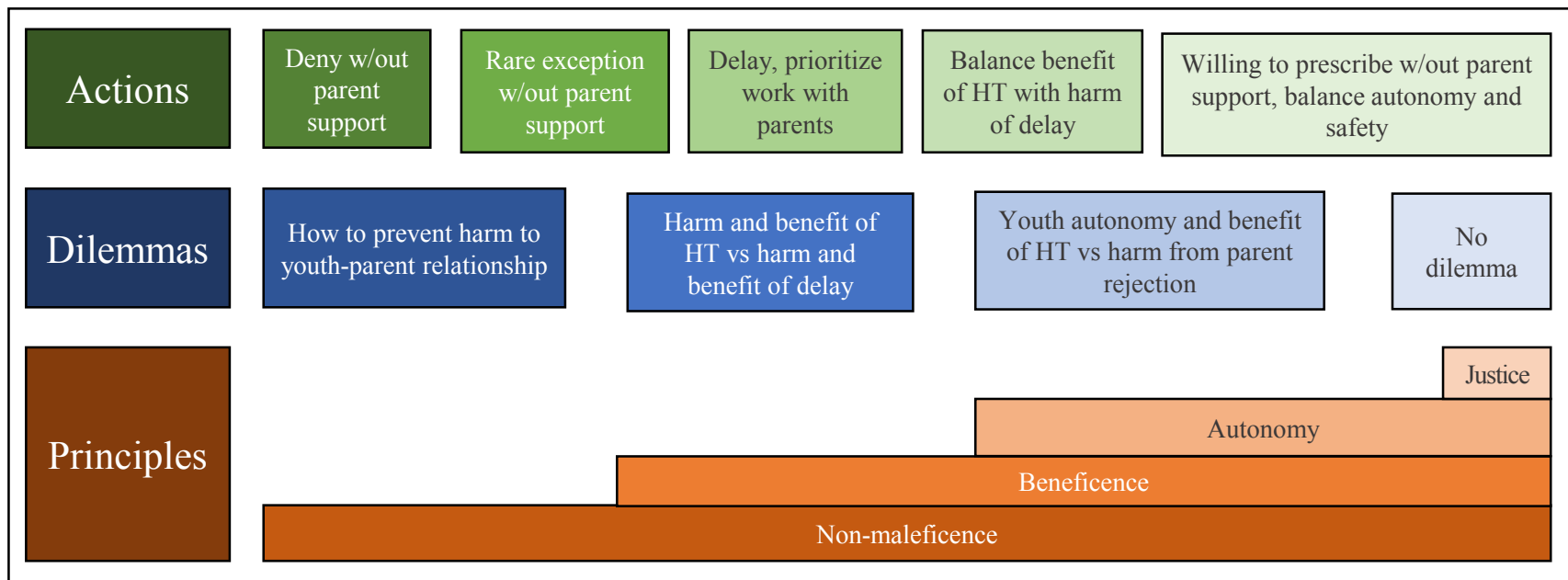


Figure 5.5 Ethical Principles, Dilemmas, and Actions of Health Care Providers

5.2.3.2 Actions

The main action of interest in this study related to the decision about whether and when to initiate hormone therapy for Aidan. The continuum of dilemmas aligns with a continuum of actions following decisions about whether and when to proceed with hormone therapy initiation for Aidan. Figure 5.5 illustrates how the principles applied, dilemmas constructed, and courses of action proposed aligned across these health care provider interviews.

On one end of the spectrum was the action of denying access to hormone therapy in the absence of parent support, exemplified by this health care provider's statement, "It would be harmful to give this kid hormones with his mom not being aware." The course of care described by some participants involved working with Aidan and his mother in an attempt to find a plan that worked for both of them. For example, "Could she understand the impact of support versus non-support on his overall developmental outcome, and could we negotiate some kind of process that would satisfy his needs and hers?" Another provider indicated an unwillingness to support hormone therapy, approaching the situation with interim care to support Aidan's gender health goals: "We just have to be patient with them and help Aidan understand that his relationship with his mother is too important to destroy it over something like this... Tell him to hang on."

In the middle of the action continuum was delaying access to hormone therapy while prioritizing work with parents to bring them on board. These participants expressed a preference to delay hormone therapy while also acknowledging that if Aidan were experiencing an extremely high level of distress, the harm from delaying could outweigh the benefits of waiting to bring his mother on board. These health care providers were willing, in extreme cases, to support hormone therapy initiation without having parents on board. As one participant stated:

My approach would involve some stalling....Stalling would also give you some time to figure out anything else for this guy so that you wouldn't have to [initiate without parent

support]...he's going to need hormones at some point...can we arrange that this happens for him in a safe way so that he's supported?

The approach to prioritizing family support involved strongly encouraging both the youth and family to engage in this process.

Finally, there were participants who expressed willingness to take action to initiate hormone therapy without parental support, assuming Aidan demonstrated decision-making capacity and his safety was accounted for. For example, "I do think this is someone I would [support hormone therapy initiation for]. It's appropriate in every way, except there's this social situation that isn't ideal." Parental support was preferred, but out of respect for Aidan's autonomy, this health care provider emphasized asking for his consent before initiating contact with his mother: "We would prefer to get the family on board in many ways, so I would ask the client, 'I'd really like to meet with your mom if you think that's okay.'...If they are absolutely against it, then I wouldn't push them." These providers talked about evaluating the family resistance and safely moving forward with hormone therapy in terms of collaborative, patient-centered care. One health care provider summarized this approach as follows:

My role as clinician would be to do my best to assess the situation, problem-solve the situation, connect that youth with support and make a safety plan, and provide care when I feel ready to do that and we feel ready to move forward with it together, and then continue to provide close follow-up and support, and problem-solve anything that does come up with them.

5.2.3.2.1 Beliefs

In terms of beliefs, it should be noted that all participants believed parental support was beneficial to trans youth and that they had an ethical duty to do no harm. However, many participant beliefs—like their application of ethical principles, construction of dilemmas, and proposed actions—can be placed on a spectrum. Those who were focused primarily on harm

tended to question youth capacity to consent to health care in general, view identity within adolescence as fluid, and believe in the importance of in-depth psychological evaluation prior to initiation of hormone therapy. On the other end of the continuum, providers who accounted for autonomy and justice in their framing of this scenario expressed beliefs that most youth possess the capacity to consent to their own health care, youth have the right to make decisions about their care, and the health care provider role was to facilitate care at the right time via a patient-centered approach.

5.2.3.3 Interactions

The Belief-Dilemma-Action Model illustrates interactions that take place among the three main constructs. For example, the beliefs that youth identities are fluid and that youth lack capacity to make their own health care decisions were associated with constructing harm-focused dilemmas without taking autonomy into account. In contrast, belief that youth with capacity have the right to access care without parental involvement was linked with a non-dilemma view of this scenario, allowing health care providers to plan move directly to action. These findings are consistent with interactions among main constructs illustrated in the Belief-Dilemma-Action Model, specifically around beliefs both influencing dilemma construction and facilitating direct action. As shown in Figure 5.5, participants who framed a dilemma solely in terms of non-maleficence made different decisions about hormone therapy initiation than those who included autonomy and justice in their deliberation. Finally, prior clinical actions were found to influence both beliefs and dilemmas of many participants. Health care providers who discussed previously having high levels of success bringing parents on board focused on benefits of parental support in their dilemma construction. One participant who did not identify an ethical dilemma in this

situation discussed the impact of previous experience initiating hormone therapy without parental consent on current ethical deliberation and beliefs about best interests of youth:

Sometimes you've just got to not be afraid to do everything you need to do to feel safe enough with the situation, but then take the appropriate actions as a clinician and be there to see what happened and continue to provide support as needed. It doesn't always play out in the way that you're fearing. Sometimes it plays out in a way that's actually okay.

The Belief-Dilemma-Action Model illustrates how health care provider beliefs, dilemmas, and actions are interwoven in ethical and clinical decision-making and helps to shed light on possible sources of disagreement about youth gender health care practices. The broad range of health care provider actions highlighted here raises questions about inconsistencies in the provision of care, which may impact equity for trans youth. A key piece of information necessary for understanding the ethical implications of various approaches to care is documentation of relevant lived experiences of trans youth, a component typically absent from ethical discourses regarding youth gender health care. Therefore, the interview data of youth participants whose experiences closely reflected the scenario presented to health care provider participants are included to further inform this analysis.

5.2.3.4 Impacts on Trans Youth

Youth participants who had sought hormone therapy without parental support for this intervention described a range of experiences with health care providers and health care systems. The analysis presented here focused on qualitative descriptions of experiences with hormone therapy readiness assessment/care planning, which were found to be reflective of actions described by health care providers. Interestingly, youth described facing some of the same dilemmas as health care providers and presented varied perspectives on what was most salient to

them at the time they were seeking hormone therapy. This quote described one youth's experience managing personal safety within an unsafe home environment:

If I take hormones, my parents will realize differences in my body, and that's something I'm going to have to deal with. So it's kind of coming to terms with that and seeing what that would look like....this is a physical choice I'm making about my body that I really want to pursue, but my parents would feel entitled to kick me out for. So it's kind of coming to, when can I do this?

Meanwhile, the second quote centers around another youth's desire to maintain a strong relationship with a parent while still accessing hormone therapy:

I didn't want to ruin my mom's and mine's relationship again because I knew my safety line of moving in with my dad was kind of far away. And I didn't want to kind of just move out again, so it was a lot touchier territory, I guess. So at that time, I was like, well, I think I'm going to start going and getting psych eval. for it, because I might as well start somewhere. And at least if I can somewhat convince my mom or even do it on my own without parental consent.

Youth described not being given a choice about whether their parents were involved in their assessment/care planning process. One participant found family sessions with a health care provider to be a positive experience, stating this "helped [my mom] come to terms and deal with it, and understand my need for [hormone therapy]." However, required parental involvement presented a barrier to care for other youth. With parents unable or unwilling to meet with the health care provider, one youth had no option other than to terminate a first attempt at an assessment, even though the relationship with the health care provider and the overall assessment experience up to that point had been positive. This youth made a second attempt with another health care provider, who was already involved in their care for other reasons, and the parents were able to participate in this assessment process. Unfortunately, while the support seemed to be helpful for the parents, the youth found the health care provider to be inexperienced and the process neither comfortable nor affirming, leading to termination of this pre-existing health care provider relationship.

Two youth in this study had accessed hormone therapy without parental support for their gender health goals or parent involvement in the assessment process. They both reported that hormone therapy was necessary and the right decision for them, shared challenging journeys along the way to accessing care, and expressed gratitude for support from professionals. One youth, who accessed hormone therapy while living independently from her parents, described a positive and valued ongoing relationship with the health care provider who conducted her hormone therapy readiness assessment. The other youth lived at home with parents who were consistently unsupportive of her process of finding health care providers, completing an assessment, and taking hormones. Surrogate support was described as key in her experience, “[The youth worker] was basically like my second mother, and she basically did what my mother was supposed to do, and it was really, really helpful, and she brought me so far.” Reflecting on the experience with her parents, she commented, “They’re coming around. They’re still kind of uncomfortable with the whole, like, me transitioning thing, but slowly I kind of added some girl clothes to my wardrobe until now, where I just completely present as female. And they just can’t do anything about it.”

