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A Reflection on Modern Western Adolescent Transitional Care of Patients with Chronic Conditions

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A REFLECTION ON MODERN WESTERN ADOLESCENT TRANSITIONAL
CARE OF PATIENTS WITH CHRONIC CONDITIONS

by

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A thesis submitted in partial fulfillment of the requirements
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ABSTRACT

Transitional care represents a critical juncture in the continuing care of patients with chronic conditions, particularly for adolescent patients. It also represents a significant point of failure in that process for adolescents, with many patients experiencing difficulties during the transition between adolescent and adult medicine that lead to negative long-term impact on health and wellbeing. This thesis aims at addressing adolescent transitional care processes and its obstacles through a broad medical humanities inquiry in a multidisciplinary dialogue between philosophy, social sciences, and medicine. The social, anthropological, and medical concepts of adolescence and autonomy were derived from a literature review and used to identify and philosophically analyze obstacles to adolescent transitional care. Studies were used to illuminate those obstacles. For a first person-perspective analysis, an autoethnography was developed to provide patient testimony, towards improving the reflection on transitional care. This analysis tested the alignment of the author's experiences in interacting with a healthcare transition as part of the patient population with those recorded in the literature. This study has found barriers and facilitators concerning autonomy and communication at many levels and among many parties involved in the transition, such as patients, caregivers, healthcare providers, and healthcare systems operations, particularly regarding insurance management. This study recommends a focused coordination of primary care and/or transitional care specialists with the participation of adolescent patients' voices and testimony to develop and manage challenges to autonomy in transitional care.

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TABLE OF CONTENTS

INTRODUCTION	1
To Pave the Way Towards a Better Transition	1
Methodology and Methods	2
Theoretical Background	3
Significance	6
ADOLESCENCE IN CONTEXT	9
Adolescence in a Social Context	9
A Historical Lens	9
An Anthropological Lens	10
Sociological Considerations for Diverse Adolescent Populations	11
Adolescence in a Medical Context	13
A Synthesis of the Contexts of Adolescence	15
On Adolescent Autonomy in a Medical Context	15
Assessing Autonomy and Transition Readiness	17
ON BARRIERS AND FACILITATORS	19
Illustrative Studies from the Literature and an Autoethnography	19
Casey	19
Australian Psychologists	20
P	21
Autoethnography	23
On Barriers	27
Considerations by Stakeholder Perspective	27
Considerations by Patient Subpopulation	30
On Facilitators	31
A Synthesis	33
A PHILOSOPHICAL ANALYSIS	34
The Road So Far	34
The Way Forward	35

CONCLUSION	38
REFERENCES	40

INTRODUCTION

To Pave the Way Towards a Better Transition

This thesis aims at addressing adolescent transitional care processes and its obstacles through a broad medical humanities inquiry in a multidisciplinary dialogue between philosophy, social sciences, and medicine. The primary layer of this investigation concerns the area of Western adolescent transitional care for patients with chronic conditions. In this context, transitional care generally refers to the movement of patients from pediatric and adolescent healthcare systems to adult healthcare systems. A significant number of patients are required to go through such a transition at varying points and for different reasons (McKenzie et al., 2019), and many are met with significant barriers to a successful transition upon doing so, often with detrimental health impacts as a result (White and Cooley, 2018). As such, this thesis discusses barriers and facilitators via an examination of adolescence from a multidisciplinary perspective. It begins by describing the development of adolescence in social, historical, and anthropological contexts, with special considerations paid to patients from social out-groups in reference to medicine.

This multidisciplinary view of adolescence informs the reflection on the problem of autonomy applied to medical decision-making processes in health care, before giving way to a discussion on the barriers and facilitators facing transitional care. A few case studies are discussed with a focus on the barriers and facilitators contained therein regarding the transitional care apparatus in healthcare. An autoethnography is also used as a method of bioethical research that is inclusive of the patient's testimony and voice, and in particular, the reflexive voice of the adolescent patient with a chronic condition who is passing through a transition of care. Patient-centered

recommendations on implementing changes to support the development of patient autonomy are suggested to balance the maximization of patient health outcomes with respect to patient autonomy.

Methodology and Methods

The field of bioethics is inherently interdisciplinary (Sugarman & Sulmasy, 2010). Accordingly, in this thesis, an interdisciplinary theoretical investigation was conducted, focusing on the problem of adolescent autonomy. The main strands of research were on philosophical and anthropological methods, as well as in reference to medical humanities at large. Principlism (Beauchamp & Childress, 2001) was used as a theoretical framework in the bioethical analysis of the problem of adolescent patients with chronic conditions' autonomy in transitional care, inclusive of the analysis of casuistry.

Ellis et al.'s (2011) Autoethnography protocol was used for eliciting a first-person perspective documentation for this work from the author on adolescent transitional care, serving as “an approach to research and writing that seeks to describe and systematically analyze personal experience in order to understand cultural experience” (ibid). Though numerous significant challenges to the validity of autoethnography exist, there is significant value in its use, particularly in analyzing relational ethics as this study, in part, does (Denshire, 2014). To the limit of this thesis, no studies in transitional care and similar fields were found that attempted to incorporate autoethnography as part of their methodologies. In this thesis, in the pursuit of a method of widening the door for incorporation of first-person perspectives and patient-research

partnerships profiles, an autoethnography is exhibited alongside the case studies accompanying the discussion on barriers and facilitators.

A preliminary historical reconstruction of the concepts of life transitions, childhood, adolescence and adulthood, with a focus on adolescence was conducted, based on the work of Philippe Aries (Aries, 1960/1962).

A limited literature review on the medical science and humanities literature on the topic of adolescent transition of care as related to medical error was conducted with the databases PubMed and JSTOR and presented (Schepps & Garbayo, 2021), exploring barriers and facilitators to a successful transition.

Three studies were drawn from the literary investigation to illustrate patterns in concepts related to barriers and facilitators to transitional care for adolescents with chronic conditions. A first case focuses on a girl suffering from cerebral palsy as she transitions between healthcare systems upon enrolling in college; a second case focuses on a group of Australian psychologists' struggles with the autonomy of their adolescent patients, and a third case on the legal fallout stemming from a controversy surrounding a British teenager's autonomy after she declined potentially life-saving treatment following an overdose. Together, these, along with the autoethnography, render a depiction of a range of experiences that informs the analysis of barriers and facilitators to transitional care for adolescent patients.

