

THE LIVED EXPERIENCES OF TRANSITION  
TO ADULT HEALTHCARE IN YOUNG ADULTS WITH CEREBRAL PALSY

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**ABSTRACT**THE LIVED EXPERIENCES OF TRANSITION TO ADULT HEALTHCARE IN YOUNG  
ADULTS WITH CEREBRAL PALSY

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**Background:** Health Care Transition (HCT) describes the purposeful, planned movement of adolescents from child to adult-orientated care. The purpose of this phenomenological study is to uncover the meaning of transition to adult centered care as experienced by Young Adults with Cerebral Palsy (YA-CP) through the research question: *What are the lived experiences of young adults with cerebral palsy transitioning from pediatric to adult healthcare?*

**Method:** 6 females and 3 males, aged 19 -25 years of age, who identified as carrying the diagnosis of cerebral palsy without cognitive impairment were interviewed. Giorgi's (1985) method for analysis of phenomenology was the framework for the study and guided the phenomenological reduction.

**Results:** The lived experiences of YA-CPs transition to adult health care, expressed from the data is *expert novices with evidence and experience based expectations, negotiating new systems (effective/ineffective) interdependently (parents and provider support) accepting less than was expected.*

**Conclusions:** More information and support is needed for the YA-CP during transition to ensure a well-organized move to appropriate adult-oriented health care that is considerate of the lifelong impact of the disorder. Nursing's role as advocate, mentor and guide can optimize the individual's response to the transition process.

Keywords: Health Care Transition (HCT), Qualitative, Phenomenology, Meleis transition theory

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I would especially like to thank my husband Michael for his encouragement and support, all I need is to be by your side. The joys of my life, my children, James, Sara and Michael have cheered me on to my best work -I thank God for you every day. Thank you.

### **Dedication**

This dissertation is dedicated to my mother, Mary Ita McLaughlin nee Corkery, also known as Mae. Since October 2008 I have been without my mother and I miss her everyday. I recall one time, as a little girl riding on the New York City bus beside her when she stood up to talk to a lost traveler on the bus. I was a little embarrassed that she was talking to a stranger, but in a few short exchanges she shared what she knew and put the other person at ease. Upon returning to the seat next to me she said, "You should always be willing to talk, you never know when something you share might help someone else". In that simple exchange she formatted my life's mission as a person who cares, helps, get's involved, teaches and nurtures.

She made me the nurse I am today.

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## CHAPTER I

### AIM OF THE STUDY

#### Introduction

By way of introduction, I offer you this story of a 17 year old girl on her final visit to her pediatric orthopedist, Boston Massachusetts, 1975:

The language was so medical, and I saw him as such a god, and such you know, he was like on this pedestal. He could not do any wrong, and they (my parents), I mean to them he could not do any wrong. So, I do not even know what he said, and I remember both my parents were sitting there crying in the treatment room after he left with whatever he said which I vaguely remember him saying something like, oh, great job. You know. I do not need to see her now, for at least another year. You can ... I think he may have said something like, you can put the cast away, and you know you can get rid of the brace. But he did not use those terms, because I would have understood that.

Whatever he said, I did not understand it. So they're sitting there crying, (and the only other time I saw my father cry was when President Kennedy got assassinated, and I heard my father cry when his father died). So, like ... it did not happen, and then, he is sitting there crying. My mother is sitting there crying, and I am like, oh my God! What happened? What happened? And, I – and he left the room.

So the next thing I know, they are sitting there still crying, and carrying on, and I finally said, well, what just happened in there? Why – why are you crying, I – I do not understand, and they said, well, it is all over. You are all done. You are better now. I

am looking down, and I am saying if I am all better, how come I look the same.

[LAUGH] And, that is the piece that no one prepared me for.

This story is surprising and evokes a lot of emotion, but that is not the reason for its significance. What is significant about this story of transition is that the transition story line has not evolved much during these thirty-seven years.

Cerebral palsy (CP) is the most common major disabling motor disorder of childhood and is a group of permanent disorders of the development of movement and posture, causing activity limitations, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain (The definition and classification of cerebral palsy, 2006). There has been a consistent rise in the proportion of cerebral palsy cases associated with preterm births, although the total number of children with cerebral palsy has remained stable or increased only slightly since 1970, (Reddinhough & Collins, 2003). Deaths in children with CP have in recent years become very rare; unless the child with CP is very severely disabled he or she will most likely survive into adulthood (Haak, Lenski, Hidecker, Li & Paneth, 2009). The transition experience within the context of cerebral palsy- a relatively stable, chronic condition, provides an excellent introductory study of the lived experience of transition to adult care in the young adult experiencing a chronic condition or special health care needs.

Adolescents and Young Adults with Childhood Diagnosed Chronic conditions (AYA-CDC) are a growing population; more than a half a million chronically ill youth cross the threshold to adulthood yearly due to the advent of innovative technologies and medical advances (Bryant & Walsh, 2009). Increased longevity means that many more young people experience the transition from adolescence to adulthood while dealing with chronic disease. This trend challenges existing healthcare models and the professionals that work within them as the

transition to adult and independent care is negotiated (Betz, 2004, 2008). Young Adults with Cerebral Palsy (YA-CP) are veterans among this specialized population. Because the disease is less life limiting than many other health problems, greater numbers of YA-CP have been aging into adulthood (Turk, 2009). Knowing about the YA-CP individual's experience of transitioning to adult health care is a key step toward understanding the health related needs and the requisite demands of this special population.

### **Aim of the Study & Research Question**

Transition in the health care context is the purposeful, planned movement of adolescents from child to adult-orientated care (Soanes & Timmons, 2004). The aim of this study is to uncover the meaning of transition to adult centered care as experienced by YA-CP participants. The purpose of the study is to engage YA-CP participants in an exploration of the meaning of this transition, through the research question: *What are the lived experiences of young adults with cerebral palsy transitioning from pediatric to adult healthcare?*

### **Phenomenon of Interest**

The phenomenon of interest is the lived experience of young adults with cerebral palsy (YA-CP) during their transition to adult health care and the context for this study is the YA-CP undergoing transfer to adult health care. The goals of transition are “to maximize lifelong functioning and potential through the provision of high quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood. It is patient centered and its cornerstones are flexibility, responsiveness, continuity and coordination” (American Academy of Pediatrics, American Academy of Family Physicians-American College of Physicians-American Society of Internal Medicine, 2002.p 1304.). Health Care Transition (HCT) is a relatively new trend in health care and the success or failure of these

transitions may impact future quality of life, survival rates, and health care utilization by these consumers.

Young Adults with Cerebral Palsy have carried their diagnosis and the subsequent health considerations from infancy and across the developmental stages; their transition to adulthood is negotiated with the inclusion of the physiologic factors associated with the disease (Drew, White, Ferguson & Hay, 2009). The higher frequency of health care utilization and longevity of chronic conditions in this cohort make them preeminent informants of the experience of transitioning to adult centered health care. Understanding the experience of health care transition for the YA-CP has potential to influence current thinking and planning regarding YA-CP's maturation to adulthood and acquisition of an independent role in health care utilization.

### **Justification for Studying Phenomenon**

This transition to self-management and the negotiation of the adult health care model, coined Health Care Transition (HCT) is quickly evolving as a pivotal issue in the areas of adolescent and young adult health care. As the incidence of chronic illness increases worldwide, governments and health care systems are rushing to respond with an array of self-management interventions, without the support of empirical study of efforts already employed by people with chronic conditions (Drew, White, Ferguson & Hay, 2009). In a position paper on the issue the Society for Adolescent Medicine (Rosen, Blum, Britto, Sawyer, Siegel, & Society for Adolescent Medicine, 2003, p.309) set the priority for “an organized, coordinated transition to adult health care for young people with chronic conditions” with the goal “to optimize health and to facilitate each young person’s attainment of his or her maximum potential” and promotes “proactive transition to the adult health care system” that, “encourages young people to be successfully integrated into a comprehensive care system to meet their complex needs”.

The lived experience of the YA-CP's transition to adult centered health care is the target of this study. The YA-CP's lifelong acquaintance with the medical and health care milieu and the gradual acquisition of self health care roles throughout their maturation enriches the context of the study and enhances the possibility of coming to know about the experience of health care and self management transition from their perspective.

Most children who have CP receive multimodal therapy, for example, physical, occupational, and speech therapies; orthopedic surgery; spasticity management; and special educational support services. These therapies tend to be complementary (Liptak & Accardo, 2004). These adolescents may be cared for by a pediatric or adolescent primary care provider who coordinates all aspects of care along with an adult or pediatric subspecialist(s) for the care of the specific illness or disability. The pediatric subspecialists are trained in the medical or surgical subspecialty and further specialize in the developmental and physiologic attributes of the pediatric and adolescent population. This dual training is supportive of the developmental age and stage of the young patient while providing highly complicated and often life sustaining, "cutting edge" care of the chronic disease or impairment. The pediatric subspecialist practice embodies developmentally appropriate care to this highly specified population and often follows the care of the individual into late adolescence. Within that practice consideration, developmental growth toward autonomy is paramount and the adolescent patient is central to the treatment team, along with parents and family supports (American Academy of Pediatrics, 2010).

Despite receiving extensive services during childhood, adults with CP have a high rate of complications that may interfere with their ability to achieve their full potential in society. Adult survivors with CP may have co-morbid conditions such as seizures (40%), mental retardation

(34%), and learning disabilities (26%). Secondary conditions include significant pain (84%), hip and back deformities (59%), bowel problems (56%), urinary problems (49%), poor dental health (43%), and increased spasticity during menses (35%), and gastro-esophageal reflux symptoms (28%). Other complications found in adults who have CP include fatigue, malnutrition, osteoporosis, cervical spine arthritis with neurological changes (cervical spondylotic myelopathy), and Barrett esophagitis (Liptak & Accardo, 2004). Continued research to move forward policy and systems of health care transition in the CP population has the potential to minimize the impact of those comorbidities and secondary conditions that are now becoming apparent in the older person with CP (Liptak & Accardo, 2004). The potential risks associated with aging out of pediatric services and transition to adult services provides a rationale for research to inform an evidence-based model of care that promotes successful transition to adult health care despite the potential loss of services as the individual ages into adulthood.

### **Relevance to Nursing**

As the healthcare community continues to formulate models and systems to address the logistical considerations of transitioning emerging adults with chronic conditions, nursing must play a part in the movement to develop appropriate models of care and advocate for a comprehensive approach to transition practice. Multiple empirical studies and several reviews of current Health Care Transition (HCT) practice point out the need for an educator and facilitator role to support the transition process (Betz 2009; Rudy, 2006); both elements are within the domain of nursing. Additionally, nursing research focusing on the subjective voice, as descriptive phenomenology does, promotes the voice of the individual to inform practice and policy development that ensures a comprehensive approach to the multifaceted requirements of AYA-CDCs as they transition to adult centered health care.

It is not possible for nurses or any other health care providers to predict or prescribe the meaning of the lived experiences of our patients, yet many programs and policies of care are generated with little or no participant input. Learning from our patients, through phenomenological methods, what they know through their everyday living can provide information that can be shared with people who are less experienced with a similar condition (Wilde, 2003). Phenomenology concerns itself with a search for meaning of some lived experience; as such it is the perfect means to study the experience of health care transition and reveal the meanings, structure and essences of the YA- CP's lived experiences of transition.

Examination and qualitative analysis of the lived experience is a powerful source of understanding human perspective and is key to the premise of individualized and responsive nursing care. In response to a review of forty-six empirical studies of HCT in the AYA-CDC/CP Wang (2010) states that further investigation is needed; research that focuses on individual, practice and systems experience of this transition will inform systems and policy makers, but "patient focused" nursing must start with the individual. The process must begin with the initial assessment of the issue from the many involved perspectives; nursing's focus on the individual's response validates further investigation and is the driving energy of this study.

### **Assumptions and Biases**

My expectation is that YA-CPs will reveal an active or at least participatory voice about the experience of transition. I think they may discern internal factors that motivate them and might identify external factors that will affect them. I imagine that this cohort is already familiar with what they need and want in terms of their care in a way that may be distinct from adolescents with other types of chronic conditions.

I believe that YA-CPs are not defined by their cerebral palsy, but I also have to acknowledge that the participants in this study coming from an orthopedic milieu have worn their disability on the outside either through their gait or assistive devices and their experiences may be colored by this difference they exhibit. I assume that the YA-CP participant will share experiences that are full of expectation and perhaps dread. I anticipate that they will be opinionated about the process. Personal preferences and relationships with their pediatric team are expected to be topics of their descriptions and I will need to take care to bring them back to their experiences. I am eager to hear what the YA-CPs participating in this study have to say.