5.2.4 Discussion

Health care providers were asked for their initial reaction to a practice scenario involving a complex family situation. While this ‘gut instinct’ response is not akin to in-depth ethical deliberation on the given scenario, this approach allowed for insight into ethical thinking, in particular, whether an ethical dilemma was identified within the scenario. This complex family situation was one with which health care providers were universally familiar. However, while it was not the first time they had encountered this general practice scenario, it may have been novel

for some to discuss this in ethical terms. Health care provider participants generally used a North American bioethics framework to talk about their ethical thinking and actions, therefore this underpins the analysis and discussion of the data. The Belief-Dilemma-Action model was a useful analytic tool for identifying interactions among beliefs of health care providers, their constructions of ethical dilemmas (or non-dilemmas), and their actions.

5.2.4.1 Ethical deliberation

In health care, there is a duty to ‘first, do not harm’, drawn from the Hippocratic oath. The principle of non-maleficence was identified as important by all participants, and for some was the sole focus of their ethical analysis. Risks and benefits related to hormone therapy initiation were generally acknowledged, but weighed differently. Some of the deliberation appeared to be influenced by the type of research available regarding parental support. There is clear evidence that trans youth who are supported by their parents have better health outcomes (Travers et al., 2012; Veale et al., 2015), however there is a lack of research to balance this, specifically on the impacts of denying, delaying, or initiating hormone therapy for youth whose parents are not supportive of the intervention. While participants frequently cited concern that youth would experience rejection and loss of parental support, rarely present in their ethical analyses was the idea that youth experiencing gender-based parental rejection would not be losing support if they initiated hormone therapy, as they could not lose what they did not already possess. As documented in section 4.1 of this dissertation, youth who initiated hormone therapy without parental support for this intervention reported: positive outcomes surrounding wellbeing, development of new skills and self-efficacy, no regret about treatment decisions, and in some cases, increased parental acceptance following hormone therapy initiation. Reframing of existing

parental support research in combination with these new findings may challenge health care provider beliefs regarding parental support and potentially shift both ethical framings and the actions that reinforce beliefs about families.

There was a strong reliance on the available parental support research among health care providers who are represented on the left side of figure 5.5. Moving toward the right side of the continuum, participants took youth autonomy into account alongside consideration of harm and benefit. Honoring the autonomy of young people to make their own health-related decisions was given greater weight by some participants, with the imposition of required parental support considered a violation of autonomy for these youth who did not want to involve their parents. When autonomy was given more weight in ethical analyses, health care providers were more open to the possibility of initiating hormone therapy without parental consent. Discussions of hormone therapy initiation also included reference to the law governing youth consent to health care in British Columbia, as well as to confidentiality.

5.2.4.2 Best Interests and the Harm Principle

At the root of health care provider discussions of the practice scenario were the legal and ethical imperatives to act in the best interests of youth. For youth with capacity, health care providers in British Columbia would legally need consent of the youth, not the parent, to initiate hormone therapy. However, many struggled with the best interests component of the *Infants Act*, specifically with how to determine what was in a youth's best interests. Approaches ranged from prioritizing the youth-parent relationship over the benefits of hormone therapy (except in cases of clear abuse or neglect) to supporting a youth's decision to initiate hormone therapy once adequate social supports (parental, professional, and/or chosen family) were in place. The latter

approach afforded youth greater autonomy in deciding when to move forward with hormone therapy, as health care providers assumed a role of ensuring the plan was safe enough. While health care providers are not required to compromise their professional integrity by providing an intervention they view to be against the best interests of an individual, they are compelled both ethically and legally to act to prevent harm to a minor, although the exact mechanism to do so may be unclear. The broad range of proposed actions seemed to stem, in part, from the law's lack of clarity about the definition of best interests, leaving this standard open to wide interpretation and influence of health care provider beliefs.

The best interests standard itself is a controversial one, faulted for being impractical to apply, a criticism that seems warranted in the context of this study (Diekema, 2004). The harm principle has been proposed as a practical alternative to the best interests standard, supporting intervention when there is an imminent and serious risk of significant, preventable harm to a child (Diekema, 2004; Schoeman, 1985). For example, the harm principle is useful in determining when parental decision-making authority should be overridden due to failure to consent for a treatment that is likely to have significant benefit and in helping health care providers identify at what point they need to act to prevent serious harm (Diekema, 2004). For example, parents may act in ways that others perceive are not fully in the best interests of their child, but when they do so without placing a child at any significant risk of serious harm invoking the harm principle is not warranted.

However, critics of the harm principle find this approach similarly problematic to the best interests standard in terms of subjectivity and challenges in rendering consistent judgments (Birchley, 2016; McDougall, 2016). Other avenues to working with proxy decision-makers in pediatric care have been proposed (McDougall & Notini, 2014). For example, Rhodes and

Holzman (2004) propose a ‘not unreasonable standard’ for proxy decision-making, arguing that health care providers have a duty to evaluate both the capacity of a proxy decision-maker and the reasonableness of the decision at which they arrive. Another approach is to allow parents to choose only among medically reasonable alternatives (McCullough, 2010; McDougall & Notini, 2014). McCullough (2010) views parents and health care providers as co-fiduciaries regarding the health of a child, assigning responsibility to the health care provider for presenting all medically reasonable alternatives for care, and limiting the parent(s) to choosing among those alternatives (without allowing rejection of all such options). However, the approaches outlined place a great deal of decision-making authority with health care providers, who may or may not take the values and perspectives of the youth and family into account when determining the range of reasonable options in a particular situation.

Application of the medically reasonable alternatives approach, the best interests standard, the harm principle, and the not unreasonable standard are examined in the following two sections within the context of the complex family scenario. From participant narratives, it was clear that if Aidan were situated in a home with parents who were fully supportive of hormone therapy, most health care providers would have endorsed moving ahead with this intervention. No one questioned the benefits of providing hormone therapy, and, without the confounding issue of insufficient parental support, concerns about consent and best interests would have been alleviated. In this scenario, the key factor in ethical deliberations was the lack of parental support for Aidan’s gender health goals.

5.2.4.3 Capacity and Autonomy

Ethical decision-making in this scenario should involve several components, including evaluation of Aidan's capacity and weighing of the four principles of bioethics. First, is Aidan capable of making a decision at this time about hormone therapy initiation? Does he understand the proposed treatment, is he able to weigh the relevant risks and benefits, and does he ask relevant questions? Is Aidan able to apply his own values in his analysis and make a decision that is both consistent with these values and consistent over time? Could additional or surrogate decisional supports (e.g., father, other relative, professional) enhance Aidan's decision-making capacity? The capacity evaluation should go beyond Aidan's understanding of the physiological risks and benefits of hormone therapy, and extend to his comprehension of the implications of enacting such a decision within his family and larger social context. In other words, integral to evaluating his capacity to make this specific health care decision is his understanding of the implications of enacting this decision in an under-supportive home or choosing to pursue alternate supports (e.g., changing living situation).

Respect for Aidan's autonomy to make a decision to start hormone therapy without his mother's support should be central to care planning, and if he demonstrates capacity to provide informed consent based on the criteria outlined, this should play a strong role in directing care (Canadian Paediatric Society, 2004). The only barrier to moving ahead with hormone therapy would be a determination by the health care provider that hormone therapy was not in Aidan's best interests, after balancing potential benefits, harms, impacts on autonomy, and justice of all reasonable approaches. It would arguably be challenging to establish that Aidan had the capacity to make this decision within the context of his family situation and to then deny access to hormone therapy on the basis that it was not in his best interests. However, in such a case, the

health care provider would not be obligated to support initiation of hormone therapy. If Aiden were found to lack capacity to make this health care decision, according to Rhodes and Holzman (2004), the health care provider would then be responsible for ensuring his parent possessed capacity to fulfil the obligations of a proxy decision-maker and that parental decision-making met the ‘not unreasonable standard’. Therefore, if hormone therapy were medically indicated for Aiden, according to this framework, refusal of hormone therapy could constitute an unreasonable decision on the part of the parent, thus disqualifying the parent from serving as Aiden’s proxy decision-maker for this decision.

5.2.4.4 Gender Health Care Considerations

As noted earlier, the best interests standard is problematic and value-laden. In gender health care, this is of particular relevance due to sociocultural complexities, including the pathologization of trans experiences and the potential impact of health care provider bias on care provision. The following considerations are relevant for health care providers evaluating what is in the best interests of a youth in this context. First, hormone therapy is effective in supporting gender health for many trans youth and there is no medical alternative available. Second, parental support is beneficial for trans youth who receive it, however, alternative supports (e.g., extended family, chosen family, professional) can be put in place for those who lack parental support. Third, following a gender affirmative model, only a youth can know their own gender and it is the youth who must decide if and when hormone therapy is needed to support their gender health goals. Lastly, in evaluating best interests, the potential harms of delaying or withholding hormone therapy (e.g., suicidality, self-harm, non-prescribed hormone use) need to be carefully weighed against risks of family-related harm (e.g., rejection, homelessness,

violence). Likewise, the potential benefits of initiating hormone therapy without parental support for this intervention (e.g., aligning body with gender, reducing distress and safety risks in the community, increasing health care skills and self-efficacy, increasing parental support following hormone therapy initiation) must be weighed against the potential benefits of delaying or withholding this care (e.g., increasing time to gain parental support). It was clear that health care providers in this study struggled with determinations of best interests and how to weigh what were perceived as immeasurable risks and benefits, especially those involving family relationships.

In situations such as these, it has been suggested that health care providers may find the harm principle helpful in guiding decision-making under some circumstances (Diekema, 2004). For example, if deciding whether to move ahead with hormone therapy for a youth when that young person does not yet possess full capacity to make this decision and their parents are unsupportive of hormone therapy initiation. Evaluation of the risks of harm from withholding, delaying, or initiating hormone therapy is necessary to determine whether a proposed course of action (or refusal of an intervention) would cross the harm threshold. The harm threshold refers to the point at which there exists an immediate and significant risk of serious harm that can be prevented through intervention. In order to cross the harm threshold, the potential harm would need to be immediate, preventable, significant, and serious (Diekema, 2004). These elements can be difficult to evaluate (Powell, 2011); however, if parents refuse care that is likely to be beneficial, health care providers have a duty to reject this refusal and take action to prevent harm to their patient (Rhodes & Holzman, 2014). Three potential harms relevant to youth gender health care are considered here, followed by an exploration of clinical applications of the harm principle.

First, the development of irreversible pubertal changes presents a significant risk of serious harm for some youth, due to psychological distress and unwanted physiological changes (accompanied by the potential need for subsequent medical treatment that may be more invasive, higher risk, and less effective than hormone therapy in meeting gender health goals). Unwanted pubertal changes are preventable with treatment, however the immediacy of this harm may be unclear and both the level of significance and seriousness must be assessed on an individual basis. It should also be noted that this harm is not a one-time occurrence, but can function as an ongoing and escalating harm, as additional and more pronounced pubertal changes emerge.