Theoretical Background

To better structure a discussion of Western transitional care, we take time now to define and differentiate some key terms. To start, Kumagai et. al define “transition-related healthcare

intervention,” scoped to this specific patient population, as “the purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented healthcare systems” (2020). What is relevant to note here is the direct intent with which a transition is carried out; the process of transitional care, while occasionally sudden, is never unexpected, and is therefore always carried out with clear intent by health providers, patients, and their guardians. de Hosson more precisely defines the term transitional care as “the process by which adolescents and young adults with chronic childhood illnesses are prepared to take charge of their lives and their health in adulthood” (2019). Here we begin to see transitional care as a crucial occasion to develop autonomy of adolescent patients. Additionally, de Hosson defines the term “transfer” similarly to Kumagai et. al’s definition of “transition-related healthcare intervention,” referring to transfer as “an event or series of events through which adolescents and young adults with chronic physical and medical conditions move their care from pediatric to an adult health care environment” (2019). Whereas a transition marks an important milestone in the care of an adolescent patient, an accomplishment of sorts for the patient, a transfer acts as a mere event or events that set up a transition, something that is done to, rather than by, the patient. Less structured and seemingly less permanent than a transition, a transfer carries with it a lower threshold of intent and lies somewhat outside the scope of study herein, as it is theoretically able to occur even in the absence of a transition.

What these similar but clearly distinct definitions reveal is the complexity of transitional care. It is not a single act, but a moving process, occurring over an extended period of time and space, that may contribute to the development of a patient’s self-determination. It often involves numerous separate but related parties coordinating and cooperating, attempting to work as a unit

and requires keen and proactive communication on the parts of all involved parties. It is a process carried out with clear intention—to provide for the continuing care of the adolescent patient—but this intention may not always be more specific than as mentioned. Moreover, transitional care can be further complicated by structural factors such as the accessibility of treatment and other circumstances surrounding the transfer, particularly in cases involving the transitions of patients with chronic conditions (Betz, 1998). Succinctly put, adolescent transitional care is a complex and unique entity with innumerable potential obstacles to the uninterrupted and satisfactory continuation of care for the adolescent patient

Another key lexical term, “adolescents,” refers to patients “who [are] no longer [children] but who [have] not yet become [adults]” (Collins Dictionary, n.d.). Of note is that this term is in use in its Western colloquial parlance, as opposed to its use in a medical context.

The World Health Organization (WHO) defines adolescents as those people between 10 and 19 years of age. The great majority of adolescents are, therefore, included in the age-based definition of “child”, adopted by the Convention on the Rights of the Child, as a person under the age of 18 years. Other overlapping terms used in this report are youth (defined by the United Nations as 15–24 years) and young people (10–24 years), a term used by WHO and others to combine adolescents and youth (WHO, 2014).

Apparent in this construct, then, is the inherent influence society plays in defining this analysis’ patient population as it is (Aries 1960/1962). Additionally, “chronic conditions” can be taken to refer to any health condition that is “continuing or occurring again and again over time.” This term can refer to a wide range of conditions, from cancer and diabetes to gastrointestinal

conditions like Crohn's Disease, to mental illnesses, among others (Bernell & Howard, 2016). Such a broad framing of chronic conditions allows for the consideration of inclusivity to patients spanning the entire range of possible conditions.

Significance

Transitional care for adolescents with chronic conditions is a highly significant problem in today's healthcare environment. Medical error is an important outcome of such transitions, leading to the deterioration of health of adolescents with chronic conditions (Campbell et al, 2016).

There are difficulties also in conceptual and metric integration across communities in the world. For example, estimates of the size and scope of the patient population at risk can be difficult to achieve for a variety of reasons, starting with misalignment of definitions of adolescence, which vary regarding age ranges, and misalignment of definitions of chronic conditions between regions. For instance, definitions of what constitutes chronic asthma can differ wildly, ranging from exhibition of severe symptoms to simply seeking treatment to anything in between. This variance can cause measurements of the overall prevalence of chronic conditions in adolescent patients to reduce by around half globally (Michaud et al., 2007). With that limitation in mind, in North America, about 15-20% of patients ages 12-17 live with a chronic condition, of whom 90% need continuous care into adulthood (Marani et al., 2020). However, as many as 83% of those patients with "Special Healthcare Needs" and 86% without those needs are inadequately prepared for their transition, as determined by their ability to speak alone with their physicians about their last preventative visit, about developing self-care skills, about their changing future

healthcare needs, and about continuing care into adulthood (White and Cooley, 2018). It is crucial to note that, particularly given the necessarily structured, intentional nature of the transition, the lack of preparedness can be a crucial point of failure within the process of transitional care, and, by extension, in the overall care of these patients. White and Cooley further explain that a failed transition or unstructured transition is associated with numerous negative consequences for a patient's health outcomes, including:

1. higher likelihoods of medical complications,
2. limits on overall health and wellbeing,
3. decreased adherence to care and continuity of care, and
4. lower patient satisfaction, among others (2018).

Thus, a significant patient population is affected by transitional care as presently constructed, though that patient population is so broad and diverse as to render any attempts to cast their experiences as a monolith to be moot. Nevertheless, a significant portion of this population experiences repeated patterns of obstacles or barriers in completing a transition and/or in preparing for one. These obstacles result in direct harms, both tangible and intangible, to those patients who experience them. Conversely, facilitators to overcoming these obstacles, such as adequate preparation for a transition, can bear positive impacts on health outcomes.

As such, it becomes critical to question not only in what form these barriers and obstacles arise, but also how and why they arise by engaging in a dialogue with the medical humanities and other social sciences. Additionally, it becomes important to note what differences exist, if any,

between the types and frequencies of certain barriers across various segments of the patient population, and the historical, social, and anthropological sources of those differences. Startlingly little cohesive literature exists on this subject, and to complete such an investigation requires an examination not only of modern healthcare, but also of the historical, sociological, medical, and anthropological concepts of adolescence and autonomy. To do so enables the construction of contrasting social and medical views of the patient population. This construction becomes invaluable in considering the origins and rises of the barriers and facilitators affecting transitional care, and therefore in any critical, multidisciplinary reflection of them. Such a reflection empowers the development of recommendations to prevent and mitigate harms to the patient population. Thus, this investigation begins with an exploration of childhood and adolescence, wherein the roles of their developments on both the general and medical autonomy afforded to the patient population will become overwhelmingly evident.