My previous work in adolescent health care practice as a pediatric nurse practitioner has nurtured an appreciation of the young adult's need to have some say in the management and planning of their lives, specifically as it pertains to treatment plans and how they will impact other plans. This priority might be described as willfulness or fighting authority, but I have come to see it as strength; fidelity with one's self to not accept less than is wanted, if at all possible. This strength of purpose is fascinating and there is the perception of an intrinsic self-manager working beneath the outer persona of the adolescent, which is similar to a generally assumed motivation in adulthood. I am aware that this bias makes me more likely to pick up on resilience and readiness characterizations during the study. The ease with which I use the "buzz words" of resilience and readiness, in the previous sentence makes apparent some of the underlying theoretical assumptions and experiential bias.

### **Summary**

Chapter one introduces the intent of this study to explore the young adult with cerebral palsy's (YA-CP) lived experiences of transition from pediatric to adult care. The evolution of Health Care transition (HCT) issues and research is described and employed as a context and

rationale to justify the proposed study. The study framework grew from the original interest in knowing more about what transitioning to adulthood meant with respect to health and health care, and the consideration that health care transition may resonate more among adolescents and young adults with a childhood diagnosed chronic illness and that they may have more to share on the subject due to their relatively greater experience and familiarity with the health care system.

The rationale for use of the qualitative research process of descriptive phenomenology as a means to convey the subjective voice of the individual that is absent from within the HCT research literature was introduced. The study outcome's relevance to nursing in practice, policy and research was identified. Further considerations related to nursing's concern with human responses and nursing's role in the realms of advocacy, education and innovation were highlighted. Assumptions and biases were identified in order for them to be bracketed and kept aside from the study as participants shared their experiences.

## **CHAPTER II**

### **EVOLUTION OF THE STUDY**

#### **Introduction**

The purpose of this study was to explore and describe the lived experiences of young adults with cerebral palsy's transition from pediatric to adult health care. This chapter discusses the rationale for initiating the study and provides insight to the historical and theoretical underpinnings of the study population/topic. The experiential context for the study grew out of personal experience of this researcher providing support to adolescent and young adults with chronic health issues and my curiosity about young adults' initiation of self-care and its potential impact in eliminating health care disparities and improving healthy outcomes in that group. Effective adoption of health promotion /maintenance activities as a young adult may have an impact on overall level of health and health related outcomes associated with preventable illness (Pender, 1996). The successful transition to independent/ adult healthcare may influence the individual's adoption of health promotion and health maintenance practices.

#### **Rationale**

YA-CPs' effective adoption of health maintenance and promotion practices may impact not only longevity but also functional status and their potential to be successful and self-sufficient members of the community (Krakosky, Huth, Lin & Levin, 2007). Quality of life is a key index of the care and treatment of persons with CP. Investigating the individual's experience of the transition to adult/self-managed health care is suggested in order to add to the research concerning the YA-CP's developing autonomy in health care and self care practices in order to improve their quality of life.

## Historical Context

The pediatric, adolescent and adult medical communities have acknowledged that as adolescents and young adults mature and progress toward adulthood it is no longer developmentally appropriate for their care to be maintained by a pediatrician or pediatric sub-specialist; however their transition to adult care may be perceived as daunting to themselves and their providers (Reiss, Gibson, & Walker, 2005). Between 1999 and 2008 there were 46 empirical studies published those address the various aspects of the health care transition process (Wang, 2009). These studies emphasize that the inclusion of the individual's preferences is integral to development of transition services that will foster successful transfer to the adult health care model. Despite that need to focus on individuals, the literature concerning health care transitions research for AYA-CDC generally and AYA- CP specifically lacks participant input accessed through qualitative inquiry. Studies regarding transition experiences so far tend to limit choices for participant expression, thus in essence, overlooking the subjective voice of the transitioning young adult.

Review of the HCT research which focuses on the transition from child oriented to adult oriented health care, supports the need for appropriate termination of pediatric relationships as part of the transition process; as pediatric and adult-oriented medicine represent very different medical subcultures (Reiss, Gibson, & Walker, 2005). Researchers assert that young adults' and family members' lack of preparation for successful participation in the adult health care system contributes to problems with transition. Transition planning, to address this lack of preparation is a large component of the HCT research reported (Por, 2004; Lotstien, et. al., 2005, Scals & Timmons, 2004). Attributes such as developmental readiness (Telfair et al, 2004; Scals & Timmons 04, Telfair, et al, 2004; Lotstein et al 2005, Wojciechowski et al, 2002); preparation of

youth for transition (Anie & Telfair, 2004; Lotstein et al, 2005; Por, 2004), a team approach (Reid, 2004), nurse as facilitator (Christian et al, 1999; Fiorentino, 1998), family focused (Cervia, 2007; Anie et al, 2004) and multidisciplinary approaches (Britto, 2006) were reported as contributors to transition success. Other HCT literature focused on the development and testing of frameworks, that include policies, processes and guidelines operationalized in practice settings, with the outcome measure for success defined as completion of an initial visit at an adult center (Reid, 2007), continued good health outcomes (Lam, Fitzgerald & Sawyer, 2005) and access to care (Park & Previn, 2008).

While the transfer to an adult health care service is the defining measure of transition for the purposes of this study and in much of the HCT research (Wang, et al., 2009) it is important to note that there are other transition services models and approaches to managing the care of a growing number of persons with childhood acquired chronic illness or disability surviving and living into adulthood. In response to the growing number of children with childhood diagnosed chronic conditions surviving into adulthood and the lack of adult providers with knowledge or experience adequate to meet the needs of these patients, many pediatric specialty care providers and centers continued to care for these patients past the chronologic age when transition typically occurs. The evolution of lifespan transition programs developed by and within larger hospital based pediatric and adolescent centers seems a natural progression of the strong foundation of those center's multidisciplinary collaborative approach to the child growing up with a chronic condition. The transition to adulthood in this approach is accommodated with the addition of adult providers as team members (Stewart2009, Linroth, 2009). Life course/lifespan approaches were included as part of best practice guidelines, developed in Canada, for the transition to adulthood for young people with disabilities due to that models holistic approach (Stewart 2009).

The lifespan model has been widely integrated as the model of care for the management of spina bifida (Swanson, 2010) and has been supported by nursing leaders as an effective guide for modeling transition programming (Betz, Linroth, Butler, Caruso, Niemeyer & Smith, 2010).

The pool of research about HCT for chronically ill young adults transitioning to adult care is growing and a variety of points of view have been investigated. There are many shared facets discussed within the research reports, articles and editorials on the matter. Frequently the findings are presented with the caveat that individualization should be provided in caring for adolescents and young adults during the transition to adult oriented health care (Reiss, Gibson & Walker, 2005). The current evidence on HCT supports the movement away from service driven models of transition to holistic, life course/lifespan approaches (Stewart, 2009). Nurses and other professionals are implored to increase their awareness of issues facing AYA-CDCs making the transition to adult health services (Davidson, 2010).

### **Theoretical Context**

Erickson's (1950, 1968) Theory of Human Development stresses autonomy and intimacy as the major endeavors to be undertaken in the transition to adulthood. The primary developmental challenge of that period is the establishment of autonomy from parents and the attainment of intimacy with a chosen partner. This separation from parents is more a movement toward mutuality and equality as adults, not to be viewed as a complete separation or cut off. Erickson portrays identity formation as a collaborative project between young people and the circumstances of their experience, their context (Schwartz, 2005). Erickson remarks, "In all youth's seeming shiftiness a seeking after some durability in change can be detected...this search is easily misunderstood and often it is only dimly perceived by the individual himself." (Erickson, 1965 p.3) This dimly perceived element may be revealed within the discourse of this

phenomenological study. This inner awareness of the self in transition may be voiced through the unstructured exposition of the lived experience.

Age parameters were not part of Erickson's theory; however, of all the developmental stages laid out in that theory the two most relevant to this investigation are adolescence and young adulthood. The pace at which an individual moves through each stage was left open and the possibility of a prolonged adolescence or psychological moratorium for persons in industrialized societies for free role experimentation was introduced (Erickson, 1968). This extension of adolescence has become more and more common as increasing participation in secondary education and later entry into the work force and independent life has become more of the norm. This interval between adolescence and young adulthood, possibly including the late teens through the twenties has more recently been theoretically conceptualized and termed "emerging adulthood" (Arnett, 2000). The YA-CP facing transition falls within this category of emerging adult.

Emerging adulthood is distinguished by relative independence from social roles and from normative expectations; having left the dependency of childhood and adolescence, and having not yet entered the enduring responsibilities that are normative in adulthood, emerging adults explore life directions and are in a time when little about the future has been decided for certain and the scope of exploration of life's possibilities is greater for most people than it will be at any other time of life (Schwartz, 2005). The theory of emerging adulthood is rooted in Erickson's developmental theory (Schwartz, 2005) and complements it with the identification of the moratorium effect. The theory is considerate of the context and life circumstances of the persons of this developmental stage; it highlights the sense of activity and expectation of the process of experimentation and experience. Emerging adults don't see themselves as adolescents or as

adults (Schwartz 2005), this being in-between or in process of transformation seems related to the concept of transitioning.

### **Experiential Context**

Over the past fifteen years, while providing primary care to adolescent patients with chronic illness or special health care needs in a school-based clinic it has become evident that when given the opportunity most adolescents will take on an active role in seeking out health related support such as treatment of illnesses, health education, prevention and promotion campaign materials. The access afforded by the clinic as an installation of the school building allows the adolescent to engage in services, previously consented for by parents, at any time.

Providing primary care to adolescents in a school-based clinic gave me the opportunity to engage young adolescents in a conversation about their health and the perceptions they had about their role in their health care. Once the student became enrolled, with parental consent, they were permitted to request services as they felt the need arise. For the student with the chronic illness of asthma it would usually begin as an acute visit for treatment of an actual asthma attack, at which time I as the provider would assist them with medication to alleviate their symptoms. As the treatment was provided health education would also be addressed and would range from an explanation of the etiology of the disease, the action and purpose of the medications and a review of preventative factors that may be helpful in decreasing the number of acute asthma attacks. Because the clinic was at school fulltime while classes were in session, the students could count on follow-up from the provider, and likewise I could reach out and follow up, with my patients at any time during the school day. Very often the acute asthma patient would develop into a regular visitor to the clinic for other services. The asthma would be noted to be more controlled as the student would take the information provided at the visit and try it out.

Students would check back in and boast of their progress and several remarked how surprised and happy they were to have gone so long without a severe attack or need of hospitalization. These students transformed to health seekers and enjoyed the added benefit of being in control of not just the illness but other aspects of their growth and development. This growth in health seeking behaviors and active participation was appreciated in other diagnostic groups; including students with diabetes, attention deficit hyperactivity disorder and mood or behavioral disorders.

The school health clinic setting places the adolescent centrally in the encounter of health promotion and prevention visits as primary informant and manager of care. That direct connection with the resources of the health care provider and the interplay of that relationship seems to impact the adolescents' experience of health care, putting them in the proverbial "driver's seat" as an active manager of their health care. Further understanding of this self-management/ self care transition experience and its possible meanings, motivations and essences may provide unique information for use structuring a nursing approach and informing models of care for transition related nursing practice.

### **Summary**

Chapter two outlines the rationale for the evolution of the study through consideration of the phenomenon of transition from a historical, theoretical and experiential perspective. Transitioning in this demographic has been a recurring theme in the recent history of health care trends; it is a core concept of developmental and social science theories; and has been witnessed in the clinical practice setting. The literature suggests that there are great concerns and considerations to be dealt with as the YA-CP moves out from the safety net of pediatric care and pediatric sub-specialists and embarks on the independent journey as health care seeker. My new found awareness of this group of individuals and exposure to the stories of their experiences

have given me first hand knowledge and a greater sense of trepidation about the uncertainty of effective transition and success in maintaining the level of care they need as they grow older with the diagnosis of cerebral palsy.

## CHAPTER III

### THE PHENOMENOLOGICAL METHOD

#### Introduction

Giorgi's (1985) method for analysis of phenomenology was used as a framework for the analysis of the data from interviews with YA-CPs concerning the lived experience of their health care transition. Giorgi's method involves four steps. Initially, the researcher will read the entire description in order to get a (1) *Sense of the Whole*, (2) *Discriminate Meaning Units Within a Psychological Perspective and focused on the Phenomenon Being Researched*, (3) *Transformation of Subject's Everyday Expressions into Psychological Language with Emphasis on the Phenomenon Being Investigated*. (4) *Synthesis of Transformed Meaning Units into a Consistent Statement of the Structure of the Phenomenon*.

#### Background of Giorgi's Phenomenological Method

Phenomenology as a movement has been in existence since 1900. Edmund Husserl (1970) defined *phenomenology* as "the science of essence of consciousness" and focused on defining the concept of *intentionality* and the meaning of lived experience, from the first person point of view. Intentionality is the directed awareness of an object or event and refers to the relationship between persons and the object or events of their experience. An important tenet of the Husserlian approach to science was the belief that the meaning of lived experiences may be unraveled only through one-to-one transactions between the researcher and the objects of research. These transactions must involve attentive listening, interaction, and observation to create representation of reality more sophisticated than previous understandings (Husserl, 1970).