Second, the possibility of self-injury or suicide in the absence of hormone therapy may constitute an immediate and significant risk of serious harm. In such cases, failure to initiate hormone therapy could cross the harm threshold, warranting preventative action. If a youth is an appropriate candidate for hormone therapy, suicidal as a result of not having access to this care, and the parents are refusing to provide consent, this may constitute medical neglect and warrant intervention to override parental authority in order to protect the wellbeing of the youth. A prominent challenge for health care providers applying the harm principle in this situation is assessing how immediate and significant the risk of self-harm or suicide is for an individual youth. It is important to note that while the physiological effects of hormone therapy develop over many months, the short-term psychological and emotional benefits of hormone therapy initiation may effectively mitigate an identified potential harm of self-harm or suicidality; this idea is supported not only by data from the youth in this study, who described feelings of relief and improved wellbeing following hormone therapy initiation, but also through research on health care access in which more positive self-reported mental health status is correlated with access to gender-affirming health care (Clark et al., 2017). Therefore, hormone therapy may be

considered effective in preventing self-injury and suicide-related harms, making intervention in the absence of parental support justifiable.

Third, health care providers may be concerned that initiating hormone therapy for a capable youth could elicit a harmful response (e.g., violence) from a parent and hence consider delaying or withholding this care as a protective measure. Whether this constitutes a significant risk of serious harm, whether the harm is immediate, and whether it is preventable are all important factors. To act in accordance with the harm principle in this situation, the health care provider would consider whether it would be the prescribed hormone therapy that would move the situation across the harm threshold, or whether circumstances already constituted neglect or abuse on the part of one or more parents, thus warranting intervention to ensure youth safety with or without hormone therapy initiation. In other words, if hormone therapy were otherwise indicated, invoking the harm principle as a reason to withhold this treatment would need to be made on the basis that withholding treatment would be effective in preventing a serious harm that is highly likely to imminently occur.

In clinical practice, Diekema (2004) has established eight conditions as rationale for state intervention based on the harm principle in pediatric care. First, the refusal of consent must place the youth at “significant risk of serious harm” (Diekema, 2004, p. 252). Another consideration is imminence, both in terms of imminence of risk and the amount of time needed to produce a significant benefit from treatment or non-treatment, as a violation of autonomy may be greater for ongoing treatment than a one-time intervention. Third, the state intervention must be necessary to prevent harm. Rationale must also clearly include sufficient likelihood that infringing on parental or youth autonomy will result in intended benefits that outweigh potential harms, in other words, that such intervention is very likely to be effective in preventing harm.

Health care providers considering a parent's request to withhold or delay treatment (i.e., nonintervention) must evaluate whether the benefits of initiating hormone therapy outweigh the burdens more favorably than the parental request to withhold or delay access to this care. Other options to prevent serious harm that are more acceptable to the parent must be evaluated; however, with respect to hormone therapy, there are no alternative medical options that yield similar results, making it unlikely that this condition would be applied outside of a compromise regarding timing of initiation of hormone therapy. Procedural justice is addressed in the seventh condition, which requires that state intervention be generalizable to other similar situations. The final conditions that Diekema (2004) proposes is that most parents would agree that the intervention was reasonable. Unlike the seven previously outlined conditions, the eighth could be problematic in the context of hormone therapy initiation, or for other socially contested medical interventions (e.g., abortion), as state intervention to prevent harm would be based on an individual health care provider's judgment of whether most parents would agree that hormone therapy should be provided to a youth in the absence of parental consent. This does not ensure just treatment of trans youth, as it leaves their rights to access health care, to respect for persons, and to be protected from harm up to perceived values of a potentially uninformed populous regarding a socially contested issue. While some facets of applying the harm principle are straightforward, it requires health care providers to make subjective judgments about risk, such as evaluation of the potential level of harm associated with pubertal changes, suicide, or parent behavior, while relying in large part on youth self-report.

Two examples of ethical dilemmas that arise in other areas of youth health care are overriding parental and/or youth autonomy surrounding religious objection to a life-saving blood transfusion and mandated feeding of a youth with a life-threatening eating disorder. The harm

principle may be applied in ethical deliberations in both these situations. In the first scenario, providing a blood transfusion carries a significant benefit with a brief intervention in a situation where no treatment alternatives will yield the same results. The consequences of this intervention in terms of religious objection carry permanence, which must be considered as a potential harm, however the risk of death without intervention is typically given greater weight in such deliberations. Meanwhile, mandated feeding for a youth with a life-threatening eating disorder may involve weeks or months of treatment against the youth's will in order to achieve the proposed treatment goal, a goal which may or may not actually be achieved even with the intervention, making this intervention more difficult to justify.

Four considerations relevant to hormone therapy and the harm principle in the realm of youth gender health are offered here. First, hormone therapy is highly effective in alleviating gender-related distress and producing desired physiological changes. Second, there are no alternative treatments that are effective in addressing the gender health goals targeted by hormone therapy. Third, this is a partially reversible intervention with physical effects that take months or years to manifest, leaving ample opportunity to change the course of treatment, if needed. The final consideration is immediacy. While many of the outward physical effects of hormone therapy may take months or years to develop, initiating hormone therapy can result in immediate psychological and emotional benefits associated with gender affirmation by a health care provider, prevention of further unwanted pubertal changes, and understanding that desired physical changes will develop over time enabling the youth to achieve their gender health goals. Furthermore, trans youth in this study consistently expressed eagerness to access hormone therapy, and distress when it was withheld and relieved when it is provided. Ongoing treatment would then not be forced without a youth's consent/assent or constitute a violation of bodily

autonomy, but given against the wishes of a parent (who might or might not be the legal decision-maker), resulting in a different situation from that of mandated blood transfusions or feeding. While treatment will continue for decades for many trans youth, initiation of hormone therapy can swiftly achieve a treatment goal of reducing suicidality by providing relief from gender-related distress, while ongoing care functions to provide continued benefits and prevent further harm.

As discussed here, it is clear that the ‘best interests standard’ and the ‘harm principle’ can be difficult to apply in youth gender health care practice. The vagueness of the ‘best interests standard’ and the high threshold for invoking the ‘harm principle’ may leave unresolved ethical dilemmas regarding how to proceed with care, especially for youth with complex family situations. Judgements may be made based on the capability of the parent to serve as a proxy decision-maker and whether their decisions satisfy the ‘not unreasonable standard’. Another approach to require proxy decision-makers to choose only among medically reasonable alternatives (McCullough, 2010; McDougall & Notini, 2014). If refusal of hormone therapy is not presented as a medically reasonable alternative, the health care provider would be obligated take action to replace the parent as decision-makers if the parent refused all of the medically reasonable alternatives presented to them (McCullough, 2010). In summary, all of these ethical frameworks may provide guidance in the context of youth gender health care, however they are open to wide interpretation on the part of health care providers, leaving the field of gender health care open to continued inconsistent practices due to variability of beliefs and approaches to clinical care that fail to fulfil obligations related to procedural justice for trans youth and their families.

5.2.4.5 Justice

Justice was largely overlooked in the discussions of this practice scenario; however, it is important to consider, especially in terms of how health care decisions are made for youth who lack parental support for their gender health goals. Without support from parents, trans youth may be disadvantaged in multiple ways, including lack of system navigation, transportation, financial (e.g., medication costs), and decisional support. Conflict that emerges between a youth and a parent concerning gender health care, as described in Aidan's situation, may be addressed through family mediation or therapy. However, the limitations on resources for such supports, combined with an unwillingness to participate on the part of some parents, can create more inequity for this subgroup of trans youth. Furthermore, if parental support is required for a youth to move forward in a hormone readiness assessment, parents are essentially provided with veto power—by refusing to engage, they may be able to prevent their child from accessing hormone therapy even though the youth may otherwise have legal authority to do so.

Judgements that result in denial or delay of a medical intervention to a particular group of people based on social characteristics (e.g., parental support, gender, age) must be approached carefully so as not to violate the principle of justice. There is no evidence that cisgender youth in this jurisdiction with other endocrine-related needs (e.g., insulin-dependent diabetes, precocious puberty, contraception) are regularly evaluated for treatment eligibility based on parental support for medical intervention, making this inconsistently applied criteria one that is likely specific to youth gender health care. While diabetes and precocious puberty can be diagnosed according to medical criteria, the need for interventions such as contraception and gender-related hormone therapy are based in large part on youth self-report. However, youth seeking hormonal contraception (e.g., estrogen, progestin) are not subjected to the same level of scrutiny as trans

youth seeking hormone therapy to support gender health (e.g., estrogen, progestin, testosterone). Youth are even afforded special protections for access to contraceptive care in some jurisdictions, likely driven by societal values related to preventing youth pregnancy coupled with rights to reproductive freedom and bodily autonomy. Meanwhile, youth seeking gender health care often have their motives scrutinized, their reproductive choices questioned, and their bodily autonomy restricted. It remains to be seen how shifts in societal awareness and perceptions of trans experiences, along with increased access to youth gender health care, will influence how this care is delivered in the future.

Historic and ongoing pathologization of trans experiences complicates the provision of youth gender health care, as hormone therapy readiness assessment/care planning conducted by mental health professionals may signal a perception that being trans is a mental health condition, regardless of how this care is provided. Additionally, sociocultural factors, including cisnormativity and bionormativity, may influence evaluations of youth capacity. It is well-recognized that the greater the potential implications of a health care intervention, the greater the capacity required to make a decision (Canadian Paediatric Society, 2004). However, health care provider perception of the magnitude of the decision to initiate hormone therapy is subjective. If perceived as an intervention with extremely high implications, the threshold for capacity required of youth may be higher than if hormone therapy is considered a lower-risk, routine aspect of gender health care. Such perceptions of magnitude are likely influenced by beliefs about gender and cisnormative biases regarding the value of trans lived experiences (e.g., life as a trans person being as, or less, desirable than life as a cisgender person). Ultimately, standards for access to gender health care differ not only between youth and adults (e.g. informed consent care for adults), but also between trans youth and other youth seeking endocrine-related care.

In summary, the best interests standard and the harm principle may assist health care providers in deciding on ethically permissible courses of action involving individual youth seeking hormone therapy, however, they both have shortcomings. The subjectivity inherent in making judgments about best interests and harms to an individual can result in inconsistent practices. Additional empirical evidence regarding risks and effectiveness of specific interventions would be beneficial for developing evidence-based guidelines and fostering consistency among health care providers. As seen in the approaches of health care providers in this study, taking a greater number of bioethics principles into account was associated with different ethical decision-making outcomes, as compared with consideration of fewer of these principles. Justice was rarely taken up in discussions, consistent with critique that this principle is insufficiently addressed through a North American bioethics framework (DeGrazia, 2003; Hodges & Sulmasy, 2013; Marway & Widdows, 2015). This indicates that training around clinical ethical decision-making—inclusive of both North American bioethics and other approaches to health care ethics (e.g., relational ethics, queer bioethics)—and support from clinical ethicists may be helpful in supporting ethical decision-making in practice. Lastly, increased attention should be paid to the principle of justice, in particular to how circumstances beyond the control of the youth are impacting the care they are given, to ensure that trans youth are not experiencing undue barriers or provided with a lesser standard of health care.