ADOLESCENCE IN CONTEXT

Adolescence in a Social Context

A Historical Lens

Today, Western childhood and adolescence are typically defined relative to puberty. For example, childhood is often referred to roughly as the period between infancy and the time an individual enters biological puberty (Encyclopaedia Britannica, 1998), and adolescence is referred to as the period between one's entrance to puberty and the time at which biological development stops (Csikszentmihalyi, 2021), with adulthood constituting the remainder of one's lifespan. However, as Aries writes (1960/1962), before the 1500s, children from almost every background transitioned directly into adulthood via apprenticeships and the like starting at the age of seven, meaning there was no adolescence in Western cultures. This trend changed alongside the rise of formal schools for the masses in Europe and the rigid disciplinary codes that were imposed within them. Not only were students separated from adulthood by the physical boundaries of the school grounds, but also by the disciplinary codes and social expectations placed on the students during their time there. This separation both extended the boundaries of childhood into a person's early teens and exacerbated an increasing focus on the preservation of the Western child's moral integrity (Schepps, 2019).

The increasing focus on preserving the child's moral integrity continued into the nineteenth century, when older teens became distinct from children via their enrollment in formal military academies (Aries, 1960/1962). This explicit connection between military involvement and

adolescence has mostly disappeared, but both the focus on the moralization of youth and the distinction between younger children and early adolescents remains in Western society (Schepps, 2019). This can be seen in the continued employment of disciplinary techniques in classrooms in an attempt to correct behaviors ranging from chewing gum to bullying that are seen as immoral (Nucci et al., 2014).

Altogether, adolescence has emerged over time to fill the gap created between childhood and adulthood by the rise of formal primary education in Europe in the 16th and 17th centuries. From its military roots to its modern incarnations, among its many other benefits, one of the primary impacts of schooling has been the moralization of youth. However, in response to this moralization, it seems that Western society has in turn taken to reorienting its own framing of children and adolescents as primarily moral beings, whose sanctity must be preserved. While there have doubtlessly been overwhelming benefits to this reframing and preservation of youth, it has come at the expense of their moral agency, particularly during adolescence. This impact, directed specifically towards healthcare and particularly the care of those adolescents with chronic conditions, offers an area of potential development insofar as autonomy is key to the kinds of medical decision-making necessary for a successful transition to adult care to occur.

An Anthropological Lens

Anthropology offers another mechanism through which the experience of adolescence in Western culture can be explained. Specifically, Johnson-Hanks' anthropological theory on vital conjunctures attempts to define development as a process that is simultaneously universal and fluid. Broken up by common major events and changes such as weddings and births, Johnson-

Hanks' version of the life cycle provides another meaningful contrast against the largely biological foundation on which modern medical understandings of life stages are built, as will be discussed shortly. Adolescence, under this model, marks a period of near limitless possibility for the future, but that lacks a defined start and end point, and is entered and exited fluidly, with the exact timing dependent on a variety of cultural and individual factors (2002).

Anthropologically, then, adolescence can again be understood as a means of bridging the gap between childhood and adulthood. However, unlike a historical analysis regarding the advent of formal education which would align adolescence roughly along the boundaries offered by standard Western grade levels, an anthropological analysis provides a more dynamic alternative for the framing of adolescence. By not limiting adolescence to defined chronological entry and exit points and instead pointing to developmental markers as the boundaries of adolescence, such an analysis gives a viable explanation for the varying timescales along which autonomy is developed in adolescence. When subsequently applied to the realm of medical decision-making, then, this analysis provides both a useful framework against which to evaluate the development of an adolescent's capacity to handle their own care and a poignant contrast against modern legal and structural frameworks, which are often based around standard, age-based benchmarks (Alderman et al., 2003).

Sociological Considerations for Diverse Adolescent Populations

A sociological perspective allows for an understanding of the role that being in an out-group, such as an ethnic or racial minority, has in the experience of adolescence, including adolescence in a medical context. Given the social and cultural implications of being a racial and/or ethnic

minority, or of a non-male gender, in the West, adolescence is itself borne out differently among patients within these populations. Rivas-Drake and Livas Stein affirm this hypothesis, particularly in reference to an anthropological perspective on adolescence, noting that adolescents in these groups experience tangible impacts on their health and wellbeing as they pass into adulthood as seen through an anthropological lens as a result of factors like acculturative stress, a phenomenon in which competing cultural expectations manifests in heightened levels of physical stress. Discrimination is also a unique, major factor affecting minority adolescents, with evidence suggesting that 50% of Latinos aged 18 to 24 and 87% of African Americans aged 12 to 17 experience some form of ethnic or racial discrimination in the United States. This particular factor is also resonant with youths of other ethnic and racial minorities (2017). As such, it can be seen that, through a variety of negative, external factors, such as discrimination and acculturative stress, Western societal expectations surrounding minority adolescents, and thus the moral agency afforded to them, are tangibly different from those facing their majority counterparts, and from each other. Likewise, the internalized experience of being an adolescent in these groups is also altered by these factors, providing an alternate viewpoint from which to evaluate their effects on a patient entering a transition.

Rivas-Drake and Livas Stein continue by explaining that minority adolescence is not merely shaped by negative factors from outside. Rather, factors, like positive self-identification and instillment of cultural values, derived from the minority communities themselves also play an instrumental part in shaping adolescence for minority patients. In doing so, those factors can impact the patients' interactions with transitional care as a consequence. For example, a minority adolescent's internal relationship with both his or her own ethnic and/or racial identity and with

the values instilled by his or her individual community carries correlative impacts on both the tangible health and wellbeing of the individual and on his or her own qualitative experience of adolescence (2017).

Differences can also be seen along the lines of sex and gender. For example, Lindsay et al. explains that women both perceive themselves as more autonomous than men and are more responsive to social support factors during a transition than men. In the same study, women were found to have a preference for same-sex physicians that was not found in men, a factor which was linked to the intimacy of care, particularly for psychosocial conditions (2016).

As such, it can again be shown that the experience and agency of an adolescent in a social out-group is fundamentally different from those of their counterparts in other groups. While the groups and effects listed above do not represent a comprehensive list of all manifestations of out-group socialization on an adolescent's experience of transitional care, they do successfully illustrate the fact of differences in that experience arising from that socialization. As will be demonstrated later in this investigation, these differences, in turn, manifest in differential outcomes following interactions with the process of transitional care among and within these patient populations.