The descriptive phenomenological approach initially conceived by Husserl included three steps: First, the *assumption of transcendental phenomenological attitude* is prescribed. The

phenomenological attitude differs from the natural attitude. To assume the transcendental perspective means to assume an attitude of consciousness free of worldly and empirical assumptions. To do this bracketing is used. Bracketing means consciously putting aside all knowledge of the phenomenon under investigation. Knowledge from readings, secondary sources and experiences are purposefully excluded from consideration through the use of bracketing. In this way the researcher considers the given simply as it exists in the consciousness of the reporter. It is taken to be something present to one's consciousness—a phenomenon, not a reality (Giorgi, 2007). Husserl wants us to examine the sheer presence of the object and refrain from saying that it exists in the way that it presents itself to us. This is also the basic meaning of phenomenon in phenomenology. It means how the given presents itself to consciousness (Giorgi, 2005). Second, is the step of *bringing to consciousness an instance of the phenomenon to be explored, and with the help of free imaginative variation intuit the essence of the phenomenon investigated*. To use free imaginative variation is a technique to imaginatively subtract one feature, then another, discovering in the process which features are essential and which are incidental. If an imaginative elimination of an aspect causes the phenomenon to collapse, then that aspect is considered essential (Giorgi, 2007). Husserl's final step prescribes *careful description of the essence that has been discovered*. This essential aspect or *essence* must then be described carefully, strictly adhering to what was presented in the instance the phenomenon that was shared; nothing is to be added or subtracted from what presents to consciousness

Maurice Merleau-Ponty (1908—1961) expanded upon Husserl's work with the consideration of perception and embodiment, that is our connection to the world and others through our body. At the core of Merleau-Ponty's philosophy is the argument for the

foundational role that perception plays in understanding the world as well as engaging with the world (Merleau-Ponty, 1962). Giorgi (1985) acknowledged that Merleau-Ponty's method consisted of description, reduction, the search for essences and the recognition of operative intentionality. Intentionality is presupposed and refers to the fundamental fact that a human being is always directed toward or oriented toward something that is not him/herself; consciousness is always directed or oriented toward something that is not consciousness itself (Giorgi, 1985 p.43).

Giorgi (1985/2005) developed a phenomenological method based on the thought of Husserl and Merleau-Ponty. The modifications employed by Giorgi's descriptive method (1985/2005) were in response to the demands of contemporary scientific practices. The psychological phenomenological reduction is a mixed one; the objects of the experience are understood to be within the reduction, taken as they present themselves, but the stream of consciousness of the participant is understood as a real process because of the specifically human mode of organization and consciousness in which psychology is interested (Giorgi, 1981). In this method imaginative variations are done in dialogue with the empirical variations that are given in the descriptive data and the structure that is discovered and described is considered to be typical rather than universal (Giorgi, 2007). In Giorgi's belief about phenomenology, the researcher tries to determine the psychological essence of the phenomenon first; rather than the philosophical essence; and then the essence or the most invariant meaning structure with respect to the specific context perspective, in this case the nursing perspective.

### **Description of the Method**

#### **Giorgi's Existential Phenomenological Method**

Giorgi's (1985) method for analysis of phenomenology was used as a framework for the analysis of the data from interviews with YA-CPs concerning the lived experience of their health

care transition. Giorgi's method involves four steps. Initially, the researcher will read the entire description in order to get a (1) *Sense of the Whole*, (2) *Discriminate Meaning Units Within a Psychological Perspective and focused on the Phenomenon Being Researched*, (3) *Transformation of Subject's Everyday Expressions into Psychological Language with Emphasis on the Phenomenon Being Investigated*. (4) *Synthesis of Transformed Meaning Units into a Consistent Statement of the Structure of the Phenomenon*.

### **Sample and Recruitment**

To be included in this study participants needed to: 1) be 18-25 2) carry the diagnosis of cerebral palsy, without cognitive impairment; 3) be able to articulate language 4) report that an extended interview of approximately one hour will not pose a burden to them due to its reliance on language and 5) must have made a transition to adult provider or have been notified of their transfer from pediatric/adolescent services into adult centered care, and completion of this transition is expected to occur within six months of recruitment.

In phenomenological studies of lived experience the researcher shines a light on the experience so as to direct the flow of the interview to that phenomenon. It is often connected to a meaningful life event, as in the case of childbirth, loss of spouse, or onset of new job. In these cases the phenomenon is clearly depicted. Transition status is the relevant condition of this study as it confines the context of the lived experience under investigation; it pinpoints the area of interest of the study. In order to represent that specificity for this study context the definition of this transition status is defined as having made a transition to an adult provider or having been notified of their transfer from pediatric/adolescent services to adult provider that is expected to occur within six months of recruitment. This clarity of experience is essential to confining the experience to a tangible entity to be explored in the phenomenological approach.

Recruitment began after gaining approval of the Institutional Review Board protocol from The City University of New York, Graduate Center that required a letter of collaboration from the initial recruitment site, an orthopedic practice. Recruitment materials, a flyer and a postcard that described the study and provided my contact information were shared with patients of that service, who met the study criteria. Interested individuals initiated access to the research through telephone (toll free) or email contact with me at which time I would screen them for eligibility to participate. After ensuring that interested parties were eligible, a meeting was arranged. At the start of each meeting I read through the consent line by line, alongside the participant who also had a copy within their view. I explained to each participant how their name would be kept anonymous and described how tapes will be transcribed anonymously and kept separate from the single identifiable data component- the signed consent. I requested additional signatures for consent to being taped and consent to keep their contact information in case additional studies or additional need of clarification should come up. I reiterated that they could withdraw at any time without penalty of loss of the \$50 gift card that was given for participating. I identified myself as separate and independent of the referring site and iterated and reiterated that no harm or withholding of treatment could occur related to their participation or refusal to participate. I highlighted the contacts on my study consent that could be alerted should the participant be unhappy or have new considerations about the study that they want to address. Written consent was obtained and participants were given a copy of the signed consent for their records. The plan was to recruit consecutive eligible candidates from the initial site; however, due to a lack of recruits a second site and online recruitment were added as a modification to the study and an IRB protocol modification through CUNY Hunter was requested and approved.

Nine young adults, six female and three males; ranging from 19-25 years of age were recruited from the two sites and completed interviews. Data saturation seemed apparent at interview number six. However, three additional participants made contact within the period of the IRB protocol extension and were included in the study. Saturation occurs when ongoing analysis of data from new participants added to the database reveals that no new information or new categories of meaning emerge (Munhall, 2007). There is no specification for an appropriate sample size of a phenomenological study (Fawcett & Garity, 2009); it usually ranges from one to a maximum of ten (Giorgi, 2003).

### **Summary**

Chapter three introduced and summarized the method of inquiry for the research project, The background of the Phenomenologic Method and development of Giorgi's method inherited from the works of Husserl's and Merleau-Ponty and adapted for use in the human sciences and Nursing are provided. Giorgi's Existential Phenomenological Method was proposed as the framework of the study. The four-step guideline for approaching data analysis and synthesis guided the collection and reflection of data in order to understand the phenomenon of lived experiences of YA-CPs transition to adult healthcare. Considerations taken in the sampling and recruitment for the study were shared.

## **CHAPTER IV**

### **APPLICATION OF THE PHENOMENOLOGICAL METHOD**

The four steps of Giorgi's (1985) method of analysis for the phenomenological data were operationalized to describe the phenomenon of the lived experiences of YA-CP transitioning from pediatric to adult healthcare. The study of the lived experience and the recall of the lived experience revealed immediate and pre-reflective thoughts which are thought to be most meaningful due to their readiness of recall. Husserl acknowledges that reflecting upon a partial stream of consciousness is accessing data (Giorgi, 2005). I was interested in discovering the meanings of the phenomenon from lived experience rather than universal principles.

#### **Aim of the Method**

The expected outcome of this or any phenomenological inquiry is a consistent statement that is inclusive of all the transformed meaning units, an identification of the structure of the experiences within the experiential context (Giorgi, 1970). At the completion of the study I conceived a statement that identifies the structure of transition for the YA-CP that is relevant to the field of nursing.

#### **Procedure**

Recruitment was facilitated through a cooperating provider of care to young adults with cerebral palsy. Staff members at the cooperating practice identified persons with CP who fit the cognitive and language and transition criteria and provided them with a flyer and/or a postcard (attachments A&B) that outlined the nature of the study. Further considerations stipulated in the recruitment flyer were the requirement that audio recording (for up to 90 minutes) could be tolerated, as well as the recruitment parameters of age and language status. Participants identified themselves to me directly, via email or phone, as young adults with CP who were interested in participating in the research study. I completed a brief screen of the participants to

assess how they match criteria stated in the sampling procedures and confirm that they were eligible for the study. We then set up an interview date.

The considerations for rights of human subjects were applied throughout the recruitment and the duration of the research study. At the time of the initial contact I reviewed the entire consent side by side with participants and reviewed the basic information about the aim of the study, the voluntary and confidential nature of their participation and their ability to stop and drop out at any time. The processes for assuring confidentiality through the use of an alphanumeric code to identify participant interview audiotapes and transcriptions was reviewed and acknowledged at the start of each interview and in the introduction of the audiotape.

Interviews were used to bring the transition experience to consciousness so that a rich description of that experience could be acquired for the phenomenological reduction. I requested a description of the experience of this transition through the use of an unstructured interview that was formulated to obtain participants' experience of this transition. I initiated the interview with a brief description of the aim of my study and explained that I would like to know about what they have experienced. I shared that I am interested in understanding how young adults move from seeing their pediatrician for health care to having a health care provider who works with adults. My opening question was, "You have been told that you will be moving from pediatric to adult provider; or "you have already transferred to an adult healthcare provider- could you tell me what that experience has been like for you?" Alternately the question was elaborated if they requested more clarification or in the case of them stating, "I'm not sure what you are asking me for?" If elaboration or clarification was needed a follow up similar to, "Please share with me your thoughts and experiences of this transition" and if they were stuck or shy, "Maybe you could just tell me a story about going for care at the new provider what is that like for you?"

Follow up cues to keep the flow of the description were used along with probes that included “tell me a little more about that?” and “what do you mean by...”

My focus was on attending to and being present with my participants as we dialogued in hopes that it would promote the unfolding of their individual experiences. After the introduction, interviews evolved in response to the natural recall of the participant as the participant related descriptions of the experience. These interviews were audiotaped and after each interview I played those recordings and followed up with reflective journaling. The audio recordings were transferred to digital files and sent off for professional transcription. Transcripts were available within five days and reviewed with the audio to ensure the accuracy of the data. Journaling was also used to identify any recollected gestures or tones that accompanied the descriptions.

### **Data Analysis**

The phenomenologic reduction followed the initial data collection as described by Giorgi (1985/2005). Phenomenological reduction, means that past knowledge concerning the phenomenon of interest should be put aside and what is presented to the participant’s consciousness should be seen by the researcher, without the automatic positing of existence that normally takes place. The reduction examines the sheer presence of the phenomenon and refrains from saying that it exists in the way that it presents itself. This is also the basic meaning of phenomenon in phenomenology. It means how the given presents itself to [participants’] consciousness (Giorgi, 2005). In simpler terms, the researcher deals only with the version of the story that [the participant’s] consciousness reveals, without analyzing or explaining it, understanding that its revelation makes it relevant.

The experimental environment for the descriptive phenomenological study is controlled through the Epoché (Giorgi 2009) withholding prior knowledge and withholding existential claims. To withhold prior knowledge is to use attentive and naïve openness and an attitude of

wonder as if you were seeing the world of these phenomena for the very first time while you are participating in the interview and reduction process. Bracketing is the method used to hold back prior knowledge. To bracket for this study I would acknowledge the issue, bias or assumption, bracket it and remove it, figuratively, out of view so that I could address what was shared naively. Withholding existential claims refers to focusing on what is given “as is”, to receive the description as objects, to avoid tainting them with external or personal meaning or import. In order to prepare myself to enter the experience in wonder I tuned into my assumptions and biases. Identification of my biases and my experiential assumptions about the phenomenon allowed me to be aware of how those suppositions attempt to influence the reduction and I used reflection and journaling to keep those occurrences "bracketed". In this way I was able to intentionally keep them from tainting the exploratory process. Journaling occurred alongside the reduction to keep biases on the radar and out of the analysis.

Giorgi (1985) asks that researchers take some time to dwell with the data, therefore multiple readings of the transcript, readings along with the audiotape were exercised in order to invigorate the reduction. Following Giorgi's (1985) method for analysis of phenomenology. I read the entire description in order to get a (1) *Sense of the Whole*: a general grasp of the whole statement. Rereading the interview transcripts in the attitude of phenomenological reduction allowed me to grasp the whole picture of what was being conveyed from the interview.