5.2.4.6 Limitations

Demographic characteristics (e.g., practice discipline, age, gender) were not reported in this study in order to protect the privacy of participants; however, future research with a more robust participant pool from a larger geographic area could support analysis based on health care

provider discipline. Participant framings of the scenario and proposed actions may have been influenced by the context of participating in an interview on ethical decision-making, however, the reliance on previous clinical experience in justifying interpretation and action indicated consistency between practice and discussion of this scenario. In future research, multiple interviews allowing for more in depth exploration of participant beliefs and approaches to care would augment the findings of the current study. The analysis of ethical issues is limited by the sole application of a North American bioethics framework. Finally, transferability of some findings to other jurisdictions may be limited by differences in youth consent legislation.

5.2.4.7 Recommendations

An ethical decision-making framework could assist youth gender health care providers in comprehensively analyzing practice scenarios involving ethically complex family situations. The Belief-Dilemma-Action Model may serve as a foundation for an ethical decision-making educational tool or as the basis for development of a discipline-specific ethical decision-making framework. In practice, it is recommended that health care providers attend to all principles of bioethics in their analyses, to avoid foreclosing the ethical decision-making process before all relevant issues have been taken into account. Furthermore, the integration of other ethical approaches, such as relational ethics or queer bioethics, would be of benefit in developing more comprehensive analysis of the current ethical landscape within youth gender health care. Application of the harm principle, the not unreasonable standard, and the medically reasonable alternatives approach in ethical analyses may address shortcomings of the best interests standard and give clearer direction to providers on when to infringe on autonomy (of a youth or a parent) to prevent harm; however, the limitations of all of these approaches in terms of subjectivity and

potential for inconsistent application must be considered. Consultation with clinical ethicists may also be beneficial in supporting procedural justice and consistent decision-making when complex family situations arise. Treatment of trans youth should be viewed within the context of care for other populations to ensure the principle of justice is upheld through fair and equitable treatment trans youth, a population that currently experiences inequities in health care access and health outcomes. Further research on clinical practices for parent engagement and strategies to support ethical decision-making in youth gender health care, using the Belief-Dilemma-Action Model or other frameworks, would also be beneficial.

Chapter 6: Conclusion

The *Trans Youth Hormone Therapy Decision-Making Study* was undertaken to explore decision making processes of trans youth, parents of trans youth, and health care providers surrounding hormone therapy initiation. In this final chapter, the methods and major findings are summarized, then discussed in the context of the literature. Conclusions regarding original contributions of this dissertation are presented, followed by recommendations for both clinical practice and future research.

6.1 Methods

This research was conducted on Turtle Island, in the region also known as British Columbia, Canada. Trans youth ($n = 21$), parents/caregivers of trans youth ($n = 15$), and health care providers serving trans youth ($n = 11$) participated in the study. Recruitment took place through health care and community organizations that served these three groups. Purposive sampling was used to ensure a broad range of hormone therapy statuses and care seeking experiences were represented among youth. Data collection took place in four of the province's five geographic health regions. Semi-structured interviews, of one hour in length, were conducted in participant-selected locations (e.g., home, school, office, community centre). Interview topics included hormone therapy initiation decision-making processes, shared decision-making, decision-making supports and barriers, ethical dilemmas, and ethical decision-making. During youth and parent interviews, lifeline drawings were completed as temporal representations of decision-making processes. Interview and lifeline data were analyzed using a constructivist grounded theory approach and a bioethics framework with the assistance of NVIVO software (Beauchamp & Childress, 2013; Charmaz, 2014). Rigor within this research

was addressed via collection and triangulation of rich data from three distinct participant groups through interviews and lifeline drawings, opportunities for participants to member check transcripts, and reflexive practices on the part of the researcher (e.g., peer supervision, consultation, and memo-writing).

6.2 Major Findings

In section 4.1, the decision-making processes of trans youth and parents were explored in depth. Grounded theory analysis revealed similar processes for youth and parents, which were presented in temporal models comprising three phases: discovery, (inter)action, and reflection. Health care providers held diverse views about their role in supporting trans youth who were seeking hormone therapy. Some worked toward collaboration or facilitation of gender health goals, while others took a more paternalistic approach. One consistent finding was that health care providers preferred to involve parents in decision-making processes; however, their approaches to this involvement ranged from encouragement to requirement of parental support before moving ahead with hormone therapy initiation. Many youth experienced strong support from parents and/or health care providers in meeting their gender health goals. For others, lack of parent support and challenges navigating systems of care caused significant barriers; at times these barriers were compounded by health care provider requirements for parental support. Overall, youth with the strongest levels of parental support experienced the smoothest access to care, while those with lower levels confronted the greatest barriers and were sometimes unable to access needed gender health care. The term ‘parallel process hormone therapy’ initiation was introduced to call attention to the potential for health care providers to engage in collaborative

decision-making with capable youth surrounding hormone therapy initiation, while simultaneously offering support to resistant parents (with youth consent).

Shared decision-making approaches were addressed in section 4.2. Many elements of shared decision-making were present in descriptions offered by youth, parents, and health care providers. Five conditions necessary to support shared decision-making in the context of youth hormone therapy initiation decision-making emerged: (1) strong relationships among participants; (2) strong communication among participants; (3) agreement about which decisions would be shared and which would not; (4) a collective understanding of each person's role in the decision-making process; and (5) sufficient time for the process to unfold without compromising the health and wellbeing of the youth. While these conditions were not always met, and it was evident that it was not always possible to productively include parents in these processes, shared decision-making approaches hold promise in situations where potential participants are all able and willing to engage in these collaborative processes.

Ethical dilemmas and decision-making processes of health care providers were the foci of section 5.1. Participant beliefs, dilemmas, and actions emerged as the core constructs involved in the construction and resolution of ethical dilemmas in clinical practice. The Belief-Dilemma-Action Model illustrated interactions among these constructs, within the context of both health care relationships and sociocultural influences. The construct of beliefs included six salient categories: youth ability to know their gender; health care provider role; family; rights; capacity; and best interests. Four main dilemmas were raised by health care providers, which related to: care of youth with complex family situations (e.g., parents opposed to hormone therapy initiation); youth capacity to consent to care; potential harms (e.g., future regret related to potential fertility implications); and resource scarcity impeding access to needed care. Participant

actions took the form of assessment, consultation, deliberation, decisions about hormone therapy initiation, care provision, and evaluation of clinical approaches. The three main constructs of beliefs, dilemmas, and actions were found to interact in all directions, revealing a complex web of ethical decision-making processes. Participants emphasized the importance of integrating empirical evidence when available, lamented the lack of extant literature to inform many areas of practice, and expressed openness to changing approaches to care as new and compelling evidence became available.

Finally, in section 5.2, the challenges of working with youth whose parents were unsupportive of their gender health goals were addressed through health care provider analysis of a hypothetical practice scenario. In response to a single scenario, participants generated diverse framings of emergent ethical issues. These were categorized as the harm dilemma, the benefit-harm dilemma, the autonomy-benefit-harm dilemma, and the non-dilemma. The principles used by participants to construct dilemmas/non-dilemmas and predicted actions fell along a continuum that also corresponded with approaches to parental involvement. Overall, as more ethical principles were taken into account in analysis, there was greater openness to hormone therapy initiation without full support of parents. Youth experiences with different health care provider approaches to parental support were explored, revealing that youth were navigating similar dilemmas to those faced by health care providers and that requirement of parental involvement was experienced by some youth as a barrier to needed care.

6.3 Discussion

6.3.1 Decision-making Processes

How do trans youth and parents of trans youth make decisions about hormone therapy initiation? Temporal models of youth and parent decision-making comprised three phases—discovery, (inter)action, and reflection—a conceptualization which may help health care providers better understand the processes youth and parents experience prior to, during, and after their interactions with the health care system. Youth were clear about their hormone therapy needs and preferred roles in health care decision-making, findings consistent with literature indicating that youth want to be active participants in their health care (Coyne et al., 2014). Youth, by self-report and parent report, also consistently demonstrated the key components relevant to hormone therapy decision-making capacity, as would be expected from research indicating youth typically develop such capacity by age 14 (Canadian Paediatric Society, 2004; Weithorn & Campbell, 1982)

The Health Belief Model, the Integrative Behavior Model, and the Behavioral Model of Health Services Use all align with some aspects of the youth and parent decision-making models developed in this study (e.g., weighing of benefits and barriers, impact of barriers to care, and influence of norms) (Andersen, 1995; Montaña & Kasprzyk, 2015; Skinner et al., 2015). However, none of these models fully represented the breadth of decision-making and decision-enactment experiences of trans youth and parents. Data indicated that sociocultural factors specific to trans youth (e.g., stigma, harassment, and discrimination faced in homes, schools, communities, and health care settings) influenced youth participant experiences of safety and

impacted decisions they made and enacted about hormone therapy (Clark et al., 2017, 2018; Gridley et al., 2016).

How do trans youth, their parents/caregivers, and their health care providers engage (or not engage) in shared decision-making practices around hormone therapy initiation? Many elements of shared decision-making processes described in the literature were present in participant narratives, for example, the presence of strong relationships, communication, role agreement, and consensus regarding decisional agenda (Charles et al., 1997; Elwyn et al., 2000; Murray et al., 2006). Many health care providers described decision-making processes focused on sharing of youth goals and medical information; these approaches were well-aligned with established shared decision-making characteristics (Charles et al., 1997; Murray et al., 2006). However, in some situations, the decision-making processes described were individual, paternalistic, or conflictual, and thus not characteristic of shared decision-making. For example, the expertise and values of youth and parents were at times disregarded, indicating some decision-making processes were unbalanced (Crickard et al., 2010; DeMeester et al., 2016). Additionally, conflict that emerged when youth, parents, and health care providers were not in agreement about process highlighted the need to honor patient autonomy in the selection of a decision-making approach (Murray et al., 2006).

As seen in the youth gender health care literature, parent involvement in decision-making was often present and regularly encouraged by health care providers (Bernal & Coolhart, 2012; Giordano, 2007; Holman & Goldberg, 2006; Swann & Herbert, 2000). However, time emerged as an important element with respect to parental involvement in shared decision-making (Murray et al., 2006). Parental willingness to engage, youth distress, and secondary sex characteristic development were all context-specific considerations relevant to the time needed for shared

decision-making processes to unfold. Parents were sometimes unable or unwilling to engage in shared decision-making or to support their child's gender health goals, which is unsurprising given the literature documenting health outcomes of youth whose parents are unsupportive (Travers et al., 2012; Veale et al., 2015). However, the narratives documented in this research affirm the idea that parent support for youth gender health goals typically strengthens over time.