Adolescence in a Medical Context

As Smith writes (2019), pediatrics began as a specialty in Europe in the 1800s before spreading westward into the US during around the time of the Civil War (Schepps, 2019). Subsequently, adolescent medicine rose in the same formal education facilities, like military schools, that originally divided childhood from adolescence later in the 1800s (Alderman et al., 2003). These

ties to formal schooling prevailed and served to provide concrete boundaries, translated later on the timeframe of adolescent healthcare, and thereby on the timeframe of the transitional care process. In doing so, the ties to formal education created a very rigid and somewhat narrow definition of what constitutes an adolescent in a medical context, as illustrated by the WHO's definition which contains adolescence between the ages of 10 and 19 (2014). This analysis of the definition of an adolescent in a medical context becomes useful in evaluating the causes of some of the barriers and facilitators to transitional care.

In any case, Schepps (2019) continues by explaining that adolescent medicine evolved continuously throughout the 60s and 70s, when official rules concerning adolescent care began to form and official training protocols for adolescent medicine arose. A set of legal decisions affirming adolescent patients' rights to confidentiality took place during this period. Finally, the Task Force on Pediatric Education released a report that legitimized adolescent medicine and ultimately resulted in sub-accreditation for the subspecialty under the umbrella of pediatrics (Alderman et. al, 2003). This formalization, while legitimizing the field in such a way as to render the study of transitional care possible, did little to change the construct of the adolescent patient in the healthcare setting. Grounded in temporality and limited in scope, the adolescent in the healthcare setting is a somewhat rigid construct, and one that acts in contrast to the way adolescence itself functions in Western society. In this conflict between the social and medical contexts lies at least one route of examining the sources of barriers affecting transitional care.

A Synthesis of the Contexts of Adolescence

In sum, it can thus be understood that adolescence in general, while not as statically bound as a historical formal education framing would imply, traces much of its modern nature to a historical decline in autonomy that is rooted in the Western societal framing around childhood as it morphs into modern “adolescence.” Furthermore, the social experience of adolescence for patients within social out-groups is fundamentally different from that of those in in-groups. It is important to keep these facts in mind when viewing the modern framing of adolescence through the lens of healthcare during and immediately surrounding a transition when these constructions may affect barriers, facilitators, and the potential remedies to the challenges facing transitional care for patients in this population.

On Adolescent Autonomy in a Medical Context

Autonomy can be regarded as a main pillar in the ethical practice of medicine in alignment with a norm to respect persons—according to Principlism—alongside the principles of beneficence, non-maleficence, and justice. Autonomy is defined at the individual level as, “at a minimum, self-rule that is free from both controlling interference by others and from limitations....”

Applied to medical decision-making, autonomy is essentially the principle that ethically requires the respect of the ability for a patient to make his or her own decisions regarding his or her care.

This ability is functionally contingent on two factors: liberty, or the freedom from external controlling forces in making medical decisions, and agency, or the mental capacity to do so (Beauchamp & Childress, 2001).

Adolescent patients tend not to receive full autonomy in healthcare (Parsapoor et. al, 2014). Notably, it is rare for Western adolescents with chronic conditions to be afforded the authority to make decisions absent external controlling forces (Schepps, 2019). Partridge suggests that this lack of authority is explainable in several ways. Commonly cited as a reason is the fact that adolescents are not fully neurologically developed. As a result, although adolescents under many scenarios have been shown to be able to make comparable decisions to adults, they are still relatively impulsive and less capable of assessing the long-term impacts of decisions that they make. Additionally, adolescents are more prone to making decisions based on expectations of how those choices may impact peers' perceptions of them as opposed to other, more ethically pertinent consequences of the decision (2014). Adolescents have also been found to be more susceptible to environmental stressors in making decisions than adults (Duncan et. al, 2015). All of these factors come into consideration independent of additional, patient-specific impediments to informed decision-making, such as limitations imposed by the patient's condition, for example. Thus, as Schepps writes (2019), it is often the role of the healthcare provider to decide, based on the patient's assessed ability to make informed medical decisions, how much autonomy for making decisions regarding his or her care to leave to the patient (Parsapoor et. al, 2014). Responsibility is also nearly always distributed between the adolescent patient and adult caretakers, with some decision-specific exceptions (Salter, 2017). It should be emphasized, therefore, that while adolescents are the main stakeholder in those medical decisions made regarding their care, it generally remains to their benefit that others be involved along the way, as will later be demonstrated in the case of P. Likewise, it is also key to note that it comes to the distinct gain of those with stake in the transition that adolescent autonomy, to the extent that it is

related to medical decision-making, be developed in advance of the transition within limits imposed by the patient's specific condition and circumstances, as this development enables patients to be better prepared to assume control over their own care following a transfer.

Assessing Autonomy and Transition Readiness

Several tools have been demonstrated as effective in assessing either the capacity to make autonomous medical decisions or transition readiness, including the MacArthur Competence Assessment Tool for Treatment (MacCAT-T) for the former and the Transition Readiness Assessment Questionnaire (TRAQ) for the latter (Hein et. al, 2015; Kiziler et. al, 2017). To measure autonomy, MacCAT-T uses a semi-structured interview to evaluate participants for four aspects of the capacity to consent:

1. the ability "to communicate a choice"
2. the ability "to understand the relevant information"
3. the ability to "appreciate the medical consequences of the situation" and
4. the ability to "reason about treatment choices" (Turrell et al., 2011).

TRAQ, meanwhile, consists of a single, twenty-question form that measures an adolescent's ability to manage their healthcare transition through five lenses, which are "a) managing medications, b) keeping appointment [sic], c) tracking health issues, d) talking with providers, and e) managing daily activities." Responses to each item are scaled from 1-5, giving the entire form an overall score from 20-100, with higher scores representing increased transition readiness (Kiziler et al., 2017).

However, more research is likely needed as to these tools' broad applicability, particularly across national and cultural borders, given their relatively low usage rates. Encouraging though the early returns on such tools may be, the startling fact of their limited and relatively recent appearance in the medical literature regarding non-adult patients serves to emphasize both the lack of autonomy afforded to adolescents in medical decision-making, and the vast ground yet to be covered by this particular branch of healthcare research.