Once a sense of the whole was grasped I went back to the beginning and read through the text with the aim of (2) *Discriminating Meaning Units* which are common threads, or perceived discriminations within the subject's description. The meaning units exist only in relation to the attitude and the set of the researcher, what stands out depends very much upon researcher perspective (Giorgi 1985). While reading the interviews, shifts in meaning were perceivable and

those meaning units were revealed in the words of the participants. Throughout this exercise I was aware of my role as an instrument in this study; it was through my ears, eyes, and appreciation of the subtleties of speech and gesture that the meaning came through from the participants' stories.

Once the meaning units were delineated I went over them in order to arrive at a general category supported from the description. Meaning units that had similar content or focus were clustered and integrated based upon their adherence to each other. This process involved working over the meaning units from the experience, exploring the possible variations and testing their adherence with one another, as well as noting extraneous or nonessential meanings. The process results in transformed synthesized meaning units or themes; central themes were then searched for repetitive statements, which were removed. In this way redundancies were eliminated and meanings clarified so that their relationship to one another could be recognized.

(3) *Transformation of Subject's Everyday Expressions into Psychological Language with Emphasis on the Phenomenon Being Investigated.* The nursing disciplinary perspective was adhered to throughout the reduction. Integration of meaning units involves sequencing similar meaning units, in the words of the participant. The process of free imaginative variation was used to find essential meaning from the transformed meaning units. This device allowed meanings that were not necessary to the identity of the phenomenon to be extracted and further expressed the meaning. The results are the essences, the essential characteristics, and quality, defining the phenomenon; without them the phenomenon would not exist. The essences were identified through further clarification and reflection of the essential themes that presented in the interviews. The essences were used to synthesize the statement of the structure of the subject's experience in order to complete the final step of the method (4) the *Synthesis of Transformed*

*Meaning Units into a Consistent Statement of the Structure of the Phenomenon.*

### **Reliability and Validity**

Rigor is the value term for reliability and validity in the qualitative research environment. Morse and colleagues (2002) argue that reliability and validity are appropriate indicators of rigor in qualitative research and urge researchers to implement verification strategies, which involve checking, confirming, making sure and being certain. Once the phenomenological analysis of the data was complete, I initiated a critical analysis of my work. The critical analysis included verifying that concrete detailed descriptions of participants were obtained and the phenomenological reduction was maintained throughout the analysis. The raw data was revisited to substantiate the accuracy of the findings. The raw data descriptions justified both the essential meanings and the general structure. Consensus critical analysis was provided through consultation with panel members who are proficient in the phenomenologic method; they reviewed the analytic process and validated the thematic reduction and synthesis of structure.

### **Summary**

The focus of the study was to illuminate the meaning of the experience of young adults with cerebral palsy's transition from pediatric to adult health care. The use of language in interview allowed participants to convey their stories and give voice to their transition experiences. Giorgi's method relies on the subjective voice of participants' narratives, so it was the method of choice for this qualitative study. The method prescribed by Giorgi provided a framework to guide the phenomenologic reduction for this study. Considerations for the control of experimental environment, reliability and validity were discussed in this chapter.

## **CHAPTER V**

### **FINDINGS OF THE INQUIRY**

#### **Introduction**

This study explored the meaning of the experiences of young adults with cerebral palsy as they make the transition from pediatric to adult health care. The participants in this study represented individuals with the diagnosis of cerebral palsy from several states, including New York, New Jersey, Iowa, Illinois and Delaware. Giorgi's Existential Phenomenological Method (1985/2005) was used in analyzing and interpreting the data. This chapter includes a description of the setting, study sample, study participants, and the findings of the research.

#### **Setting**

Recruitment flyers and postcards were shared with patients at the cooperating practices. They instructed interested individuals to make contact via email or telephone directly to the researcher. Once a participant/volunteer made initial contact, I conducted a brief screen for eligibility to participate and then an interview date was agreed upon. All interviews were conducted in person. All participants consented to audio recording and individual names were not used on the tape, instead I assigned a numeric that was referenced as part of the introduction on each of the interview tapes. Privacy and quiet was assured in each of the interview venues. Most of the interviews took place in participant homes and dormitories. The remaining interviews were held in meeting rooms in a library and an office park. Audio recordings in digital format were sent electronically to a professional transcription service and returned electronically for review. Pseudonyms were assigned alphabetically in order of interview, for labeling the descriptions of the participants.

### Study Sample

The study sample consisted of 6 female and 3 male young adults who self identified as carrying the diagnosis of cerebral palsy without cognitive impairment. Participants' actual age ranged from 19 through 25 years old. Six were college students currently enrolled in classes. Two participants were college graduates; of these, one was actively employed and the other one, actively seeking employment. One participant was involved in assisted employment services and volunteerism. All were unmarried at the time of the interview. One participant resided independently in her own apartment; five participants resided part-time away at college and at parental homes when school is not in session; and the remaining three participants lived at the parental home full time. Levels of physical mobility related to cerebral palsy impairment varied across the sample and included: independent walkers (n=2); walkers using adaptive devices (n=3); and wheel chair reliant, rollers (n=4).

### Description of the participants

The first essential step in Giorgi's phenomenological data analysis is the reading *of the entire description in order to get a general sense of the whole statement*. In listening to the tapes and re-reading the transcripts for a sense of the whole, each encounter was reviewed and an overall picture came through. Much of that extraction is conveyed in the participant descriptions that follow.

#### **Annie:**

Annie welcomed me to her room in her family home in a quiet suburb of New York City. Her large blue eyes shined from under her glasses and her smile made apparent her interest and readiness to get into the discussion. Dressed in jeans and a comfortable sweater she is the picture of the average 19-year-old college student home on winter break, with a few exceptions, the

main one being her use of an electric wheelchair outfitted with pockets for her phone, wallet and other personal items. She has occasional spastic movements to her hands and her head but her voice is steady. Annie has recently begun seeing two new adult providers in the past three months. She relates her experience with the confidence of an expert orator.

I think it's all a little overwhelming mainly because like I was saying before, a lot of the kids' doctors are somewhat familiar with CP because it is a developmental disability...and then once you get towards adult doctors, there is a lot of them do not even really know what CP is.

Most recently, I have been to an adult GYN. They mean well, but they do not always know what to do because I do not think they are used to people being so impossibly tight all the time. So you can imagine any kind of pelvic exam takes a great deal of effort because a lot of doctors will just usually say, 'Can you relax a bit?'... No, not really.

She asks and answers the physician's question in that story; she does this abruptly and with a zing of sarcasm. She shares that exchange as proof that the physician is unaware of what to expect related to her underlying diagnosis. During our interview she returns to that moment and conveys the feeling of not being understood through the inflection in her speech.

Next, she clarifies that although she is ready and able to inform her new providers and answer any questions and consider options for herself, she is never actually able to be on her own for these visits, owing to her need for personal assistance in being moved and positioned throughout the encounters. I was immediately struck and embarrassed by my naïveté to the mobility considerations that apply to Annie. I sat entranced as she reviewed the need to be

moved, the occurrence of being “talked around” and the feeling of being considered, always, as the dependent one in the encounter with providers.

So, some things that they direct to my mother, there is really no point because I could fill it in just as well. I know it is probably not intentionally so because very few people mean to come off this way. But it is kind of condescending, especially since most people know that I do not have any cognitive impairment and sometimes they still will talk around me. And like I said, not that they do it on purpose, but I think sometimes people just have an instinct to be sort of awkward. There is definitely a rampant stereotype that we must be childlike in some way. I would say that needs a little bit of work in general. I think sometimes, because a lot of us do come with other people to move us and what not, it is tempting for people to talk around us.

Annie shares that these challenging experiences occur pretty frequently. She uses the terms “sensitivity” and “missing links” in describing the systems she is working within.

She shares a recent postoperative experience at a "specialty hospital" that provides CP related orthopedic services; a place that she expected would have the experience and background in cerebral palsy. "The OR nurses and the recovery room did not realize that I had CP and they would say -to my mom-, your daughter can get up and walk when she feels up to it."

Her physical functioning and the maintenance of it, as she gets older is her primary health concern.

I would say I am in good health. I mean, most of my worries for my adult would be related to musculoskeletal stuff. I would say ideally, I would keep the spasticity in check with aging; I have to be careful about... I just really have to watch my joints with

spasticity and make sure it does not get too out of hand because I do know that the effects of aging tend to be sped up on people with CP.

As the interview rounded out Annie told of her appreciation of supportive parents who foster her independence and self-advocacy. She shared a lot about the systems she is using at school to ensure her personal care and keep her independent and able to attend college away from home:

I have twelve different aides and they all work in different shifts. And it is a little bit like running a circus because you have to figure out when everybody is coming and what time. And it can be really consuming sometimes.

Throughout the interview I was struck by her clarity and honest depiction of her transition experience and I feel enlightened. This is a dimension I had not considered and as I hear her go over her processes for scheduling her personal care around a full time academic schedule I find it to be more than a little overwhelming. As a health care professional I am embarrassed by the shortfalls in the care provided and reviewed in Annie's experiences. As the originator of this study my resolve to bring this voice to the forefront of the HCT discussion is reinforced by the information shared and the advocacy conveyed by this young adult participant.

**Barbara:**

Barbara met me at the door of her home. Ambulating upon elbow crutches she led me up the 8 steep stairs to her living room where we sat for our interview. She is a college graduate actively seeking employment and currently anticipating that she may have a call back for a position that may interrupt our interview. Barbara exchanges the terms “transition” and “change in control” during her story telling. The first experience shared was her first solo attempt to access health care at college:

It's actually really funny that you asked that and we're talking about kind of the transition from parents to dealing with things yourself because I remember the first time I had to go, I might have been maybe 19 and I hadn't gone to the health center at school and I didn't want to go by myself and I was like oh, no, I remember my Mom was coming up in a couple of days and I refused to go until she got there.

It was just, you know, they—they don't care. You go in, you would—What are your symptoms? They give you your medication and they send you on your way, you know.

Transition from a pediatrician to the adult general practitioner is described next. She relates the visits as quick trips that are symptoms focused and shares her impressions.

Moving from pediatric to (adult) GP and, um, the whole like okay, I've had this doctor for so long, then I have to go find a doctor that I trust who, you know, is a GP and all that, other than that, like once I actually went to the doctor, it was pretty, you know, normal and it is a little weird the first time you go just because, you know, they don't know you as well as your former doctor did so you have to go get back, ah, on to that, you know, that common ground with the doctors.

Barbara then told of a recent health need, an injury. She lost her balance and fell and fractured her knee. This recent injury to her knee required that she have physical therapy. She reviewed the steps in the process of getting that accomplished.

And so when I did fracture my knee, I had—you know, I went to my orthopedist to find out what's going on. He let me know what happened. And I had to go to physical therapy for a while for the injury.

Being that I hadn't been to actual physical therapy in a couple of years, you know, I

started to, ah, wonder, okay, how do I go find a PT now? How do I find these—these things that I need, you know. So that was definitely, ah, you know, a—a learning process and a—a big eye opener. So I definitely had to go back to my Mom for that... And, you know, she walked me through what she would usually do and then she said okay, go do it.

In the end, the physical therapist she connected with had past experience with cerebral palsy that made her more comfortable with him as a provider. She had the feeling he was someone she could work with and would benefit her due to his CP knowledge and experience.

The person that I was working with actually works—has worked with kids with CP. So I felt like he knew a lot more and like he knew, um, kind of more of the things that I either could do or how to do them and he like asked me more questions about me specifically and my, you know, my experience and my feelings and things about my disability and where we should kind of go from there.

Barbara considers her plans to stay healthy and prevent CP related problems throughout her life. Additionally she conveys her awareness that there is more to come related to this diagnosis of CP that she refers to as her disability. The constraints she experiences and what sounded like her frustration with the systems are also related.

I feel like—like I said when you—like when you're trying to get, you know, your physical therapy covered by insurance or whatever, it may be what's wrong with you? I have CP. But why do you need to go to physical therapy? Didn't I just say that? Like no, nothing's broken, nothing hurts right now, but—but I have a lifelong disability. It's not going away like kind of thing.

Barbara spent a lot of time reviewing what her role in the transition was, is and will continue to

be. She conveyed fiercely her belief that advocacy and establishing a network for support were priorities for her.

I've definitely learned more, you know, growing up to be an advocate for yourself. It's— it's definitely, ah, an interesting transition because, you know, going from, you know, having a parent who will, you know, help with all those things or kind of be your voice when you can't be—I have to be my voice, I have to know the answers to all the questions and I've been doing this transition for a while now...it's a work in progress.

As I returned to my car at the completion of our time together I felt both inspired and worried. Knowing all of her expectations and her somewhat marginal experiences of transition make me nervous and a little agitated. It is apparent to me that in addition to the usual health care systems annoyances there are many additional considerations for youth growing up with CP as they negotiate health care.