How can trans youth, parents/caregivers, and health care providers be better supported in shared decision-making processes related to hormone therapy initiation? Youth, parent, and health care provider participants all discussed challenges they faced in making decisions about hormone therapy initiation. Shared decision-making was explored as an approach that could better support these parties, with potential benefits of: supporting emerging autonomy; developing health care decision-making skills; encouraging ongoing engagement with the health care system; strengthening youth-parent relationships and communication; and empowering youth (Crickard et al., 2010; David et al., 2017; Edbrooke-Childs et al., 2016; Hetrick et al., 2008; Langer & Jensen-Doss, 2016; O'Brien et al., 2011). Integration of the five conditions for shared decision-making, along with uptake of previously established procedures for shared decision-making in the context of youth care and work with marginalized populations, holds potential for augmenting decision-making practice in youth gender health care (Crickard et al., 2010; DeMeester et al., 2016; Hetrick et al., 2008; Langer & Jensen-Doss, 2016; Légaré et al., 2011; Makoul & Clayman, 2006; O'Brien et al., 2011; Peek et al., 2010, 2016; Ruggeri et al., 2014). As trans youth continue to face a wide range of barriers to care (e.g., gatekeeping, delayed or limited access, lack of care coordination, lack of trans cultural competence), awareness of the cultural needs and values of trans youth—developed through examination of normative beliefs, intersectionality, trans culture, and the trans lived experience—will be important for

implementation of culturally safer shared decision-making approaches (Clark et al., 2017; DeMeester et al., 2016; Foglia & Fredriksen-Goldsen, 2014; Gridley et al., 2016; Peek et al., 2010, 2016).

6.3.2 Youth Experiences of Care

How do youth experience barriers and facilitators to enactment of decisions regarding hormone therapy initiation? Many health care barriers described by youth and parent participants (e.g., cost, travel, and other typical system-based impediments) were consistent with published research (Clark et al., 2017, 2018; Gridley et al., 2016); however, the requirement of parental support for gender health goals also functioned as a barrier to hormone therapy initiation for some youth. Within the Integrated Behavior Model, knowledge and skills are important factors influencing health behavior (Montaño & Kasprzyk, 2015). This model does not address youth decision-making specifically, however it may be helpful in understanding the role knowledge and skills play in youth ability to enact decisions. Youth in this study who were not supported in care seeking by their parents—the people who would typically offer their knowledge and skills to support a youth in health care system navigation—experienced this lack of support as an additional barrier to care. While some found support in surrogate adults or persevered in acquiring the knowledge and skills necessary to successfully navigate relevant systems of care, others had been unable to access the care they needed at the time of their interviews. Overall, youth, along with parents, experienced frustration and distress when barriers (e.g., wait times, lack of trained providers, lack of system navigation support, unsupportive professionals, lack of parental support, cost of services) prevented timely access to care, especially as unwanted and preventable pubertal changes occurred.

How are health care provider approaches experienced by trans youth? Health care provider participants were well aware of research connecting better trans youth health outcomes with stronger parental support, and understandably preferred to have parental support in place for trans youth before hormone therapy was initiated (Ryan et al., 2010; Travers et al., 2012; Veale et al., 2015). While one study does confirm current findings that trans youth under the age of majority are consenting for their own hormone therapy under the *Infants Act* in British Columbia (Khatchadourian et al., 2014), evidence-based practices for youth whose parents are uninvolved or unsupportive of hormone therapy have yet to be established. In the absence of relevant practice standards or research, some health care providers relied heavily on studies highlighting the importance of parental support. Approaches to care were problematic when research correlating parental support with health outcomes was interpreted to mean that hormone therapy initiation should be contingent on parental support or consent. There is no known empirical evidence to support the idea that youth will have worse health outcomes if they access hormone therapy without parent support for this intervention or vice versa; meanwhile, it is accepted that withholding access to hormone therapy can have negative implications (Antommara, 2014; Coolhart et al., 2013; de Vries et al., 2014; Delemarre-van de Waal & Cohen-Kettenis, 2006; Vrouenraets et al., 2015). An unbalanced application of available research and practice guidelines, combined with a lack of research on this specific area of practice, resulted in inconsistent practices that affected youth access to care.

Youth who urgently needed hormone therapy, and/or had parents who were highly resistant to hormone therapy initiation, experienced health care provider-imposed delays and refusals to support hormone therapy initiation as a double barrier to care. Likewise, some health care providers acknowledged that differential treatment of youth in these circumstances resulted

in delayed access. This compounded the barriers to care experienced by youth with the lowest levels of parental support, while youth with higher levels of support moved much more quickly and easily through systems of care. However, in this study, when youth without parental support for hormone therapy went ahead with this intervention, positive outcomes were reported. These included increased parental support for gender health goals following initiation of hormone therapy (in some cases) and satisfaction with the decision to start hormone therapy (in all cases). Collectively, this evidence suggests that more harm than benefit may result from requiring parental support for gender health goals prior to initiation of treatment, however additional research on this topic would be beneficial for informing evidence-based practices.

6.3.3 Ethical Decision-making

What ethical issues do health care providers find challenging in hormone therapy readiness assessment/care planning practice with trans youth? Overall, there was a disconnect between the beliefs held by some health care providers about youth capacity and both research on youth capacity and lived experiences of trans youth and parents (Weithorn & Campbell, 1982). Issues around impulsivity and susceptibility to influence or coercion were raised, though research indicates these are not significant developmental barriers to youth health care decision-making (Grootens-Wiegers et al., 2017). Some health care providers also questioned whether youth could know their own gender, a concern inconsistent with both the gender affirmative model of care and research findings around gender awareness of young children (Ehrensaft, 2016; Olson & Gülgöz, 2017). However, multiple health care providers expressed confidence in youth capacity to consent for hormone therapy as well as youth ability to know their own gender. Approaches to capacity that involve generalized judgments about the ability of trans youth to

know their own gender or to consent to care—as opposed to individualized, decision-specific capacity evaluation—places youth autonomy in jeopardy. Inconsistent practices contribute to perpetuation of an unjust system wherein youth across British Columbia do not have equitable access to care. While there was overwhelming endorsement among health care providers that they provided ‘gender affirming care’, use of this terminology was inconsistent, and at times incongruent, as some practices were reflective of pathologization and disregard for youth knowledge of their own gender and health care needs.

Issues of beneficence and nonmaleficence were raised frequently by participants, as they are in the youth gender health literature (Baltieri et al., 2009; Holman & Goldberg, 2006; Stein, 2012; Vrouenraets et al., 2015). Medical neglect was a novel concern within in the current study, pertaining to parental refusal to consent (or express support) for hormone therapy. Participants were uncertain about how make determinations around whether parent behavior qualified as medical neglect in the context of gender health care. Some expressed concern that youth might regret a decision to start hormone therapy if, in the future, they experienced fertility-related challenges stemming from long-term hormone therapy use. This is a concern more commonly cited in relation to surgical interventions when it is present in the literature (Milrod, 2014), but also present in some analyses of hormone therapy practices (Abel, 2014). Uncertainty regarding long-term effects of hormone therapy yielded caution on the part of health care provider participants, consistent with existing literature (Bernal & Coolhart, 2012; Khatchadourian et al., 2014; Swann & Herbert, 2000). However, given evidence of the effectiveness of hormone therapy in addressing youth gender health needs, lack of alternative treatment options, harms of withholding or delaying care, and data from both trans populations and general youth populations regarding the long-term safety of sex hormone use (e.g., contraception), these

ongoing concerns are somewhat surprising. This raises a question of whether concerns regarding initiation of long-term hormone therapy use with trans youth are solidly rooted in physiological risks, or if social factors (e.g., cisnormative, heteronormative, and bionormative biases) are primary drivers of these concerns.

In accordance with international human rights agreements, a just health care system affords youth several rights, including: non-discrimination, having their best interests given primary consideration, healthy development, involvement in decision-making, access to health care, and attainment of the highest possible standard of health (United Nations, 1989; World Health Organization, 2006). Health care providers were all dedicated to providing trans youth with access to needed gender health care. They acknowledged the influence of stigma on the lived experiences of youth, but gave minimal attention to how this might impact their own practice or to ongoing pathologization within gender health care services. Several participants cited resource scarcity issues as a challenge when attempting to ensure that all youth received the best possible care. Many such issues have been discussed in the literature as barriers to care, however participants in this study specifically framed these issues as ethical concerns, for example, cost, lack of family support, scarcity of culturally competent health care providers, and geographic barriers (Clark et al., 2017; Reisner, Bradford, et al., 2015a; Rosenthal, 2014).

The issue of stigma-driven pathologization of trans experiences can be conceptualized as a driver of resource scarcity. Taking a depathologizing, gender affirmative approach—in which trans experiences are considered a natural part of human diversity—supports provision of care based on individual needs. Ongoing requirements of some health care providers for extensive psychological evaluation of all trans youth seeking hormone therapy is reflective of the perpetuation of pathologization and can contribute to delays in access and scarcity of youth

mental health resources. Meanwhile, many youth without highly complex mental health concerns are receiving gender health care in primary care settings with positive results. It is within the scope of primary care to provide a wide range of mental health screening and services, should such issues arise, providing a safety net to ensure youth with complex mental health issues are appropriately referred to specialists. From an ethical perspective, allocation of specialized youth mental health resources to youth with complex mental health concerns and mobilization of primary care resources for youth with less complex presentations is justified, in order to alleviate strains on a system with finite resources, reduce distress and improve health outcomes through timely access to care, and reduce pathologization of trans experiences.

How do health care providers construct and resolve ethical dilemmas that emerge in hormone therapy readiness assessment/care planning practice with trans youth? Health care provider participants referred to bioethics principles and occasionally to professional codes of ethics, but did not identify formal decision-making tools in the construction and resolution of ethical dilemmas in practice. The model emerging from this study centers beliefs, dilemmas, and actions as the constructs of interest in understanding health care provider ethical decision-making processes: interactions among these constructs were complex. Two key findings related to: (1) the impact of internal belief tension and congruence on construction of ethical dilemmas and actions and (2) and the function of imagined dilemmas in shaping beliefs. This aligns with previous research on the influence of values and cultural awareness on clinical practice (Bosek & Savage, 2000; Garcia et al., 2003; Smith et al., 1991, 1991).

A range of views on the nature of gender indicated that health care providers may be influenced to varying degrees by traditional cisnormative, heteronormative, and bionormative thinking (Baylis & McLeod, 2014; serano, 2017). While health care providers acknowledged the

impact of stigma on the lives of trans youth, they did not directly attend to the ways in which stigma could impact the care they provided. The ways in which cultural awareness and identity affect ethical decision-making, as highlighted in the literature (Bosek & Savage, 2000; Garcia et al., 2003; Smith et al., 1991), are worthy of further investigation. It is also important to note that health care providers were open to changing their practices in response to new evidence, however, these participants were inconsistent in how they appraised and integrated the current literature into practice, indicating an effect of beliefs on whether specific pieces of evidence were accepted or disregarded.

In the context of the hypothetical practice scenario, application of principles of bioethics varied widely, as did importance placed on parental involvement and willingness to consider supporting hormone therapy initiation in the absence of parental support for this intervention. A primary concern amongst participants was how to act in the best interests of a youth (e.g., when their need for hormone therapy conflicted with the benefits of strong youth-parent relationships), a standard established in the *Infants Act* (Infants Act, 1996). However, when health care providers included multiple principles of bioethics in their analyses of the scenario they proposed different courses of action than those who focused solely on harm. Of note, greater willingness to initiate hormone therapy for a capable youth without parental support was associated with integration of more principles, in particular, the addition of autonomy and justice along with nonmaleficence and beneficence.