ON BARRIERS AND FACILITATORS

Illustrative Studies from the Literature and an Autoethnography

Casey

Our analysis of the barriers and facilitators facing transitional care turns first to accounts derived from literature and the first-person experience of the author in interacting with the process. Specifically, we now turn to a study on a patient named Casey derived from Schepps (2019). Casey is an adolescent patient making the transition to adult care after beginning college. Casey is seeking long-term care for a seizure disorder and cerebral palsy (Betz, 1998). These disorders place Casey into a category of patient experiencing both physical and neurological impediments as a result of her conditions. Casey enters the process of transitional care unable to assume autonomous control over her long-term care despite her having an understanding of the nature of her conditions. So, a nurse cooperates with Casey, Casey's parents, and both the adult and adolescent healthcare providers to craft a plan to help develop Casey's capacity for autonomy and independence. To develop this plan, the nurse evaluates both Casey's "developmental readiness" to take control over her own care and completes a separate assessment of Casey's capacity for such control based on the nature of Casey's conditions.

As Schepps (2019) describes, Casey keeps working with the nurse to develop her autonomy, arrange for housing and educational accommodations, and arrange referrals to adult care providers near Casey's college campus. Communication between the nurse, Casey, and Casey's parents continues in the meantime. This communication allows the nurse to answer questions

from, and give feedback and support to, Casey's parents as Casey continues to transition and work towards her goals, both in her care and in her career. In doing so, the open communication helps to assuage Casey's parents' fears of losing control. Additionally, the nurse aids in the communication regarding Casey's medical history between Casey and her two healthcare teams (Betz, 1998).

In addition to affirming the powerful role that effective communication and preparation can have in facilitating a successful transition, Casey's story also illustrates the potential that a healthcare professional acting as an intermediary between the patient and the healthcare apparatus can have in aiding that communication and preparation effort. Not only does the liaison act as an effective advocate for the patient in the healthcare setting, but they can also act in a developmental capacity to help build the adolescent's capacity for medical autonomy given the limitations imposed by the patient's condition.

Australian Psychologists

We now move to a study involving respect for adolescent confidentiality among Australian psychologists, demonstrating the obstacles facing patients who suffer from neither physical nor cognitive conditions, although reduced mental capacity may presumably be present in some. Generally, confidentiality is maintained in all cases except where a clear risk of danger is posed either to the adolescent client or others. In Duncan et. al's (2015) article, a group of psychologists was interviewed regarding several cases representing ethical dilemmas on adolescent patient confidentiality, including the psychologists' decisions and reasonings.

The study draws a direct relationship between respect for confidentiality and perceived client autonomy, with maintenance of confidentiality representing full perceived autonomy (Duncan, et. al, 2015). In doing so, the authors echo a finding of an unrelated study noting autonomy as something that occurs on a spectrum and is therefore a capacity that is developed gradually over time, rather than a binary capacity that is either present or absent (Nagel, 2013). Additionally, the authors of the Australian study make a point of emphasizing the complexity of the studied dilemmas, underscoring the complicated nature of bioethical dilemmas regarding adolescent patients (Duncan et. al, 2015).

Worth noting here in particular is the capacity for autonomy in a healthcare context as something that can be developed. Unlocking this potential for development, then, would theoretically serve to both lessen the burden of underpreparedness on the process of transitional care for adolescents with chronic conditions, and to facilitate the smooth completion of the transitional care process on the whole. Also worth noting is the important direct relationship between confidentiality and autonomy in the fiduciary relationship between a physician and a patient. This relationship makes the maintenance of proper confidentiality against external constraints with vulnerable adolescent patients suffering from chronic conditions critical in continuing the development of these patients' autonomies.

P

Next, turning to a legal perspective, Brierley and Larcher describe a case involving a British teenager, referred to as "P", who had suffered from a chronic personality disorder with a history of self-harm, and who had refused treatment at a British hospital following a drug overdose

event. The legal case was brought by the hospital representing its staff, which sought to administer treatment in spite of both their determination of P's having competence to make autonomous decisions regarding her own care and P's refusal of treatment. In reviewing the case, the judge took into account not only P's competence and refusal, but also the severity of her symptoms following the overdose, and the high probability of grave harm or death as a consequence of non-treatment of those symptoms. As such, the judge granted the hospital staff's request to administer treatment, citing the fact that it was in the best interests of the patient for treatment to be administered (Brierley & Larcher, 2016).

This case illustrates numerous complex ethical quandaries associated with healthcare. For instance, a clear tradeoff is shown between respect for patient autonomy and beneficence in this instance. Worth focusing on for our purposes are the inherent benefits to patient health outcomes associated with placing limits on adolescent autonomy in medical decision-making in certain cases. Though P was deemed both competent to render a decision regarding her care and made a subsequent decision to refuse said care, limitations imposed by external systems—the courts in this instance—resulted in an outcome that was ultimately in P's best interests, at least insofar as her best interests regarding her own physical health are concerned.

This case further illustrates some of the deficits inherent in adolescent decision-making, as while Brierley and Larcher note that adolescents do often exhibit similar capabilities to adults in terms of long-term planning and information processing, they nevertheless also write that neural development in the areas of the brain responsible for impulse control and complex decision-making continues through a person's late teens (2016). As such, this case reflects the importance

of addressing the development of adolescent autonomy in such a context as to maintain limits on said autonomy so as to maximize the patient's health outcomes.

Autoethnography

The field of autoethnographical research is a relatively new and controversial innovation within the social sciences, originating around the 1960s and 1970s (Denshire, 2014). Despite some authors' concerns regarding the objectivity, applicability, and validity of data taken from autoethnographical research, the tool provides a unique mechanism through which the role of culture can be examined through the lens of self and provides an accurate lens through which subject-researchers can use their personal experiences as a gateway to research about those very experiences (Winkler, 2018). The method accomplishes this without any of the epistemological filtration inherent in third-person methods, such as an interview, or in more objective first-person accounts, such as a self-administered survey. In this context, my role as a patient provides an insightful avenue to explore the first-person perspective, which gets applied in the broader discussion surrounding transitional care and its barriers.

In the summer and fall after my high school graduation, I was in the midst of my third unsuccessful course of treatment for a chronic gastrointestinal condition for which I had not received a conclusive diagnosis. Self-administering weekly injections of an immunosuppressant in a hopeless attempt at reversing the deterioration of my symptoms, which had first appeared a year and a half prior, I grew increasingly frustrated and anxious. My feelings were not simply the results of the treatments not progressing at the rate at which my pediatric gastroenterologist and I had hoped. Rather, they were also the result of my staring down the uncertainty of entering the

next stage of my treatment in an unfamiliar environment, surrounded by unfamiliar people following the upcoming transition of my care to an adult enterology practice located closer to where I would be attending university the following semester.