**Courtney:**

I met Courtney at her college dormitory for our interview. She came out to sign me into her dormitory and led me back to her suite ambulating with the assistance of two canes. She shared that she was anxious and unsure if she could tell me about what I wanted to know. She reclined on her bed as she started her transition story. At 19 her parents and she initiated Courtney's move to adult care. She described the change to an adult health care provider and related her general perception of the medical profession.

It was a little what's the word—a little um, jarring maybe. Um, just something I wasn't really used too. You know like pediatric is—its more you know warm and fuzzy. You

know they'll cut you off in the middle of a sentence and you know start scribbling something down on a pad and you know I'd be like wait, I wasn't finished.

Sometimes I do wish they'd be a little more specific but I think that's you know—sometimes, they don't really tell you exactly what you have or they don't talk—not really talk to you but I don't know that's a—that's a quality of all medical professionals out there. Like the doctor examined me and she goes- 'oh, you have a little bronchitis". And I'm like oh, so does that mean I have bronchitis or like I don't know."

She shares her consideration that there is not enough awareness by the medical community about cerebral palsy.

Most medical professionals I encounter really don't know much about CP I don't think. It would be nice to have doctors who are more educated about CP in general and how different issues may interact with CP. And you know could offer me some good suggestions that you know how to keep myself stretched I think.

Courtney reviewed her process in identifying that she was having an issue with anxiety and how she went about getting treatment. There were geographical complications due to her residing away at school and so she came to be under the care of a neurologist for the medication management while she is attending school. The neurologist represents her second transfer to an adult provider.

I hadn't seen him before but he's very nice. I like him a lot. And his daughter actually has CP so that made me feel better that you know he sort of gets the whole having CP thing. He's probably one of the better medical professionals I've encountered. And I don't know if that's because he has a daughter with CP so he knows you know this stuff or if he's just generally a better practitioner.

There is a certain interest in relationship and comfort that she restates throughout out interview. I appreciated that she was uneasy about sharing although her personality is that of advocate. She often would become expansive in discussing disability in a societal context. We carried on with the interview and we managed to keep it about her experiences. She made a surprising observation that the person's level of disability, and what that looks like, has an impact on the success of the transition and the provider response.

And I think also the probably has to do with you know I'm more presentably disabled as I—as I call it. You know it's—it's easier to handle when you look more like a normal person. You know and I don't have a lot of the concerns that a lot of other kids with CP have, and the less the presentably disabled you are the less likely you are to be taken seriously.

All I can think is wow! The concept of presentable disability swirls in my head the entire trip home. I suppose this concept is from the societal context that Courtney kept referring to. It sounds like there are tiers or a type of internal class system to consider when considering disability.

**Diane:**

I met Diane in her dorm room. She was just finishing up an in-home medical visit for the refilling of her baclofen pump and was finishing up on the phone with her father with an update of how that visit went. Diane was smiling brightly and very excited about sharing her story. She was seated in her electric wheel chair and used a halo headband attachment on her wheelchair to keep her head in the upright position while she sat. Diane uses a great deal of energy and force to deliver her speech and has a lot of head movements throughout our dialogue.

Diane shared that her primary care provider had notified her that she will no longer be able to see her and so she is getting ready to find another provider.

I haven't transferred to uh, an adult doctor, you know, general doctor because, um, my doctor has, does a lot of help with insurance and frankly, hooked me up with insurance in getting like my wheelchair and like equipment that I need. Um, so I am stilling going to her for now uh, she said she could see me until about the age of 21 and I am 20 now so I'm right on the verge of needing to switch, but I am just finished switching to this school from (other school named) ...so with all of that I didn't want to worry about going to a new doctor just yet.

Diane and her parents are in the process of planning for her transfer; in the meantime they are sticking with a provider who has given them positive results in negotiating insurance and accessing equipment they need. It's interesting to me that I had not considered the multiple transitions of the college-aged person and how that may or may not impact transition in health care.

Diane related that the spasticity in her arms and hands (for which she gets Botox injections every three months) and negotiating her ability to empty her bladder in a way that can be coordinated with her personal care assistants are the major considerations for her, health wise. Scheduling personal care aids is a new skill that she has managed independently while at school with the support of her peers and her parents from home.

Diane was very animated and smiling as she shared her many experiences of taking care of herself on her own away at college. At the conclusion of the dialogue she remarked that she is very happy that I am doing this study and she would like a copy of it. I responded that I was

happy that my study has brought me to meet and come to know young persons like Diane and that I will send a copy of the study to her.

**Elaine:**

Elaine met me outside of her dormitory in her electric wheel chair with a black thin brimmed fedora. She brings me back to her dorm room that is on a higher-level floor of an ordinary appearing high-rise dorm. At first she comes across as hard to reach, aloof and sarcastic but she opens up with the start of the tape. Elaine relates that the transition was hallmarked by notification from her public insurance that her parents are now to relinquish control of her benefits to her. She recalled thinking it was going to be a clear transition and later said there is more attention in the transfer in banks than what she appreciated in the health care field.

Elaine shared her experience of using her new authority in gaining access to rehabilitative care by drafting a letter for her physician to sign directing a referral for therapy and aqua therapy.

At the moment I'm sort of doctor less, which is always amusing, 'cause like even when I signed up for physical therapy here, which is wonderful, they ask you to put down a care physician, and I was like, I have none. So I went to ... the hospital here, and looked up who the physician is- then I was just like (to the doctor) I'm going to need you to fill out a Consent to Therapy form, and she's like, what do they look like? What do I say? So I went home and wrote it and just told her to sign at the bottom.

That has been sort of my alternate stage in adult health care is just doing it myself, is having people sign, which is horrible. On some level I realized I'm committing a degree of fraud, but I don't know what else to do about it. You know, it's not like I wouldn't want them to get to know me and make a decision in an informed way; but it's not something I need anyone's help to decide.

As I hear this story of Elaine getting the care she knows is right for herself I am impressed with her initiative in finding a solution on her own. I am also concerned that in the long term she could find herself without a care provider in a time of need.

Health goals identified by Elaine were “to just maintain where I’m at, trying to get better you know- Not let it to ever overwhelm me”. Elaine shared that a second need she determined for herself was in mental health support and she conveyed her past experience as awful, but was happy with the provider she has recently started to see.

Elaine highlights the issues and disparities in care as you move into adulthood with cerebral palsy and surmises that there is an interest in keeping adults with CP from taxing resources.

It’s just all based upon, you’ll need things in the short term, not, this is a lifetime disease with a lifetime of consequences that needs a lifetime of care, which is strange. I mean, it’s not like anything about our disease says that once you hit age X, then stop worrying about it, and you’ll stay the same.

Elaine's story above highlighted the difficulties that occur due to the medical definition of CP as a "non-progressive" disorder and how that terminology sets her up for the fight for supportive care that she needs, such as PT. Her awareness of having been "set up" to fail is described as:

When we’re children, they’re always wanting to send our parents tons of information to get us everything and anything. And then once we’re working on the adult health care system they want to give us as little information as possible, in the hopes that we aren't taxing up resources that so many people already need, because my theory on this all, being the cynic that I am, is that people love to say we’re helping children. Helping middle-aged adults? Not so impressive.

The tragic irony of this statement nags at me. As I hear it, I nearly wince as she pointedly states that health care providers (*like me*) are not meeting the mark and have let her down in some way. Despite the fact that she self identifies as a cynic this remark stings and I am afraid may hold some truth.

Elaine offered further consideration of her negotiations with the health care field:

I realize that I already have no before I ask, so I might as well ask and either confirm the no I was already with or get the yes I was hoping for. If they're not the right avenues, then I try again. I've just learned not to be so attached to things and not to be so attached to one solution that things will work out.

It seemed to me there is so much embedded knowledge shared within these innocent interviews. I suppressed my instinct to shout, "you go girl" as she wraps up the last line. What started out, as a bit of a standoff with Elaine, who at first was a bit aloof and measuring her words, had come to feel more like a comfort zone, there was ease in our dialogue. As she laughed I sensed she felt understood and was amused at what that sharing felt like for her-the cynic. We made a little small talk at the end of the interview and she shared that she was really glad that she volunteered and hoped that her words would be shared so that change might be considered.

**Fran:**

Fran and I decided to meet at Starbucks's and then walk back to her apartment for the interview. I sat in Starbucks ten minutes past our appointment time before calling Fran to ask if she was close by, as it turned out she was already there but, because she has no outwardly visible symptoms of her cerebral palsy, I did not identify her as my intended company. The walk back

to her place took several blocks during which I confessed to my awkwardness in not making a plan for identifying each other at the meeting point.

Fran's story telling involved her most recent experience of transfer in healthcare. Her primary care physician experience has lacked sensitivity to her general and specific concerns.

I think it's, it's a challenge I think also to, to find a doctor that you connect with, um, and also, um, making the time is also a challenge. In terms of like what prevents me from, seeking, like making that physical appointment on a yearly basis. Um, it's just, you know, one more thing that I have to do.

She reports annoyance that when she brings a health concern to her providers they do not have consideration that the complaint may be related to her CP diagnosis.

I had brought up, [to her gynecologist] the fact that like, CP and like, muscle tightness, like muscles are tight everywhere else, like could that be an issue. And she's like, I don't really think so. So that lack of sensitivity to like, maybe the fact that I have CP is a contributing factor here and like, maybe I'm not just like a wuss. I couldn't be but maybe you want to entertain the fact that maybe it might be something medical.

Fran offered a very considered discussion of the movement into adult health care and highlights how in her time of need, when she had an actual health concern and she actively tried to engage her providers she got no support.

If you can't, if you can't go to the doctor to get those questions answered and feel that you have that forum...it only deters people more from, from going back and like, seeking other care.

Health insurance considerations and systems have also been a major part of the transition to her managing her care on her own. Without always being able to identify the exact term the

overall impression for Fran is that her transition experience is lacking needed elements and sensitivity is one of them

At this sort of like, unique age, that not only do they like, don't have the sensitivity towards the fact that like, we're dealing with like, insurance for the first time but like, there's also like, life experiences that we're having for the, like, the first time. Um, that their not sensitive to, either.

Provider sensitivity and availability are major concerns for Fran. She concludes our visit with the assertion:

No sensitivity to the fact that like –this was my first, like, oh I need you for something else besides like, the regular exam. Um, and it was just sort of like a lack, like, this is my first time having sex like, maybe you could be little bit sensitive and like, explain some things because like, you don't know what my background is like, sex ed. and like, the last time I had sex ed. was like, probably ten years ago.

Fran's CP is not visible to the eye unless you are looking for it or she offers those clues to you but CP's impact on her health and development are ever present. Her providers and her employers overlook her CP in more than a visual way. Her needs related to CP and general accommodations are overlooked. To have the ability to know what you need and know something is not right with your health and not be able to have it addressed can cause emotional pain. To have a team for care that cannot meet your needs is such a loss.

**Greg:**

Greg and I met in the lobby of the office building where he works. Within minutes of encountering him it is apparent that relationships are important in his life. He said hello to

everyone we passed and was well known and received by all. He was eager to share his experiences and also to tell me about his many relationships with important people.

Greg's transition story included two new providers and a deep appreciation for the providers who have worked with him from his youth until his last experience. He related that he and the provider knowing each other is important to his experience. Greg shared his latest transfer to a new provider who is a pain specialist who has provided him several short-term therapies for flexibility and comfort.

The newest person I have is a doctor who I see for my back. And I've known her for what, a year now, a year and a half. It's good too, you know, that she's so, um, what, what's the word here. She knows me. There's already like a humor with us. We already have like all the old jokes and everything, you know. So she knows me, and I know her, which makes me feel more comfortable really.

Having a sense of humor or inside joke is common to his experience of providers throughout his lifetime. Familiarity is important to Greg; "It's just better when I'm with someone I have known". He relates that he and she discuss her proposed interventions, have open communication about the effect of the treatments, and engage in decision making for follow up. Greg shared his expectation to have a discussion about options and to make decisions for himself.

Greg's version of the experience of a procedure with his new provider is what he has come to expect.

I know what the deal is by now you know the nurses gotta ask a million questions and then you wait around and wait around and none of them explain what's gonna happen and then you finally go in and get it done.

He relates that although he was with a new provider he found comfort in the face of an old friend that he encountered once he got into the treatment room.

Totally calm the whole way. Totally, you know, do whatever you gotta do. And I think the reason for that is that my anesthesiologist was a guy I've known for like 15, 20 years. Well, not that long. More like 10 to 15. He's been with me a long time. And we haven't seen each other in a long time. So it's kind of like a reunion .

Greg's view of the changing role of his parents and the way that change played out was also conveyed in his story telling.