Inconsistency in health care provider approaches may relate to the lack of a clear definition of best interests or guidance on how to operationalize this standard in practice. A need for more education on evaluation of youth capacity and medical neglect was also evident. With respect to capacity, analysis of health care provider responses to the hypothetical practice

scenario highlighted the need for youth capacity evaluation to include understanding and reasoning in relationship to both the medical information and the social context relevant to decisions about hormone therapy initiation. In terms of best interests, health care providers should consider the effectiveness of hormone therapy, the lack of medical alternatives, that surrogate supports can be effective when parental supports are insufficient, that only youth can know their gender and gender health care needs, and the potential harms and benefits associated with initiating, delaying, or withholding hormone therapy. As suggested in the literature, the harm principle may be a useful standard for application in pediatric care for identification of when health care providers need to act to prevent harm (Diekema, 2004). The harm threshold describes situations where an immediate and significant risk of serious harm exists that could be prevented through intervention. Three such potential harms were identified with respect to hormone therapy initiation: self-injury or suicide; distressing, unwanted pubertal changes; and parental rejection. The ‘not unreasonable standard’ and ‘medically reasonable alternatives’ approaches may further inform health care provider decision-making around when to accept a proxy decision-maker’s decision about the care of a youth. However, in ethical deliberations it is important to note the high threshold for intervention based on the harm principle and the challenges to procedural justice stemming from the subjectivity inherent in evaluating best interests, potential harms, and reasonableness of decisions with respect to youth hormone therapy initiation.

The principle of justice received the least attention from participants, but should not be overlooked. In clinical practice, there are many contextual features that can influence ethical decision-making. Eliciting youth values may serve to bring some of these to the forefront in order to better inform decision-making, however this was not a practice explicitly identified by

participants (Jonsen et al., 2015). A second concern is that health care provider biases may result in differential treatment of a particular group of people based on social characteristics, which has potential to violate the principle of justice. In this study, trans youth were treated differently based on their level of parental support, compounding the disproportionately high level of barriers many already faced in accessing needed care. Justification for differential treatment of this subgroup should clearly identified. On a larger scale, some aspects of youth gender health care provision are inconsistent with the delivery of other similar health care services (e.g., youth contraceptive care), highlighting concerns about justice and systemic discrimination rooted in biases related to trans experiences. Lastly, cismnormativity and bionormativity may contribute to perceptions that hormone therapy is an intervention with extremely high implications, thus setting a high or unattainable threshold for youth capacity to consent to this care; conversely, views of hormone therapy as a lower-risk, routine part of gender health care may result in requirements for a level of decision-making capacity more in line with what is expected for other youth health care services (e.g., contraceptive care). Supporting justice for trans youth requires understanding the multitude of factors impacting both the equitable treatment of individual youth and the standard of care for the population as a whole.

How can health care providers be better supported in ethical decision-making processes related to hormone therapy initiation? Various ethical decision-making frameworks have been developed to support clinical ethical decision-making. Such approaches are inclusive of elements such as virtues, values, codes, culture, and pragmatic considerations (Cottone & Claus, 2000; Garcia et al., 2003; Manson, 2012; Wiggins & Williams, 2005). Process/rational models, reflective models, and cultural models all have potential to support health care providers working in youth gender health care (McAuliffe & Chenoweth, 2008). Bioethics principles and codes of

ethics informed the ethical decision-making of participants, however no health care providers in this study utilized a specific ethical decision-making framework in practice. The Belief-Dilemma-Action model could be operationalized to support health care provider education and clinical ethical decision-making, and may be transferrable for use with other populations.

Ethical decision-making could be supported through specific clinical approaches, education initiatives, and clinical ethicist services. First, clinical approaches of shared decision-making and parallel process hormone therapy initiation may provide frameworks to support productive exploration and resolution of some ethical dilemmas. Education focused on relevant laws, the best interests standard, the harm principle, youth capacity evaluation, and working with youth and families in conflict could support development of relevant knowledge and skills. Health care providers may also benefit from training on ethical decision-making practices that integrates exploration of the constructs of beliefs, dilemmas, and actions in relation to cisnormativity, heteronormativity, bionormativity, empirical evidence, and the lived experiences of trans youth and their families. While health care provider participants indicated that they did not access clinical ethicist services, and in some cases were unaware that these services were available within their institutions, clinical ethicists can provide support in navigating ethical dilemmas surrounding application of the best interests standard and the harm principle. Finally, resource scarcity and allocation, along with empirically and ethically sound clinical practices, may be addressed through improved health policy concerning efficient and effective delivery of youth gender health care services.

6.3.4 Limitations

This is the first study known to explore the hormone therapy initiation decision-making processes of trans youth and parents and the shared decision-making processes among youth, parents, and health care providers. Therefore, there are limitations on the extent to which these findings can be contextualized within the extant literature. Semi-structured interviews were found to be appropriate for the aims of this exploratory study, however the collection of data via single individual interviews did not allow for documentation of decision-making processes over time, observation of interaction among participants, or in-depth study of health care provider values and beliefs. Bias is likely present in terms of who self-selected to participate (e.g., parents supportive of youth gender health goals) and what information they elected to share. This was addressed through triangulation of participant data across the three groups and clarification of experiences through completion of lifeline drawings. Theoretical sufficiency was determined to have been reached over the course of the interviews and rigor was promoted through use of constant comparative methods, memo-writing, researcher reflexivity, and researcher supervision. Ethical analysis was limited in scope due to the centering of a North American bioethics framework. Transferability of findings outside of Canada may be limited due to the legal context, however conducting research in this setting enabled exploration of decision-making in an environment with fewer constraints on youth autonomy.

6.4 Conclusions

6.4.1 Decision-making Processes

The experiences of youth and parents were explored to generate understanding of hormone therapy decision-making experiences. Health care providers can draw on the following results to enhance practices related to hormone therapy readiness assessment/care planning: temporal models illustrating youth and parent decisions and decision-making processes; the circumstances under which youth seek hormone therapy from health care providers; and the systemic, parental, and health care provider barriers that prevent youth from enacting decisions related to hormone therapy initiation. It should be noted that the role of the health care providers is significant, but typically constrained to a small segment of the overall youth or parent journey. Findings concerning in-depth youth deliberation and concerted efforts to bring parents to a supportive stance regarding hormone therapy prior to care-seeking can inform the ways in which health care providers approach interactions with youth and families.

Health care provider approaches to care were diverse, some more paternalistic and others revealing characteristics of shared decision-making. Paternalistic approaches can be counterproductive when not aligned with youth and parent expectations and needs, leading to tension and conflict for participants. Use of shared decision-making approaches holds potential for fostering strong relationships among youth, parent, and health care providers, thus laying a foundation for care planning that meets the needs of all involved. Recognition of conditions necessary for parties to engage in shared decision-making and appropriate training is needed in order to fully integrate this underutilized model within youth gender health care.

6.4.2 Youth Experiences of Care

Youth with greater parental support for their gender health goals experienced lower barriers to care than those whose parents were not supportive of hormone therapy initiation. When health care providers imposed a requirement for parental involvement or support, this became an additional barrier to care for some youth. While support in addressing parent concerns was appreciated by some youth, requiring the involvement, support, or consent of parents had the potential to infringe on youth autonomy and cause harm related to delayed access to care (e.g., emotional distress, secondary sex characteristic development, disengagement from health care systems). The inclusion of youth participants not engaged with health care providers, and those who had accessed hormone therapy without their parents' support, provided new insight into the experiences of these subpopulations. Of particular interest was the small group of capable youth who reported positive outcomes after accessing hormone therapy independently of their parents.

This study supports the idea that youth with safe-enough home environments can move ahead with hormone therapy and be well-supported by their parents in areas of their life other than gender health goals, even when parents are staunchly opposed to hormone therapy. Honoring capable youth autonomy to make their own health care decisions, in line with the *Infants Act*, may signal to parents that the authority to make this decision belongs to the youth and help them to move to a place of greater acceptance. As indicated by many participants, parents tend to become more supportive over time. Delaying or withholding hormone therapy has the potential to cause harm, and moving ahead with initiation may have benefits, including potentially facilitation of increased parent support for gender health goals (rather than decreased global parental support as feared by some health care providers). It is acknowledged that some youth could face violence from their families in response to seeking gender health care and that

these perspectives were underrepresented in the study cohort. However, this study does offer support for prescribing hormone therapy to capable youth in the absence of parental support for gender health goals with sufficient evaluation of the risk of imminent, serious, preventable harm.

6.4.3 Ethical Decision-making

The *Infants Act* provided a unique context for this study of youth gender health care, and specifically youth consent for hormone therapy. Many ethical issues raised were reflective of those identified by health care providers in other parts of the world, however some issues raised around parental involvement were unique due to the legal authority of capable youth to consent to their own gender health care. Health care providers have an ethical responsibility to support autonomy, balanced with protection from harm, acting to benefit clients/patients, and ensuring just treatment. Wide variation in the application of the principles of bioethics in ethical analysis of the practice scenario presented in this study led to variability in proposed courses of action. However, when empirical data are lacking related to a particular area of care, sound ethical decision-making that fully incorporates all four principles of bioethics, can support ethically-grounded, individualized care for trans youth.

The relationships among health care provider beliefs, construction of ethical dilemmas (or non-dilemmas), and actions are complex and worthy of further investigation to identify opportunities for education that can lead to more evidence-based and theoretically sound practices within youth gender health care. The Belief-Dilemma-Action Model holds potential as an analytic tool, and may also provide a useful theoretical foundation for development of an ethical decision-making framework and health care provider training to support ethical decision-making in youth gender health care. Ethical decision-making practices can be supported through

better understanding of belief congruence and tension, the law, capacity evaluation, complex family situations, evidence-based practice, and education about the lived experiences of trans youth that challenge harmful sociocultural norms and highlight beneficial ones. A broad approach clinical ethical decision-making, inclusive of bioethics principles, relational ethics, queer bioethics, and justice-doing, would also enrich ethical decision-making in this context.

6.5 Recommendations

6.5.1 Decision-making Processes

Accurate gender health information should be made available online for youth and parents, as well as health care providers. Key topics include gender, trans communities, medical transition options, health care system navigation, peer support, and personal stories of trans people. A culturally and developmentally-informed shared decision-making framework which incorporates the five conditions (i.e., relationship, communication, roles, decisions, time) could be developed for application with this population and within this legal context. Research into the effectiveness of such a tool should be undertaken; outcomes of interest include ease of use, impact on barriers to care, effects on youth-parent relationships, decision satisfaction, and cultural safety. The five conditions and any related shared decision-making frameworks developed may also be transferred to other health care contexts; such application is worthy of empirical investigation. Education on culturally-informed shared decision-making approaches should be offered for youth gender health care providers to build trans cultural competencies and address current health care system deficiencies. Offering training for those working in settings

where youth are already served (e.g., youth clinics, family practice) may serve to reduce disparities in access, minimize wait times, and address overall resource scarcity.