I had been given very little direction or preparation beyond the name of the new practice. Little was communicated to me regarding what handling my own medical care may entail or look like, or what difficulties, if any, I may come to experience as a result of that process. Instead, focus was placed on the resolution of my symptoms biologically, rather than on the process of getting to that point and what my role as the patient in that process may be. The sudden shift in medical autonomy from near zero to full, while not overwhelming, was rather jarring. Cliché though the phrase may be, it did truly feel as though I had been thrown into the deep end of the pool without a life preserver in order to see if I could swim, at least at first.

As a result, even simple tasks, such as transferring medical records between practices, became difficult due both to my failures in communicating exactly what needed to be transferred to whom and when, and to the practices' failures in communicating with each other regarding the same. Remaining constant, of course, throughout this first year was the fact that my care was, from my perspective, focused primarily on addressing my symptoms biologically, rather than as a product of a holistic experience of disease and illness. Thus, despite the best efforts and intentions of my care team, I continued to fumble through the logistics of managing my own care, particularly as I transitioned between my university and permanent residences intermittently throughout the calendar year.

Obstacles to a smooth transition of my care persisted as I moved on from the unsuccessful treatment regimen I referenced previously during the spring and summer following the completion of my freshman year. Opting to pursue a more aggressive, infusion-based treatment, my symptoms failed to improve initially, prompting me to obtain a prescription for a doubling of the dosage. In the case of this particular treatment, this entailed doubling the frequency of the infusions rather than increasing the physical volume of the immunosuppressant administered each time.

Here, another variable was introduced in the form of a requirement for a prior authorization from my insurance carrier. I was once again left feeling helpless, unprepared to handle the intricacies of acting as the intermediary between the liaisons acting on behalf of my mother's employer, the carrier, and both gastroenterology practices as I navigated through the various levels of appeal in order to obtain the authorization. After some weeks of dispute and delays due to failures in communication by all involved parties, I received the authorization. However, much to my dismay, for reasons I still fail to understand, I was forced to re-enter the appeals process upon returning to university the following autumn, reintroducing many of the same delays that I had encountered a mere few weeks prior. All told, several months had elapsed between my being prescribed the doubled dosage and my being able to ultimately receive it, with my symptoms worsening gradually throughout.

Ultimately, my condition turned a corner following the doubling of that dosage and, as the years have passed, I have grown more comfortable in managing my own care. As the barriers I faced to a successful transition fade into the distance, I have tried to reconcile my own experience with those of others in an attempt to understand how common or uncommon my own trials were, and

how exactly they may be explained. It is not my impression that the obstacles I faced throughout my transition were due to the actions of any one individual or individual party, but rather that they were the products of the system in which the transition took place. Specifically, I feel that a clear line can be traced from the healthcare system in which the paradigm of treatment values addressing the biology of illness over the experience of it, and where the preparation for and administration of care is taken as separate from, and in many cases secondary to, the results of care, and the outcomes described herein.

My impressions are supported by data collected from the literature I have read regarding transitional care, particularly for patients in similar positions to mine, since embarking on my journey of research in this area during my sophomore year of college. Although I do not doubt that my experience as a patient has had a great deal of influence on my path as a researcher, and though my path as a patient is not yet completed, I nevertheless feel confident that my unique experience provides in itself a valuable contribution to the ongoing research in the field. By intertwining my roles as both the message and the messenger of this particular line of research, I aim both to contribute to the understanding of the role that communication deficits may have in medical error regarding transitional care, but also to inform how that understanding may be shaped by those that come after me. While much work remains to be done in fully understanding the roots of the many deficits faced by patients experiencing transitional care, I hope that this work marks a shift in the way that that work is performed and, more broadly, in the way that medicine is practiced, towards a more open-minded and patient-centered paradigm.

On Barriers

Considerations by Stakeholder Perspective

We turn now to an analysis of the barriers facing adolescent patients with chronic conditions as they experience transitional care, categorized first by the perspective of the stakeholder in the transition. This discussion is pertinent, as these barriers lead to significant impacts on both a patient's continuity of care, as well as on long-term health outcomes (White and Cooley, 2018). Kumagai et. al notes that physicians identify at least four main, distinct barriers to an optimal transition. Two among these—patients' having a stunted emotional or cognitive development at the time of transfer and patients' having other conditions and therefore other providers with which to coordinate care—represent uncontrollable deficits specific to the patient. The other two, meanwhile—having poor coordination with other providers, including pediatric providers, and being provided with inadequate health histories—are more or less controllable deficits that are specific to other healthcare providers (2019).

Other authors have identified different concerns from the patient's point of view. For example, White and Cooley point to a range of factors adversely affecting a patient's transition, including

1. lack of insurance
2. lack of accessible adult physicians,
3. low income, poor psychosocial functioning
4. unstable living conditions

5. lack of sufficient education for parents and/or the patient (2018).

Another group identifies six themes present in various barriers to optimal transfer. First among these is a disrupted sense of belonging, as adolescent patients are not only more comfortable seeing a physician with whom they have an established rapport, but they also tend to experience a connectedness with other patients visiting the same practice, as the other patients represent peer models with whom they can bond over a shared experience. Another, somewhat related identified theme is that of a lack of preparedness for a sudden change. Of course, this only becomes relevant in cases where the transfer is somewhat sudden, as in the result of a move. Nonetheless, preparation to assume responsibility for medical care, as well as communication and familiarity with the adult care team are both key to establishing the level of comfort and security needed to avoid disruptions to transitional care presented by this theme. Yet another similar theme is identified as “abandonment and fear of the unknown,” which manifests not only through a lack of preparedness to assume responsibility for transferring needed medical information to the new care team, but also through the shock resulting from encountering visibly disabled adults in the medical practice. A logical corollary to the second noted theme is found in the next theme, given as “anonymous and dismissed in adult care.” These concerns primarily derive from the emotionally detached nature of adult care relative to pediatric care. Lastly, the authors give the two related themes of developing autonomy and tensions over the role of the parent or guardian as posing obstacles to an optimal transition (Kelly et. al, 2020). Adolescent patients may also be inhibited from successfully transitioning to adult care by other inhibitions resulting from their specific conditions (Betz, 1998).

Finally, there are considerations regarding the concerns of parents and other caretakers involved in the transition of their adolescent child between pediatric or adolescent and adult care.