I said to my mother, I went, look, I'm 23, I've done this a million times. I don't need you to come in the room with me. I don't. I said to her it's actually better for me if you don't because then I can keep my composure a little better. So she's like, okay. You know, I'm not gonna, you're right, you're 23. I'm not gonna like, I'm not gonna make you, you know. So she kissed whatever me and then I just went in with this guy. And the first thing he says to me is, "So Greg, buddy, how's it going?"

Greg values relationships, provider expertise and being central to the conversation and decision-making. He repeats himself on these items about three or four times in the telling and retelling of his transition stories. He shares feelings of loss when relationships are terminated and demonstrates his facility with making sure his opinion is heard.

As we end our meeting and walk to the entrance I experience firsthand the frustration that accompanies reliance on other people and programs for transportation. Greg's companion took off early leaving him alone to wait for his ride. He is visibly upset and his frustration is palpable. I wait with him for the public transit as he plays over his disbelief that he was left alone.

**Harry:**

Harry and I met at his home and his mother was around during the interview. Harry starts his story telling with the revelation of his immense gratitude for providers that have allowed him to be here today. He shares that he would like to meet the original birth-day surgeon involved in correcting a congenital anomaly and making survival possible.

Transition of his role is a point he makes in his story telling; he describes being more active although interdependent in the preparation for and experience of health care alone.

I've taken more of a role. I do my primary care by myself now, which I must say, is overwhelming. You know, it's overwhelming because you won't, your biggest fear is like, you know, here I am in this situation; I just don't want to miss something. Well, like I said, it's nerve—it's nerve-wracking.

The transition story for Harry was orthopedic related. His pediatric orthopedic surgeon was no longer willing to consult on his care just as he came to need surgery this past summer and transferred to an orthopedic surgeon that follows CP patients throughout the lifespan. He conveyed his experience with a new orthopedic surgeon.

What an addition to my life because I felt confident that, you know, that there is somebody like [my new doctor] who specializes in cerebral palsy that works with adults because I often wondered about that. Like when I aged out ...where am I going to end up? If I have pain, where am I going to, where am I going to go?

I am thrilled to hear this transition story of coming into care with the expert in the CP field. In Harry's case it appears that the options for care and specialized supports improved with transition.

When I met [my new doctor], it was more of a sense of this is a bonus, this is a relief. And when he did, when he did the Botox shot and feeling all of the, um, non-tightness, let's say, you know, it was just like, okay, I can trust this man. You know, for my adult, for my adult stuff, he's been a great addition to my, my life medically, and I'm looking forward to many years, um, of going to, of going to the [that center].

The adult CP expert is on his team and there is a lot of work and habilitation in progress. Harry is in it "150%" he is glad to have choices, happy to do the work and excited to continue progressing forward. His care seems to have improved in the form of choices and alternative measures with a provider who knows how CP progresses and has an interest in minimizing its long-term impact. We say our good byes and Harry hustles to get ready for PT.

**Josh:**

Josh and I met at the visitor parking lot at his college; he was involved in conversation with another person as he approached me. After hellos, Josh led me along the campus path to the library, at a pretty quick pace, through the first floor lobby to the stairway up one flight to a group study room. His gait is imbalanced due to tightness in the hips and rotation of his lower extremities. The room was well lit and sound proof, we sat comfortably throughout our interview.

In his story telling he shares the experience of transitioning from a trusted provider/mentor- his orthopedic surgeon.

I have to find, not only a-a new healthcare provider, but a new surgeon, which is an interesting process because I've had the same surgeon forever. So that's a little bit intimidating for me, as well as, he (the orthopedic surgeon) wants the primary care doctor to have a background in Cerebral Palsy so that if I'm not regularly seeing the surgeon, at

least somebody is aware of the intricacies of the condition. And that's also quite a process because there are several in this state, but you have to find one that you're comfortable with; that-um, that's not always the easiest thing .

Being cared for by a person less knowledgeable than he about the underlying diagnosis of cerebral palsy is an experience that Josh has had severally, and he shared what that experience is like.

It was a very uncomfortable visit for me because he-he did not-he knew what he was supposed to do from the standpoint of he knew what he needed to check for—but he was not familiar with checking for it; so it was one of the most uncomfortable visits in my life. It was a lot of yanking and [laugh] -And he was clearly uncomfortable but he had to get through at least the one visit [laugh]

He shared that he would like to have the experience of being a patient and beneficiary of expert knowledge and involved in collaboration with an expert to make a plan for him.

I would feel much better if there was somebody that I could walk into their office and, you know, they can say, you look a bit-a little bit tight on your left side today because that's what I'm used to. I'm used to somebody who, I can walk into their office, they can immediately analyze how I'm moving, what I'm doing, and they can tell me what's wrong before it comes out of my mouth because they are good at their job [laugh].

He considered what might be ahead for him as he ages with his cerebral palsy:

I'm super concerned about how this (the CP) goes while I age. I am concerned about how does your body react to muscle tightness at 50 and who's going to deal with that?

You know, how is your body going to deal with that at 50, 60, 70 years of age? You know, what happens? I don't know a lot of people who have Cerebral Palsy at those ages, so I don't really have a frame of reference.

Josh's reliance on the expertise of his longtime orthopedic surgeon was shared in emotive terms and he thought out loud about rushing the next procedure so that he could enjoy the comfort of having the procedure done by his trusted friend and physician.

We've sort of mildly discussed whether a fifth one is in the cards before I transfer out or if that's going to be more of a first-procedure-with-a-new-doctor kind of thing. I'd much rather him do it. Um, I have a lot of faith in what he does based off of the progressions that I've made. I mean it's really emotional for me because I've never switched providers as a kid. So these are people that are, in essence, part of me growing up.

I was very impressed with Josh's way of thinking and considering his situation, and I tell him so. After we wrap up our discussion I spend a little time off recorder to review some of the things Josh does for maintenance of his spasticity and shared some of the insights and helpful therapies that participants have reported during previous interviews. Although I have heard much of the same message throughout these interviews I am ever impressed by the insight, consideration and tenacity that these youth embody and share during these encounters.

### **Data Analysis**

As Giorgi's method directs; *Once the sense of the whole has been grasped the researcher goes back to the beginning and reads through the text once more with the specific aim of discriminating the "meaning units" from within a psychological perspective and with a focus on the phenomenon being researched.* While I read over the transcripts meaning units were extracted and color-coded with a highlighter. Table 1 illustrates the outcome of Giorgi's next essential step, *Discriminating meaning units.*

**Table 1. Step2: Discriminating Meaning Units**

MEANING UNITS IDENTIFIED FROM THE ANALYSIS OF THE TRANSCRIPTS
<ul style="list-style-type: none"> <li>➤ Being dependent and independent all at once, modified independence</li> <li>➤ Parental support, role for parent after transition/ parent as guide mentor</li> <li>➤ Provider knowledge/ knowledge deficits</li> <li>➤ Provider regard/disregard feeling ignored, disregarded talked around</li> <li>➤ Perception of adult model as treat and go</li> <li>➤ Not being cared for -being rushed through adult systems</li> <li>➤ Recognize need for self-advocacy/ self-awareness</li> <li>➤ Getting ready to fight for services</li> <li>➤ Adult providers talking without explaining</li> <li>➤ Provider discomfort giving care</li> <li>➤ Shared experience of discomfort receiving care from non-CP aware provider.</li> <li>➤ Experiencing loss of trusted provider.</li> <li>➤ Anxiety/depression self identified carries greater stigma than CP and spasticity</li> <li>➤ Alleviation of spasticity is priority</li> <li>➤ Awareness and advocacy needs help getting things done</li> <li>➤ Feels support with peers would be optimum</li> <li>➤ Recalls the language of transfer as clear,</li> <li>➤ Transfer away from parental signature; still needs the parental support</li> <li>➤ Taking advantage of signing off on one's own care</li> <li>➤ Understand there is need for continued supportive care to maintain functioning</li> <li>➤ Awareness that care is blocked by insurance</li> <li>➤ Expecting a NO and pushing for a YES</li> <li>➤ Issues of non-progression and insurance entitlement</li> <li>➤ Health goals to keep function and maintain "pain-free" state</li> <li>➤ MD concern is stereotypical and did not focus on concerns</li> <li>➤ Appreciate a lack of sensitivity to the novice needing assistance in new role</li> <li>➤ Lack of provider empathy that CP may impact general health and functioning.</li> <li>➤ Having pain and expecting to keep the pain instead of being pain free.</li> <li>➤ Adult provider not considerate of her CP issues impacting health</li> <li>➤ Providers as trusted adults- familial connection, parent like position</li> <li>➤ Relationships with new providers are very important</li> <li>➤ Sees the provider not attending to them- inconsiderate, not being told everything.</li> <li>➤ Provider understanding of disease tone, pain and function not optimal</li> <li>➤ Experiences with adult CP expert were a bonus.</li> <li>➤ Appreciation of being heard and seen with expert better provider</li> <li>➤ Appreciation and buy in of the extra work needed to get to walk</li> <li>➤ Wish to have a CP expert that he can work with so he can "be a patient"</li> <li>➤ Are used to being active and involved in care planning from early age.</li> <li>➤ Feeling of being sent off without TRUE receiver</li> <li>➤ Disappointed that CP transition is not ready for them after all of these years.</li> </ul>

Giorgi's third essential step, *the transformation of participant's natural attitude into phenomenologically, psychologically sensitive expressions* was my next step. The meaning units were next compiled or grouped by similarity of content focus that naturally divided the data for thematic exploration. I used color coding and numbering to connect the meaning units to each other. Similar tones, voice and ideas clung to each other as they were studied. Common ideas within the highlighted phrases were clustered and these clusters became the identified themes. I removed redundancies I clarified the meaning units. Eighteen synthesized, transformed meaning units were conceived.

**Table 2.** *Step 3: Summary of Synthesized Transformed Meaning Units*

<b>SYNTHESIZED TRANSFORMED MEANING UNITS (THEMES)</b>
Informed by child guidance view - child centered multidisciplinary approach High regard for specialty pediatric providers-expert mentors Involvement in care from an early age - part of the team
Health goals are clear: maintain function, mobility & pain free. Need for supportive care as they age Importance of provider knowledge
Dealing with adult health care model Learning systems they need to use Ready to fight for care; non- progression bias; too few options Aware that insurance is a barrier to care
Need help getting things done, insurance referrals Being dependent in independence, modified independence Parents have a role during and after transition Relationship is a high priority in provider fit.
Discomfort, uncertainty and anxiety runs through the transition experience, Transferred without knowledgeable provider to receive them, Lack of transition systems not ready for them, neglect their presence Experience of provider disregard of CP in routine care

Essence is the most essential meaning for the context of the lived experience, in this case the experience of transitioning from pediatric to adult health care. Discovery of essences of the phenomenon- those things that make something what it is and without them the thing is not the same is undertaken through the use of free imaginative variation. These five essences were compiled in an attempt to describe the overall structure of the phenomenon.

**Table 3.** *Step 4: Identification of Essences*

<b>IDENTIFICATION OF THE ESSENCES</b>	
<b>ESSENCES</b>	<b>SYNTHESIZED TRANSFORMED MEANING UNITS (THEMES)</b>
<b>Expert Novices</b>	Informed by child centered, multidisciplinary approach. High regard for specialty pediatric providers-expert mentors Involvement in care from an early age as part of the team
<b>Evidence &amp; Experience Based Expectations</b>	Health goals are clear: maintain function, mobility & pain free. Need for supportive care as they age. Need provider with CP knowledge.
<b>Negotiating New Systems</b>	Learning systems of the adult health care model Ready to fight for care; non- progression bias; too few options Aware that insurance is a barrier to care
<b>Interdependence</b>	Need help getting things done, self care to insurance referrals Parents have a role during and after transition Relationship is a high priority in provider fit.
<b>Accepting Less</b>	Discomfort with situation-anxiety runs through it New providers lack knowledge-disregard CP in routine care No transition planning, adult model is not considering them

**Essence I: Expert Novices**

*The thematic expressions of: informed by child centered multidisciplinary approach; high regard for specialty pediatric providers-expert mentors; and involvement in care from an early age as part of the team, translated to the definition of the first essence of expert novice.*

Their stories conveyed a significant integration in the processes of maintaining their health and functioning to this point. The specialists provided mentorship and support, which transformed them into active and informed care seekers often engaging in very sophisticated and cutting edge therapies and surgical interventions. They experienced their voice being heard and valued when it comes to their care. Participants' narratives convey their expertise in living with the disorder of cerebral palsy; they blend this expertise with the experience of their new role in seeking care for themselves through a new system-adult healthcare. The descriptive narratives of the participants reveal the experience of feeling expert regarding their diagnosis and their care needs while feeling uncertain with the adult provider. The resulting experience of expert novice emerges from that blending. The data were reviewed in consideration of the definition of expert novice and excerpts that highlighted that essence are presented to demonstrate its validity.