6.5.2 Youth Experiences of Care

Development and evaluation of parent support opportunities and trainings for service providers will be an important step in improving systems of care for trans youth. Special attention should be given to youth experiencing high barriers to care. Parent support is one potential area for intervention, however some parents may not be able or willing to support their child's gender health goals within an acceptable time frame. A parallel process for hormone therapy initiation is therefore recommended for use when capable youth have a need for hormone therapy that outweighs their current need to bring their parents on board with their gender health goals. Parallel process hormone therapy initiation involves shared decision-making between the youth and health care provider to develop a care plan in support of gender health goals, with simultaneous provision of support and education to parents (with consent of the youth). The primary goals of this process are to ensure a youth receives timely and safer access to hormone therapy and to bring parents to a supportive stance as soon as possible. Integrating a relational ethics approach may be of benefit in supporting health care providers in navigating complex work with youth and families (Bergum, 2013). Safety of the youth should always be a priority, and appropriate referral or report made if the youth is at risk of harm from their parents or within their home. This study has offered preliminary documentation of positive outcomes for youth accessing hormone therapy without parental support for their gender health goals, however, further research on parallel process hormone therapy initiation is recommended to inform

development of evidence-based practices and promote safe, equitable, and timely access to gender health care for all trans youth.

6.5.3 Ethical Decision-Making

As practice guidelines are developed for youth gender health care, the need to account for variations in legal context is evident. Procedures that must be adopted in jurisdictions where there is a legal age of consent for health care may not be appropriate in places where youth have the legal authority to consent for their own health care. Further investigation into ethical issues in youth gender health care (e.g. family conflict, consent, fertility-related regret, and justice) would enhance the small body of youth gender health ethics literature, both within and across diverse legal contexts, and contribute to a greater understanding of the ways in which shifting sociocultural norms influence the construction and resolution ethical dilemmas in this field. Robust ethical scholarship in the area of youth gender health care could be supported through future scholarship in which additional ethical frameworks (e.g., relational, justice-doing, queer bioethics) are applied, also serving to address limitations present in a principles-based bioethics approach (Bergum, 2013; Holm, 1995; Marway & Widdows, 2015; Reynolds, 2011; Roen, 2016).

In the area of clinical ethical decision-making, it is recommended that health care providers integrate all four principles of bioethics into their deliberations in order to avoid foreclosing options before all relevant ethical issues have been taken into account. The best interests standard has been critiqued as ambiguous and difficult to consistently apply in pediatric care, and while the harm principle, the not unreasonable standard, and medically reasonable alternatives may be a helpful alternative in giving direction to providers on when it is ethically

permissible to infringe on the autonomy of a youth or parent in order to prevent harm, these approaches also have shortcomings in terms of subjectivity. Accessing clinical ethicist services is recommended to support health care providers in navigating issues such as the application of the best interests standard and harm principle in youth gender health care. Lastly, current empirical evidence should be integrated into ethical decision-making, when available. Additional research may be needed to address health care provider concerns, particularly in the area of longitudinal health outcomes and potential future regret related to fertility. Further research into health care provider decision-making, particularly around appraisal of evidence, how bioethics principles are applied, and the impacts of bias and values on decision-making, is also warranted.

The Belief-Dilemma-Action Model may be used as a foundation for development of health care provider training as well as a culturally informed ethical decision-making framework for application in youth gender health care. Health care provider competencies may be enhanced through trainings in which belief congruence and tension; the law; capacity evaluation; complex family situations; evidence-based practice; and cisnormative, heteronormative, and bionormative assumptions are addressed. Evaluation of the effectiveness of this model as an analytic tool may be undertaken through research on health care provider responses to specific scenarios. Research should also be conducted to understand impacts of trainings and applicability of ethical decision-making frameworks based on the Belief-Dilemma-Action Model within youth gender health care and in practice with other populations.

Trans youth continue to experience disparities in health and overall wellbeing. Increased availability of gender health care is essential for addressing this issue, however, many challenges exist related to the provision of youth gender health care. This dissertation has explored several ethical issues in this field, including: specific dilemmas faced by health care providers; the

application of bioethics principles in the construction of ethical dilemmas; how decision-making is impacted by health care provider beliefs; and the actions taken in response to ethical dilemmas. Documentation of youth and parent decision-making processes and youth experiences with contrasting health care provider approaches to care were intended to bridge a gap between the lived experiences of trans youth and parents of trans youth and the approaches of health care providers endeavoring to support them. The findings of this research indicate that youth are capable of making decisions about their own gender health care, that youth outcomes are affected by multiple barriers to care, that ethical decision-making practices are inconsistent and influenced by health care provider beliefs, and that practice guidelines, further research, and policy changes are needed to better support youth gender health care. With continued research to support evidence-based practices; development of youth, parent and health care provider resources; and education for health care providers on ethical and shared decision-making within youth gender health care, trans youth can be better supported in both their gender health and their overall wellbeing.

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Appendices

Appendix A



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THE UNIVERSITY OF BRITISH COLUMBIA



Stigma and Resilience
Among Vulnerable
Youth Centre

Consent Form for Youth

Trans Youth Hormone Therapy Decision Making Study

1. Who is conducting the study?

Principal Investigator: Elizabeth Saewyc, UBC School of Nursing. Tel. [REDACTED]

Co-Investigator: Beth Clark, UBC Interdisciplinary Studies Graduate Program. I am a PhD Student at UBC and this project will be part of my PhD thesis. Tel. [REDACTED]

Co-Investigator: Sheila Marshall, UBC School of Social Work. Tel. [REDACTED]

Co-Investigator: Dan Metzger, UBC Faculty of Medicine. Tel. [REDACTED]

Co-Investigator: Alice Virani, UBC Centre for Applied Ethics. Tel. [REDACTED]

2. Who is funding the study?

Funding for this research is provided by the UBC Public Scholars Initiative.

3. What is the purpose of the study?

We are interested in learning how trans youth, their parents/caregivers, and their health care providers make decisions about starting hormone therapy. This study will help us better understand the challenges people face and what resources are helpful in their journeys. The results will help us develop decision making tools that can be used to improve health care systems for trans youth. We are happy to answer any questions you have about the purpose of this project.

4. What happens in the study?

If you decide to participate, you will meet with a researcher for about 15 minutes to review this consent form and ask any questions you have. You will then participate in one interview that will last about an hour. You will be asked questions about how you made (or are making) your hormone therapy decision. You will have an opportunity to map out your decision making journey on paper. An audio recording will be made of the interview.

You will be free to stop the interview at any time and you may request that your interview not be used in the project. If you wish, we will provide you with a copy of your interview transcript and decision map. If there are parts of the interview transcript or decision map that you would like removed from our records, we will remove them up until the time the study is published.

5. Study Results

The results of this study will be reported in a graduate thesis and a community-friendly report. They may also be published in journal articles and books. You will be given information about where to find results of the research. You will also be invited to participate in a youth group that will be planning creative ways to share the results of this study.

6. Risks

We do not think there is anything in this study that could be harmful to you. If you find any of the questions upsetting or would like to be connected with supports after the interview, please let one of the researchers know.

7. Confidentiality

Your confidentiality will be respected. Information that discloses your identity will not be released unless required by law. If you tell us about suicidal intention or abuse and/or neglect of a child or an elderly person, please know that we must report this information to the appropriate authorities.

All audio recordings, decision maps, interview transcripts, and notes will be kept on a secure server and password protected computer at the University of British Columbia, Stigma & Resilience Among Vulnerable Youth Centre. Only Beth Clark and Elizabeth Saewyc will have access to your original records. Your name, and any other information that is likely to identify you, will be changed in publications and presentations about this study.

8. Benefits and compensation

You will receive a \$25 honorarium for participating in the study. Other benefits of participating in the study may include helping to improve health care systems for trans youth and being connected with supportive resources.

9. Contact information

If you have any questions or concerns about what we are asking of you, please contact one of the researchers listed at the top of the first page of this form.

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 UBC Office of Research Ethics at [REDACTED] or if long distance e-mail [REDACTED] or call toll free [REDACTED]

10. Consent and signature

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason and without any negative impact on your access to health or support services.

Your signature below indicates that you have received a copy of this consent form for your own records.

Your signature indicates that you consent to participate in this study.

Participant Signature

Date

Printed Name of the Participant

Appendix B



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THE UNIVERSITY OF BRITISH COLUMBIA



Stigma and Resilience
Among Vulnerable
Youth Centre

Consent Form for Parents/Caregivers

Trans Youth Hormone Therapy Decision Making Study

1. Who is conducting the study?

Principal Investigator: Elizabeth Saewyc, UBC School of Nursing. Tel. [REDACTED]

Co-Investigator: Beth Clark, UBC Interdisciplinary Studies Graduate Program. I am a PhD Student at UBC and this project will be part of my PhD thesis. Tel. [REDACTED]

Co-Investigator: Sheila Marshall, UBC School of Social Work. Tel. [REDACTED]

Co-Investigator: Dan Metzger, UBC Faculty of Medicine. Tel. [REDACTED]

Co-Investigator: Alice Virani, UBC Centre for Applied Ethics. Tel. [REDACTED]

2. Who is funding the study?

Funding for this research is provided by the UBC Public Scholars Initiative.

3. What is the purpose of the study?

We are interested in learning how trans youth, their parents/caregivers, and their health care providers make decisions about starting hormone therapy. This study will help us better understand the challenges people face and what resources are helpful in their journeys. The results will help us develop decision making tools that can be used to improve health care systems for trans youth. We are happy to answer any questions you have about the purpose of this project.

4. What happens in the study?

If you decide to participate, you will meet with a researcher for about 15 minutes to review this consent form and ask any questions you have. You will then participate in one interview that will last about an hour. You will be asked questions about how you made (or are making) decisions about hormone therapy. You will have an opportunity to map out your decision making journey on paper. An audio recording will be made of the interview.

You will be free to stop the interview at any time and you may request that your interview not be used in the project. If you wish, we will provide you with a copy of your interview transcript and decision map. If there are parts of the interview transcript or decision map that you would like removed from our records, we will remove them up until the time the study is published.

5. Study Results

The results of this study will be reported in a graduate thesis and a community-friendly report. They may also be published in journal articles and books. You will be given information about where to find results of the research.

6. Risks

We do not think there is anything in this study that could be harmful to you. If you find any of the questions upsetting or would like to be connected with supports after the interview, please let one of the researchers know.

7. Confidentiality

Your confidentiality will be respected. Information that discloses your identity will not be released unless required by law. If you tell us about suicidal intention or abuse and/or neglect of a child or an elderly person, please know that we must report this information to the appropriate authorities.

All audio recordings, decision maps, interview transcripts, and notes will be kept on a secure server and password protected computer at the University of British Columbia, Stigma & Resilience Among Vulnerable Youth Centre. Only Beth Clark and Elizabeth Saewyc will have access to your original records. Your name, and any other information that is likely to identify you, will be changed in publications and presentations about this study.

8. Benefits and compensation

You will receive a \$25 honorarium for participating in the study. Other benefits of participating in the study may include helping to improve health care systems for trans youth and being connected with supportive resources.

9. Contact information

If you have any questions or concerns about what we are asking of you, please contact one of the researchers listed at the top of the first page of this form.