Specifically, some parents fear feeling “out of the loop” regarding their children’s healthcare amidst the overall loss of control that transitioning to adult care typically represents (Singh et. al, 2010). Guardians have also expressed weariness over both the perceived additional threat leveled at their children due to their conditions after a transfer and the stigmatization of their conditions in greater society (Shaw et. al, 2020). Overall, these and other concerns are essentially reducible to fears of a loss of control. While this loss of control is in many cases unavoidable and/or net beneficial as it relates to the health of the patient and the success of the transition, the negative impacts of it, as will be explored shortly, are still both relevant and likely addressable.

From these reports, some major themes become apparent. First and foremost is a lack of preparedness. Although some degree of unpreparedness is to be expected given the often-sudden nature of a healthcare transition, reports of overall unpreparedness, as well as of feeling out of place, a disrupted sense of belonging, and feelings of abandonment and anonymity as Kelly et al. point to (2020) are all indicative of, among other things, inadequate outlining and communication of patient expectations prior to a transition. Moreover, communication, or the lack thereof, appears as an intrinsic barrier not only as given by Kumagai et al. as it relates to communication between physicians (2019), but also insofar as communication between physicians and caretakers and between physicians and patients is partially responsible for the barriers that appear in those areas, as well. Finally, the theme of the moralized youth re-emerges, as overprotection of these adolescent patients has borne out a decline in adolescent autonomy that manifests in these examples, demonstrated perhaps most poignantly by Singh et al. and

Shaw et al.'s analyses of caretakers' concerns surrounding the transition, but also in the other analyses, too (2010; 2020).

Considerations by Patient Subpopulation

One basic classification of patients can be drawn using patients whose conditions result in cognitive developmental delays, thereby mandating that further assistance be given for the patient to be able to act as a responsible moral agent in his or her own healthcare. Another can be drawn using patients whose conditions result in physical disabilities that represent obstacles to a successful transition that extend beyond healthcare and into accessibility concerns for housing and education (Betz, 1998). There is then, of course, a group comprised of patients with single or multiple conditions that land them in both categories.

Patients with physical disabilities are more prone to barriers outside of a healthcare setting, particularly access to suitable housing and education facilities, though the latter is also somewhat true of patients with cognitive delays. Meanwhile, patients with cognitive delays are far more susceptible to barriers associated with the development and assessment of autonomy in medical decision-making, as well as overall preparedness for the suddenness of a transition. These concerns are exacerbated in patients falling into both categories.

Additionally, patients from ethnic and/or racial minorities, in addition to having a higher risk of experiencing amplified variants of these same barriers as a result of experiencing higher rates of poverty, unemployment, and incarceration, also face the prospect of diminished health outcomes following a transition. For example, increased rates of acculturative stress are associated with

higher risks of substance abuse disorders and mental health disorders, while discrimination is associated with an array of effects that includes interference with sleep patterns, increased risk of experiencing symptoms of mental health disorders such as depression, and overall decreases in health and wellbeing (Rivas-Drake and Livas Stein, 2017). Furthermore, women are more likely to suffer from poor social support and to experience lower levels of comfort absent care from a provider of the same sex. (Lindsay et al., 2016).

Altogether, then, it can be seen that a wide array of barriers leading to adverse consequences for those experiencing them are associated with current practices in transitional care. Core stakeholder groups, and certain subpopulations within the patient group, show different, but significantly intertwined risks to certain classes of barriers. While solutions to some barriers, such as discrimination and complexities associated with health insurance specifically in the US lie outside the scope of this thesis, many of these barriers, in part or in whole, owe their origins to a decline in autonomy afforded to adolescent autonomy rooted in a societal view of adolescents as non-moral agents. As such, addressing this view within the context of healthcare offers a potent remedy to some of the barriers encountered herein.

On Facilitators

In many ways, facilitators to transitional care are the inverse of barriers. For example, adequate preparation serves as a facilitator for a successful transition (Singh et al., 2010), as does effective communication between providers and caretakers and between physicians and patients (Kumagai et al., 2020), as well as between physicians and other physicians (Kumagai et al., 2019).

Additionally, transitional care can also be aided by the involvement of specialized healthcare

professionals throughout the process. These specialists can range from any level of medical expertise, including nurses and social workers, and can act on behalf of either healthcare provider involved in the transition, or independently from both (Betz, 1998; Kumagai et al., 2020). Broadly speaking, multiple studies have found that an emphasis on patient-centeredness and shared decision making between the patient, physician, and guardian is key in not only developing the patients' faculties to autonomously make competent medical decisions, but also in implementing those decisions to facilitate a successful transition (Loos et al., 2018; Sharma et al., 2014; Shapiro et al., 2019). These facilitators hold true across all designated patient subpopulations and between all stakeholders in the transition.

Additionally, facilitators related to cultural identity are present for adolescents in ethnic and/or racial minority groups. For example, Rivas-Drake and Livas Stein explain that a positive sense of cultural identity is associated with several psychosocial benefits, including decreased rates of depressive symptoms and a decreased risk of substance abuse. They further explain that positive identity has been related to improved immune and endocrine functioning, decreased blood pressure, and lowered stress levels (2017). Furthermore, women express higher satisfaction when receiving care from a provider of the same sex, and are more prone to benefit from strong social support during a transition (Lindsay et al., 2016).

In many ways, these facilitators illustrate a similar overall theme seen through the barriers, in that a lack of autonomy afforded to adolescents with chronic conditions in a healthcare context is traceable to a societal view of adolescents as non-moral agents in need of protection.

Furthermore, they show that unique circumstances affect patients from social out-groups. As

such, measures taken within the healthcare context to address this agency deficit can act to facilitate a more successful transition as measured both through health outcomes and through continuation of care.

A Synthesis

Thus, captured in this chapter, then, are accounts of barriers and facilitators to adolescent transitional care for patients with chronic conditions. Common themes include preparedness and communication as they interact with the broader social view of adolescents as being non-moral agents. These themes are broadly supported by cases taken from the literature, as well as by my own first-person account in having engaged with transitional care as a patient. In moving forward to address these deficits and improve these facilitators, we will look towards addressing the root causes of declining adolescent agency and work towards further incorporating patient perspectives as a way of improving the knowledge base about the subject.