Although the participants are significantly aware of their condition and the evolving health needs and priorities for aging with CP; and have a history of successful participation within the pediatric and adolescent model of care, they are now facing a new system. The adult health care model and the systems involved in that model are entirely new to the participants; they are novices in that regard.

The appreciation of a difference or strangeness in the adult health care encounters was reflected in the stories of Josh:

That's a little bit discomfoting is when you're informing the physical therapist that that's not going to work out the way that they think it is. Which is scary because I-I don't particularly want to be the expert.

Knowledge of their own bodies and diagnosis and the need to have that component addressed in even routine and minor acute encounters resounds in the stories of Fran:

With the CP stuff it's a whole different level of complicated. How frustrating it is to be, to having an acute need and to have a doctor say I don't know what the effects would be because I don't know enough about Cerebral Palsy and you ask him well where should I go and they'd be like, they don't have an answer for you.

Josh:

I want to come in; I want to say this is the issue that I'm experiencing. I want for the healthcare professional to say these are your options. This is what this one entails, this is what this one entails and this is what option number three entails.

There is an expectation that they should be consulted and considered throughout the health visit, there should be dialogue.

Josh:

I want them to present me, as the person with the issue, the opportunity to choose one given all the information. I want to choose it and then I want them to tell me how to execute it. I don't want for me to sit in an office and say-and have somebody say well, you know, I'm not entirely sure how this is going to work out, but we can shoot for it.

There is dissatisfaction expressed when the opposite occurs; being talked around, disregarded, spoken about and not spoken to. Annie relates, "Sometimes they still will talk around me. And like I said, not that they do it on purpose, but I think sometimes people just have an instinct to be sort of awkward."

There is a certain amount of tension and stress in the expert-novice role. It seems apparent in replaying parts of transcripts that participants engage in challenging or questioning

exchanges with providers (in absentia and after the fact) regarding their lack of knowledge or for their stereotypical approach to participants who are clear to note they are anything but typical.

The following excerpts highlight the tension of the expert-novice role.

Fran:

"Somebody has pain on having sex the first time. You probably hear stuff like that a few times a day but like, then you like, should have a response."

Elaine:

"You know, it's not like I wouldn't want them to get to know me and make a decision in an informed way; but it's not something I need anyone's help to decide. You know, I'm not going to let them do anything that I think would put me in danger at this point."-

Courtney:

"When you get to adult medical care it is kind of rush, rush, rush."

Annie:

"And I was like really? The hands were not a tipoff? Not even here? That was entertaining, but kind of mind blowing."

Josh:

"I don't think I appreciate very much going in there and having to explain the issue that I'm going through in the moment that I'm going through it."

Greg:

"I'm a veteran in all this, you know, hospital procedures. So I don't really cry very much anymore. But I was like crying, and I said, look, if you ever have to do this again, I don't care if it's you, I don't care if it's any other doctor, whoever it is, sedate me."

Fran:

"You don't like, it doesn't seem like that. And I'm like, and then, sort of just brushed it off and I was like..." (Shakes her head).

Harry:

You know, and maybe I'm a little bit biased because of, you know, every, every little thing that, you know, goes on with me. But I, I do get worried that I'm going to miss something.

### **Essence II: Evidence/Experience Based Expectations**

*The expressed priorities related in the themes; health goals are clear: maintain function, mobility & pain free, need for supportive care as they age, and need provider with CP knowledge informed the definition of the second essence of evidence and experienced based expectations.*

Participants' lifelong engagement in developing and maximizing their potential and their awareness of inherent risk of loss of function inform their expectations of the health care encounter and influence their health priorities. Their apparent reliance and attachment to expert providers and models of care provided an evidence and experience based foundation that future expectations reflect. The transcripts were revisited with consideration of that essence's definition and exemplars were highlighted to demonstrate that essence's validity.

Participant stories demonstrate their knowledge of the inherent risks that accompany the cerebral palsy diagnosis. They are aware that although the disorder is non-progressive, it does progressively impede their abilities and increase certain risks to health and function as they age.

Josh:

I'm not concerned at 21, you know, at 21 this isn't scary. I'm aware of the fact that um, somewhere down the line, in all likelihood, this is-is going to be a little bit scarier.

Because people don't react better to these types of issues as they age, let alone when, you know, you have issues of spasticity and extreme tightness.

Annie:

I would say at this point, it is about keeping things maintained. I hope I do not have to have too much more surgeries. So for right now, I would probably want to look into some nonsurgical maintenance...-

Elaine:

I just want to stay where I'm at, you know? I don't want to wait until I'm so horribly off that, you know, I've got to do something, and it's an emergency, and I can't find those resource lists, so I'm just trying my best to maintain where I'm at in whatever ways I can.

Fran:

My priority now it's sort of trying to find that doctor that I can fit with and, and work close with and can carry me through as I get older and there are more health issues given my family history everything that that will arise and need to be monitored.

The work that they, their parents and providers have put into themselves is not lost on the participants. They have worked hard to achieve their basic comfort and functioning and are not prepared to give that up. Annie shares this sentiment.

We are people's kids and no matter how old we get, we are still somebody's kid. Just like any other kid, a lot of time and effort has been invested in us so do not just leave us flat, you know?

In many cases these high expectations have been instilled through over a decade's experience of supportive childhood programming and care networks. Participants have been mentored in taking the absolute best care of themselves by their trusted pediatric and specialist providers.

Josh:

I'm mostly still discussing it with my orthopedic surgeon, getting his opinion on the doctors, my primary care doctor right now is one of the three doctors who has a background in Cerebral Palsy. He has, his sights set on one that he thinks is going to be a better choice so...

Elaine:

I'd come from, being part of the childhood program that I could have therapy up to three times a week indefinitely. Cause it was so important to get children healthy, but suddenly when I was an adult and actually had a major problem, I wasn't that necessary anymore.

The frequency of visits related to the diagnosis of cerebral palsy in the pediatric patient is likely responsible for the acquired fluency in the health system lingo and expected milestones in their care. The more they see, the more they know.

### **Essence III: Negotiating New Systems**

*The transformed meaning units inspiring the third essence are learning systems of the adult health care model, ready to fight for care vs. non- progression bias and too few options, and insurance is a barrier to care, depict the new systems as problematic and in need of a considered approach, which resonated to me as negotiation.*

These themes suggest awareness and insight about the changes experienced during transition. The data suggest participant engagement in the work of negotiating the new system with all of its obstacles and attributes. The data were revisited in light of the definition of negotiating new systems. The change over to the adult health model is perceived as different by all participants and with this perception comes acknowledgement that factors such as care model, insurance issues and accessibility intertwine in the definition of negotiating new systems. Data from the study were reconsidered with the definition in mind in order to assess validity and provide examples of the essence of negotiating new systems.

Adult healthcare is not the first place that participants have come to know the obstacles involved in obtaining needed services or supplies. They have witnessed their parents experience in negotiating those systems from a young age. Participants recognize adult health care as a different model with different priorities:

Courtney:

They're not—sometimes you have to really ask them questions in order to get them to explain things, but I—I think that's true for all medical professionals out there. They're just sort of in medical professional land.

Barbara:

Generally when I go to my general practitioner, it's because I'm either not feeling well or—just for a normal, you know, check-up, something like that. Um, so I haven't really run into, you know, too much regarding CP. I've seen that it doesn't really come up in our—our appointments, you know, they'll—they'll check my symptoms, whatever or that's that.

Fran:

At this sort of like, unique age, that not only do they like, don't have the sensitivity towards the fact that like, we're dealing with like, insurance for the first time but like, there's also like, life experiences that we're having for the, like, the first time. Um, that their not sensitive to, either.

Participants' knowledge and experience of the realities of health care systems and health insurance regulations have readied them for the "battle" that may lie ahead. They are steeled by their absolute knowledge of what will work for them and what going without can mean to them.

Josh:

He said, you know, I'm not sure how this works for somebody in your circumstance but

it's unusual to go to therapy for manual stretching. And I was like, no, I'm aware why like someone off the street is not going to walk in and, you know, sign in for therapy to have manual stretching, but for me, there are things that you can do when you're stretching man-me manually that I can't do on my own. So, it's not that unusual, it's more of a requirement of the rest of my life [laugh] he said, you know, I-I wouldn't know how to bill that to insurance and I was like, you know, me either.

Annie:

Dealing with insurance regulations and lack of supportive programs is frustrating but they keep on trying. I already know more about health insurance than most people my age. But I think there is a lot of it that still feels a little bit over my head sometimes. Because it is a lot of paperwork and unfortunately, especially with someone like me where there are extra medical things, sometimes there is a lot of arguing and justification with the insurance companies.

Elaine:

This isn't that hard. There's no real mystery here. It looks a little fancier from the outside, but really, it's just another system to work within.

Josh:

I don't know how that works [laugh]. I don't know how any of that works. Only thing I know is in all likelihood this is what I'm going to need and this is when I'm going to come to do it. If you want to figure out how to bill it to insurance, fight it out with them; if they have questions, they can call me.

Annie highlights insurance issues and obtaining needed services as areas she expects to be encountering and shares a need for more knowledge in order to work within the medico/insurance system:

I have been aware of how insurance works for a long time...I understood that things were dismissed as medically unnecessary fairly easily. The logic is that I do not have a progressive disorder so I cannot need it (physical therapy) that much and I am not going to get any better so what is the point? And it is hard to explain to the insurance people sometimes that even though I am not progressing, per se, I can still lose function So I would say I should read a little more and prepare for battle.

On a similar point, Elaine shared:

I think what the outside world needs to know more of is just because we're adults doesn't mean we have the access to resources that other adults do. Yes, we may want to continue programs in our home. Yes, we may want to, you know, purchase this service or think about that treatment or whatever; but it's not like we have the same financial resources, or time resources or even transportation resources.

#### **Essence IV: Interdependence**

*Needing help getting things done, from self care to insurance referrals, Parents have a role during and after transition, and relationship is a high priority in provider fit conveys their need for support and defines the fourth essence, which is Interdependence.*

Participant stories demonstrated their reliance on and appreciation of the supports they have acquired throughout their life; relationship and reliance on parents, peers and providers are identified as important factors for getting the care you need. These reflections were reviewed in the data. All participants told of experiences that involved parental involvement and mentorship in the processes of health care and for making the most of encounters with providers. Excerpts

from the transcripts that embodied the definition of interdependence were considered in order to demonstrate validity of that essence.

Greg:

So, you know, let's take the primary care, for example. My mom and I always talk about, you know, my past year health-wise, you know, some things that have come up, you know. And I always make sure to bring that up.

Diane:

I don't know how I should probably do some research on what more I should be expecting from those kind of psychological treatment, uh, yeah, and then both my parents and I would both have to agree of course.

This life-long condition fostered a close-knit family dynamic that promotes independence,

Annie:

I have always been physically dependent on my parents; we are sort of like a little package when I am at home. And my parents are not overprotective in any way, and they have always allowed me to go off on my own if I wanted to and try things. But just out of necessity, we need to be together a lot.

Greg:

The truth is, I've never really been to the doctor on my own. I mean, I always go with, with my parents or family, or family member, whoever can. And the reason for that is because, you know, I mean how, if I, we have a wheelchair accessible van, you know, so they would have to open the door, and put the lift down, and all that stuff.

Courtney:

I mean I kind of wanted my mom there. I kept sort of looking for her and be like can you

help me explain this cause I don't know I feel like she knows me better than I know myself sometime. And she knows how to explain things better. Uh, so and there—there's always things that I like forget to tell doctors and she remembers and you know I mean my mom and I are very close.

Harry:

"You know, and not for nothing. I hate to get deep but I realize, you know, now my mother isn't always going to be there for me. You know, I'm going to have to start making decisions."

Josh:

My parents stopped-stopped making the decision on whether I had surgery at a-a really, super young age. It was my decision to have surgery at eight; it was my decision to have surgery again at nine; and it was 110-percent my decision to have surgery in the eighth Providers' support and expertise invaluable to the transition experience and negotiating health insurance health care referrals etc.

Greg:

I know when the pain is back and I tell her that, but she knows, you know, "Well it's been however long since your last round. If you want, you know, my recommendation would be to go back," or, you know, "Oh, let's try something else and see if this works."

Josh:

And I knew that that was coming, and he knew that that was coming, so uh, in my last two appointments it's-it's more been a mutual conversation that we knew needed to occur. You know, I brought it up the first time; he brought it up again the second time because I'm almost out of-of visits that I'm allowed to have.

### **Essence V: Accepting Less**

*The themes of discomfort with situation-anxiety runs through it, new providers lack knowledge-disregard CP in routine care, and no transition planning, adult model is not considering them, speak to the final essence of accepting less.*

Participant stories reveal a difference between expectations and experiences; stories convey participant un-ease with the difference followed by participant's rendering of explanations, excuses and acceptance after the disappointing experience. Using the definition of accepting less, the transcripts were once again considered and excerpts that highlighted those conditions were selected in order to demonstrate validity. All participants conveyed both unspecified un-ease and overt references to anxiety related to provider experiences that did not meet their expectations. There is a likeness between the un-ease described in the definition and anxiety, defined for children in the Merriam Webster's student dictionary as "fear or nervousness about what might happen."