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 UBC Office of Research Ethics at [REDACTED] or if long distance e-mail [REDACTED] or call toll free [REDACTED]

10. Consent and signature

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason and without any negative impact on your access to health or support services.

Your signature below indicates that you have received a copy of this consent form for your own records.

Your signature indicates that you consent to participate in this study.

Participant Signature

Date

Printed Name of the Participant

Appendix C



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THE UNIVERSITY OF BRITISH COLUMBIA



Stigma and Resilience
Among Vulnerable
Youth Centre

Consent Form for Health Care Providers Trans Youth Hormone Therapy Decision Making Study

1. Who is conducting the study?

Principal Investigator: Elizabeth Saewyc, UBC School of Nursing. Tel. [REDACTED]

Co-Investigator: Beth Clark, UBC Interdisciplinary Studies Graduate Program. I am a PhD Student at UBC and this project will be part of my PhD thesis. Tel. [REDACTED]

Co-Investigator: Sheila Marshall, UBC School of Social Work. Tel. [REDACTED]

Co-Investigator: Dan Metzger, UBC Faculty of Medicine. Tel. [REDACTED]

Co-Investigator: Alice Virani, UBC Centre for Applied Ethics. Tel. [REDACTED]

2. Who is funding the study?

Funding for this research is provided by the UBC Public Scholars Initiative.

3. What is the purpose of the study?

We are interested in learning how trans youth, their parents/caregivers, and their health care providers make decisions about starting hormone therapy. We are also interested in how health care providers navigate ethically challenging situations related to hormone therapy readiness assessment. This study will help us better understand the challenges people face and what resources are helpful in their journeys. The results will help us develop decision making tools that can be used to improve health care systems for trans youth. We are happy to answer any questions you have about the purpose of this project.

4. What happens in the study?

If you decide to participate, you will meet with a researcher for about 15 minutes to review this consent form and ask any questions you have. You will then participate in one interview that will last about an hour. You will be asked questions about ethical dilemmas you have encountered in practice, your approach to ethical decision making, and how you engage with youth and parents/caregivers in shared decision making. An audio recording will be made of the interview. You will be free to stop the interview at any time and you may request that your interview not be used in the project. If you wish, we will provide you with a copy of your interview transcript. If there are parts of the interview transcript that you would like removed from our records, we will remove them up until the time the study is published.

5. Study Results

The results of this study will be reported in a graduate thesis and a community-friendly report. They may also be published in journal articles and books. You will be given information about where to find results of the research.

6. Risks

We do not think there is anything in this study that could be harmful to you. If you find any of the questions upsetting or would like to be connected with supports after the interview, please let one of the researchers know.

7. Confidentiality

Your confidentiality will be respected. Information that discloses your identity will not be released unless required by law. If you tell us about suicidal intention or abuse and/or neglect of a child or an elderly person, please know that we must report this information to the appropriate authorities.

All audio recordings, interview transcripts, and notes will be kept on a secure server and password protected computer at the University of British Columbia, Stigma & Resilience Among Vulnerable Youth Centre. Only Beth Clark and Elizabeth Saewyc will have access to your original records. Your name, and any other information that is likely to identify you, will be changed in publications and presentations about this study.

8. Benefits and compensation

You will receive a \$25 gift card for participating in the study. Other benefits of participating in the study may include helping to improve health care systems for trans youth.

9. Contact information

If you have any questions or concerns about what we are asking of you, please contact one of the researchers listed at the top of the first page of this form.

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 UBC Office of Research Ethics at [REDACTED] or if long distance e-mail [REDACTED] or call toll free [REDACTED]

10. Consent and signature

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason and without any negative impact on your access to health or support services.

Your signature below indicates that you have received a copy of this consent form for your own records.

Your signature indicates that you consent to participate in this study.

Participant Signature

Date

Printed Name of the Participant

Appendix D

Youth Interview Guide

Let's start with a few background questions:

1. How old are you?
2. Where do you live? Who do you live with?
3. How do you describe your gender identity?

As you know this study is about the process people go through when they make decisions about hormone therapy.

4. Have you made a decision yet about whether hormone therapy is right for you?
5. Can you tell me about when you first started thinking about hormone therapy?

I have some paper here that we can use to help map out your journey so far. This is a timeline that starts with when you first were thinking about hormone therapy and goes up until today. Let's add the pieces we've talked about so far (time points for: started thinking about it, today, and decision – if applicable). I'd like us to spend some time filling in whatever has been important to you in deciding/thinking about hormone therapy. This could be important moments, people you've talked with, information that you have found – really anything that stands out.

6. What should we add?

Thanks for sharing all of these important parts of your journey. Another question I have is about something called shared decision making. When someone is deciding about getting some kind of health care, there are often other people involved. For youth, parents or caregivers are often involved in decision making. Doctors, nurses, or other health care providers may also have a part in making decisions.

7. When you think about your decision making process, how were other people involved?
8. What questions were (are) really important for you to have answered when you were making your decision (before you make your decision)?
9. Are there things that were important to other people that were not that important to you (e.g. what were your parents or doctors most interested in/concerned about)?
10. What helped you the most in your decision making process?
11. Are there supports/information that would have been helpful that you did not have?
12. In a few months a group of youth will be meeting to develop creative ways to share the results of this research study. Are you interested in participating in this?

Appendix E

Parent/Caregiver Interview Guide

Let's start with a few background questions:

1. Who lives together in your home?
2. How old is your trans child? How do they describe their gender identity?
3. How long ago did they come out to you?
4. When did you first start discussing hormone therapy with them?
5. Where is your child at now with hormone therapy? (Decided? In process? On hormones?)
6. Have you come to a decision about whether hormone therapy is right for your child?

I have some paper here that we can use to help map out your journey so far. This is a timeline that starts with when you first were thinking about hormone therapy for your child and goes up until today. Let's add the pieces we've talked about so far (time points for: started thinking about it, today, and decision – if applicable). I'd like us to spend some time filling in whatever has been important to you in deciding/thinking about hormone therapy. This could be important moments with your kid, people you've talked with, information that you have found – really anything that stands out.

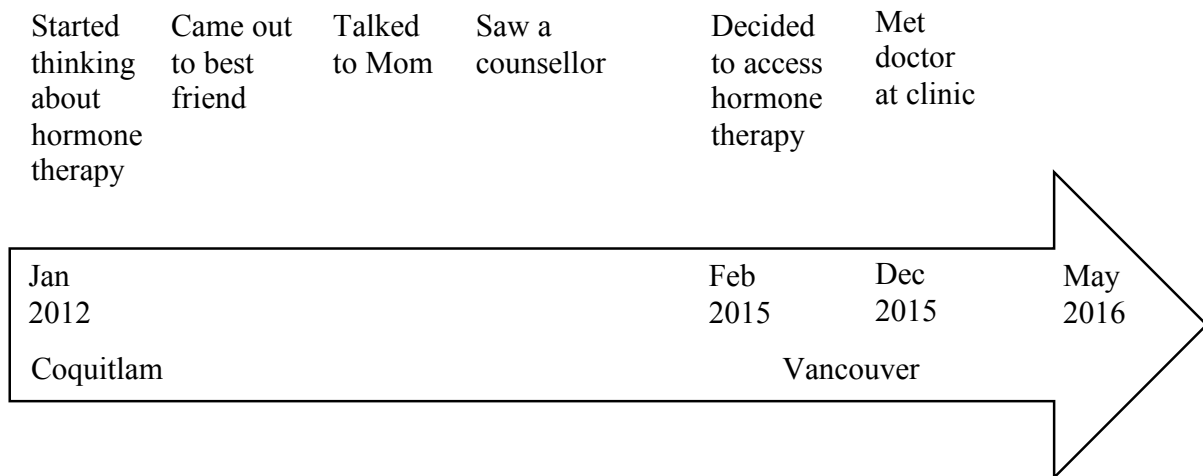
7. What should we add?

Thanks for sharing all of these important parts of your journey. Another question I have is about shared decision making. When someone is deciding about getting some kind of health care, there are often other people involved. For youth, parents or caregivers are often involved in decision making. Doctors, nurses, or other health care providers may also have a part in making decisions.

8. When you think about this hormone therapy decision making process, who was involved in making the decision (or is involved now)?
9. What questions were (are) really important for you to have answered when you were making your decision (before you make your decision)?
10. Are there things that were important to other people that were not that important to you (e.g. what were your child or the doctors most interested in/concerned about)?
11. What helped you the most in your decision making process?
12. Are there supports/information that would have been helpful that you did not have?
13. Can we contact you in the future to share the results of the study?

Appendix F

Sample Lifeline Drawing



Appendix G

Health Care Provider Interview Guide

Let's start with a few background questions:

1. What is your professional role in working with trans youth?
2. How long have you been conducting hormone readiness assessments or having hormone care planning appointments with youth under age 19?
3. Briefly, what sort of training have you had for this work?

As you know this study is about the process people go through when they make decisions about hormone therapy and the ethical dilemmas that arise in practice.

4. Can you describe one or two of the most significant ethical dilemmas you have encountered in your practice?
5. We've talked about a/some specific situation(s). Could you tell me what some of the ethical issues are that routinely come up in your practice? (e.g. autonomy/consenting to care, risks/benefits)

Next I have a case example that I'd like to get your thoughts on (printed copy given to participant).

You receive a referral for a 15-year old youth: Aiden identifies as a transguy. He is out to close friends and family. He reports that his father is fairly supportive, but lives in another province, travels a lot for work, and does not see Aiden much. Aiden lives with his mother, who is refusing to acknowledge his gender identity, name, or pronouns, and does not support transitioning at school or starting hormone therapy. Aiden would like to start testosterone as soon as possible, and to have chest surgery in a couple of years. Aiden is clear about his identity and need for hormones. When asked about what would happen if he started hormones while living with his mother, Aiden states that he will be able to hide it from her until she comes around to the idea.

6. The referring provider would like your opinion on whether or not to start Aiden on hormones. What do you see as the key ethical issues in this case? How would you approach this case?
7. Is there a particular ethical framework that you use in your practice (e.g. bioethics, disciplinary code of ethics)?
8. Are there any resources that you find helpful when ethical challenges come up?

Health care providers sometimes report moral distress around their work. Moral distress can be defined as distress that comes from not being sure of the most ethical decision in a certain situation (e.g., what is in the best interest of a youth, or how to honour autonomy or minimize harm) or it could mean having something prevent you from acting in the way that you feel is most ethical. (This is a particular kind of distress that is considered different from psychological distress or burnout, though they may be related.)

9. Can you tell me about any instances of moral distress related to your clinical work with trans youth?

The other component of this study is on shared decision making.

10. Who is usually involved in making decisions about a youth starting hormone therapy?
11. What questions are essential for you to have answered before starting a youth on hormones?
12. What kind of supports, resources, and referrals do you provide for youth and parents/caregivers?

Later on, I will also be talking with youth and parents/caregivers.

13. What would you would like to know about youth and parent/caregiver shared decision making experiences?
14. Are there clinical tools, supports or information that youth think would be helpful to you in your practice that are not available?