A PHILOSOPHICAL ANALYSIS

The Road So Far

So far, we have traced the path of adolescence's development through history, analyzing it in the contexts of healthcare, as well as of society and anthropology. In an attempt to balance respecting the autonomy of adolescent patients with chronic conditions with the maximization of beneficence measured through positive health outcomes, the healthcare community has failed in many cases to best uphold either principle. The adolescent, over the course of its development, has steadily become increasingly moralized, and has gradually lost some moral agency as a consequence. Though there may be benefits to this loss, its applications in the sphere of healthcare have resulted in a decline in patient autonomy, which has manifested in communication and preparedness deficits. Both of these deficits extend beyond interactions between the adolescent and physicians directly, or between the adolescent and the healthcare apparatus at large, and into interactions between physicians and caretakers and between physicians and other physicians. Furthermore, while adolescence has developed over time to become a fluid period, marked by dynamic entry and exit points centered around life events, the healthcare and legal systems have generally failed to account for this development, resorting instead to age and biology-based benchmarks that, while useful, serve ultimately to inhibit potential efforts to develop adolescent autonomy.

Relatedly, the many barriers and facilitators to a successful transition have been examined. Some, such as those related to the insurance apparatus or those introduced by the patient's condition or conditions, are not wholly addressable from within the healthcare system. However,

many, such as those related to patient communication and preparedness, as well as some extent of the exacerbations experienced by patients from ethnic and/or racial minorities, owe their origins to the way in which adolescence in general, and adolescent autonomy specifically, is expressed and regarded within a healthcare setting. Despite irrefutable benefits to the patient of maintaining limits on adolescent patient autonomy, particularly given the inhibitory nature of some patients' conditions on autonomy and decision-making, to develop solutions to the barriers of transitional care in line with its facilitators requires keeping a framework wherein the development of patient autonomy is prioritized in mind.

The Way Forward

Keeping in mind this construct, as well as an overarching goal of maximizing patient wellness while maintaining respect for Beauchamp and Childress' key principles of justice, beneficence, non-maleficence, and especially respect for autonomy (2001), a series of recommendations for improvements to guidelines that targets the specific areas of need identified in this thesis is in order. Current guidelines, such as the Six Core Elements framework offered by White and Cooley, do offer for aspects such as discussing transition policy, and planning for, tracking the progress of, assessing readiness for, and confirming the completion of the transition process, all of which occur at defined age range benchmarks (2018). However, the scope of these guidelines is likely too narrow. For example, the development of adolescent medical autonomy is framed here only within the realm of the healthcare transition and is grouped in stages that do not fully reflect the movement through adolescence as a fluid time period.

As such, the process of discussing and planning for a transition could be aided by a concerted effort to begin the development of an adolescent patient's medical autonomy in line with the patient's entrance to adolescence, as marked by fluid landmarks based on maturity and autonomy as a consequence of significant life events, rather than rigid ones based in age or biology. This latter point would serve to best align the treatment of the adolescent with the experience of adolescence, thereby likely reducing concerns such as feeling out of place or other similar experiences of discomfort. Such an effort would require both further study into how best to encourage the development of autonomy in a medical context, as well as study into the validity of tracking methods like MacCAT-T and TRAQ to determine the adolescent patient's progress. To best implement such practices requires adopting a patient-centered posture, emphasizing the role of shared decision-making and thereby gradually increasing the patient's ability to competently manage his or her own care.

All of these above practices would need to be considered on a case-by-case basis based on the nature of the patient's condition. For example, greater limitations on the development of the patient's autonomy would likely be required in cases in which the patient suffers from a psychosocial disorder that inhibits his or her ability to control impulses or complete thoughtful long-term planning. Additionally, efforts to develop patient autonomy could be aided by widespread adoption of a model utilizing a specialized healthcare professional to assist in the transition, although further study would be needed to determine in what exact form this profession should take and how it would be implemented. Finally, special emphasis on this development of autonomy alongside a strong self-identity could help to maximize transition success for patients from ethnic and/or racial minority groups, who are both generally most

prone to experiencing barriers as a result of a transition and are likely to experience the most benefit from such an emphasis. Additionally, special considerations to ensure the development of a strong support network and the availability of female providers for female patients could aid transition success for those patients.

As suggested by the information generated from the autoethnography included herein, future research would also likely benefit from a greater emphasis on the inclusion of patient testimonials. First-person accounts empower patient-researchers to advocate for, and amplify the voices of, those vulnerable patient groups of which they are a subset. Additionally, they serve as a valuable tool insofar as they are uniquely capable of providing an unfiltered, and therefore epistemologically accurate, account of experiences. Given that the role of patient experience is central in the success or failure of a transition, as illustrated by the role of barriers such as feelings of abandonment or unpreparedness play, a more concerted effort to emphasize patient testimonials could help to augment the success of future research in this area and other similar areas.

Altogether, the augmentation of guidelines in these ways and particularly by further adopting the suggested patient-centered posture could help to maximize health benefits to patients undergoing a transition to adult medicine. By aligning the treatment of adolescents with the experience of adolescence, benefits are further maximized, and by incorporating firsthand accounts of those experiences in research, guidelines are able to be more accurately aligned with patient experiences. Finally, by focusing on developing patient autonomy at the outset of adolescence, health outcomes are likely maximized, and that autonomy is most able to be maintained and employed after the transition to adult practice is complete.

CONCLUSION

This thesis provided opportunities for reflection and contribution to both the structures of adolescent transitional care for patients with chronic conditions and the research areas that concern it. Broad recommendations to contribute for a discussion on new guidelines to improve Western adolescent transitional care for patients with chronic conditions were generated. To do this, a philosophical analysis was conducted following a multidisciplinary dialogue incorporating views of adolescence's development derived from history, medicine, sociology, and anthropology. Generally speaking, patient preparedness and communication were identified as addressable areas in which barriers to transitional care could be overcome and facilitators could be emphasized via a focus on the development and tracking of patient autonomy, with an accompanying posture geared towards patient-centeredness and a view of the adolescent patient as a key piece in the process of shared medical decision-making. Considerations were taken and incorporated for vulnerable patient groups, including those suffering from severe impediments to autonomy as a result of their conditions and those experiencing difficulties stemming from their belonging to a social out-group.

Additionally, an autoethnography was proposed as an innovative testimonial to the power of firsthand patient experience as a type of partnership in medical research that can also be invaluable for the development of a sensitive dialogue on the ethics of adolescent autonomy. This is a pathway for future patient-researchers to participate and continuously contribute to improving research that affects them, as in quality and safety research regarding Learning Health Systems (Institute of Medicine, 2001). As in the autoethnography, this thesis also marks a crucial transformative step in an ongoing journey towards an embracing of firsthand testimony in the

research and medical pathway of this author, and hopefully of others who share similar experiences.

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