Barbara:

Is this how it's supposed to be? Like 'cause I was used to the one-on-one, you went, you had your 45 minutes or your hour or whatever it may be and you were the only one.

Courtney:

And my mom was actually the one who brought up the idea of medication. She was like do you think you need medication? At first I was like oh no, it's not that bad. And then you know I thought about it and then I was like yes, maybe. So and my mom started calling around.

Annie:

I have always been kind of an anxious person but I think I would be even if I did not have CP.

Josh:

That's a little bit intimidating for me. It-is still scary. It's a childish word but it's sort of the emotion [laugh]...it's very uneasy. It would be sort of like if your mom was like well, I can't be your mom anymore [laugh]. So um, you know, you've got to-you've got to find a new one."

Greg:

If you're a nervous wreck all the time, then you're gonna, you know, oh, I wish I had my parents here, I wish I had, you know.

Diane:

I guess I have some mixed feelings about how the counseling is going.

Elaine:

"I think that was probably the moment where I realized I had hopped over a fence, and there was no going back in the other direction to its many benefits.

In several of the interviews participants shared their "ah-hah" moment of realizing that the topic of transition to adulthood with CP should not be a new concept.

Fran:

I don't know much about this history of CP but I have got to assume that there are people with Cerebral Palsy who are into adulthood now and have been in adulthood for twenty plus years so like the fact that they're just realizing now that there's a need [for adult services] is fascinating to me, like, where have you been?

Elaine:

Once we're working on the adult health care system they want to give us as little information as possible, in the hopes that we are taxing up resources that so many people already need, because my theory on this all, being the cynic that I am, is that people love to say we're helping children. Helping middle-aged adults? Not so impressive.

Josh:

It's funny for me because we're not disappearing; we're just aging. The population is still existing in the same numbers that it does when there are children, so there should be the same demand for that um, as-as we age, and yet nobody is prepared to do that [laugh].

### **Synthesis of the Structure of the Experience**

Giorgi prescribes the final step of the analysis is to *synthesize and integrate the insights contained in the transformed meaning units into a consistent description of the psychological structure of the experience*. The structure of the experience encompasses the identification of the constituents that are essential for the phenomenon to be discernible in this particular way.

The structure of the lived experiences of young adults with cerebral palsy as they transition to adult health care as expressed from the data is *expert novices with evidence and experience based expectations, negotiating new systems (effective/ineffective) interdependently (parents and provider support) accepting less than was expected*.

### **Summary**

This chapter presented an in depth introduction to the study sample, setting and procedures used while applying the steps of the phenomenological reduction as prescribed by Giorgi and carried out by the researcher. Excerpts from the study participants' descriptions and the data accrued from interviews were considered to validate the definition of the essences. The

structure of the meaning of the experiences of young adults with cerebral palsy's transition from pediatric to adult healthcare was illuminated.

The young adult participants in this study were a group of very experienced and knowledgeable health care consumers. They all demonstrated exceptional poise and candor in sharing their experiences and they offered very considered discussion of their processes. These young adults are fully engaged in the transition process. Their perceptions of the transition to adult healthcare were focused and their health concerns and priorities as they age seem ever present, bubbling up throughout their dialogue. I learned so much from the process and the product of the study. I was happy to know from them directly that talking about their experiences was enjoyable and they were grateful to have the opportunity to share.

### **The Structure Reflected in Art**

Once the structure was expressed it came to life in my consciousness and as the dissertation progressed the following poem was inspired by the experience:

#### **Desert**

From the start they forged ahead together

Challenging what was,

Reshaping what would be...

The Future

Finally arrived and

It is what it is...

Separate

By: E.M. Carroll

The formatting of the poem reflected the cadence of my thoughts and the meaning suggests desert, so it is funny that the outline of the poem should take the form of a bull skull that might be found in the desert.

Formatting and font are a way to create word art. An essay is art in its own right. During this research experience I came to know a bright young woman with cerebral palsy, who cheered on my research and shared some of her literary compositions on the topic with me. The following essay is her reflection of the structure of the experience of growing up with cerebral palsy that she contributed to this dissertation with permission. The essay was centered and highlighted and exhibits a form. Is it that of a wise fox, an owl, a valentine, or totem; no matter, which, it is, the meaning depicted through art.

When you wonder what it's like to be disabled, you probably think of my parking spot. You might think of how fun it would be to ride in one of those chairs. But part of you is probably afraid of what's it like... because my body looks so different from yours. Because I force you to think about beauty in a different way, and to seriously consider what it means to live a valuable life. You might even think you'd rather be dead than be in a wheelchair. But I can promise, if you were me, you'd want to keep living, You'd know that your life was good, and worthy, and beautiful. You'd know that it was not you, but these things that were flawed.

- A society that measures your worth by how much your needs cost.
- A society that thinks you're brave for getting up in the morning.
- A society that makes you wonder if anyone will ever hire a person in a wheelchair.
- A society that makes you feel like mothers that can run after their children are more worthy than those that can love them deeply.
- A society that never provides a positive image of you in the media
- A society that doesn't want to stare at you, so it just doesn't look
- A society that thinks disabled relationships are "cute"
- A society that subtly or not so subtly breathes a sigh of relief when a baby is born and it isn't like you.
- A society that doesn't think much about how that makes you feel.
- A society that thinks your mobility is medically unnecessary.
- A society that doesn't always give you a choice about who takes care of you
- A society where you meet someone and the conversation often begins with "You didn't tell me you were..."
- A society where you have to call ahead to make sure your wheelchair can fit through the doorway
- A society where a bathroom you can use is a nice surprise
- A society where it's acceptable to equate lives like yours with suffering alone.
- A society where giving you your rights is seen as an act of benevolence
- A society that makes you feel guilty if you don't dream of walking like a "normal kid"

The list goes on, so I ask you this... am I the one that's broken? Think hard. The list goes on, so I ask you this, what kind of world do you want to live in? Before you make your choice, think hard, and think of me.

By: Kathleen. D

## Chapter VI

### REFLECTION ON THE FINDINGS

#### Introduction

This qualitative study was done in order to illuminate the meaning of the experiences of young adults with cerebral palsy as they make the transition from pediatric to adult health care. The structure of the lived experiences of young adults with cerebral palsy as they transition to adult health care expressed from the data is *expert novices with evidence and experience based expectations, negotiating new systems (effective/ineffective) interdependently (parent and provider support) and accepting less than was expected*. In order to fully understand the phenomenon it is critical to return to the literature and integrate the findings of this study with the knowledge base in the discipline of nursing.

#### Synthesis of the Data

As a final consideration the findings of the study will be reviewed in concert with recent literature on the topic of qualitative studies of the experience of transition to adult health care. A recent study of the transition indicators from the 2007 National Survey of Adolescents with Special Health Care Needs (ASCHN) aging into adulthood reported a significant deterioration in insurance coverage, usual source of care and receiving timely health care as ASHCNs aged into adulthood, and that this was associated with a decline in health status (Okumura, Hersh, Hilton & Lotstein, 2013). The continuing need for improved support of young adults during transition is validated from those findings. Studies evaluating models for transition continue to multiply across the fields of mental health (Paul, Ford, Kramer, Islam, Harley & Singh, 2013); attention deficit hyperactivity disorders and autism (Montano & Young, 2012), sickle cell anemia (Lebensburger, Bemrich-Stolz, & Howard, 2012).; epilepsy (Kahn, Baheerathan, Hussain

&Whitehouse, 2013), diabetes (Allen, Channon, Lowes, Atwell & Lane, 2011) and cerebral palsy (Oskoui, 2012). Despite agreement about the importance of effective transitional care, there is a paucity of evidence to inform best practice about both the process of and what constitutes effective transitional care (Watson 2012). There are additional studies indicating that while transition and transfer do occur, they are not done well or experienced as a good process (Paul et.al, 2013; Singh et. al., 2010).

### **Expert Novices**

The initial essence expert novice incorporated the themes of informed child centered view, high regard for specialty and pediatric providers as mentors and involvement in care from an early age. These themes were also apparent in recent qualitative publications in the field of health care transition. The most recent addition to this literature is a qualitative meta-synthesis of the transition literature that highlights the need for health care professionals to respect the young adults' need to be acknowledged and valued as competent collaborators in their own transfer in order to protect them from additional health problems during this vulnerable phase (Fegran, Hall, Uhrenfeldt, Aagaard, & Ludvigsen, 2013). Transition planning and support are imperative for the YA-CP as loss of child-centered health care often means loss of safety nets , access to services such as physical and occupational therapies that assist in maintaining optimal functional ability (Turk, 2009; Young, Rochon, McCormick, Law, Wedge &Fehlings, 2010). The lack of experience in the management of pediatric diseases among adult-trained clinicians and unfamiliarity with child/family-focused care, are discussed as barriers to effective transition in Brennan and Rolfe (2011).

The experience of living with and being knowledgeable about CP is the “expert” component of the essence as defined. The changeover to the new services is where the “novice”

status becomes apparent; this difference creates the uncertainty of the novice role. Pediatric medicine and adult medicine represent different subcultures; acknowledging these differences may improve cooperation during transition from pediatric to adult providers. (Huang Gotschalk, Pian, 2011). The individual's aptitude and willingness to participate in care may be an asset during transition as greater participation equated with higher reported quality of life in one survey (van der Slot, Nieuwenhuijsen, van den Berg-Emon, Wensink-Boonstra, & Roebroek, 2010). Several recent studies have supported the study findings concerning the essence of novice expert. The voice of participating young adults was apparent in the recent qualitative health care transition studies reviewed (Racine, Bastien, Bell, Majnemer & Shevell, 2012; Maggs, Palisano, Chiarello, Orlin, Chang & Polansky, 2011).

### **Evidence & Experienced Based Expectations**

The second essence reflects the themes that health goals are clear and include maintaining function, mobility and pain free state, need for supportive care as they age, and the importance of provider knowledge. Similar themes were apparent in the literature. Health care priorities focus on continued supportive care to maintain optimal function; considering that problems with mobility and self-care still prevail in young adults with CP (Nieuwenhuijsen, Donkervoort, Nieuwstraten, Stam and Roebroek, 2009). Youth and adults with CP may be impacted by the disorder over time and will require health care support throughout their lives to help them optimize their wellbeing (Young, et. al., 2010). Transition to adulthood is a critical phase for reaching autonomous participation in adult life. Providers should incorporate a lifespan perspective in pediatric, transition, and adult health care services for persons with a childhood-onset disability (Roebroek, et.al, 2009).

## **Negotiating New Systems**

Data from study participants expressed themes leading to the essence of negotiating new systems, the adult health care model insurance systems, ready to fight for care - against non-progression bias and too few options when they transition to adult health care. Current literature related to that thematic string was revealed in the review. Gleeson McCarthy and Lidstone (2012) reviewed current literature and programmatic offerings concerning transition to adult health care in England and offered a model that encompasses the push and pull nature of transition. The pediatric push should be met with an adult pull. This report suggested that it is the duty of adult physicians to assure continuity during transfer, but also to look critically at their service to determine how it can be changed to meet the needs of young people; they need to develop knowledge, skills and appropriate attitudes to communicate effectively and address a young person's developmental and health needs. It is interesting to note that the focus for appropriate transition has shifted to the receiving providers and their attainment of attributes that foster the young adult transition. Data shared from the study revealed participants' sense that the adult side of the equation was not ready for them, unprepared to take over their care.

There is a risk of fragmentation of services involved with the termination of the pediatric multidisciplinary models. Transition planning and support are imperative to the YA-CP as loss of child-centered health care often means loss of safety nets of programmatic supports from the multidisciplinary, child centered approach, such as physical and occupational therapies and social work that assist with obtaining and updating mobility aides for optimal functional ability (Turk, 2009; Young et. al., 2010). The role of the general practitioner (GP) or internist is highlighted; after transition to adult services is complete the GP may be the only health professional that has known the young person over an extended period, providing important

continuity of care (Reddinbough, 2011). After sharing the experiences of my study participants, it is clear that there is room for improvement in the reception process of the adult care provider. Tuchman, Slap and Britto (2008) studied experiences and expectations of young adults with chronic disease who conveyed feeling ill prepared for the changeover to the adult care model. That study suggested that the following would be helpful: early awareness of the planned transition, an orientation and introduction to the new service prior to transfer and a structured transition program to assist with transfer. Hovish and colleagues (2012), suggest that healthcare transition should be a gradual process, tailored to the young person's needs and managed in the context of the other simultaneous practical, developmental and psychosocial transitions.

In this study of the lived experiences of transition to adult healthcare in young adults with cerebral palsy, successful transitions to adult health providers did occur for some participants. The literature reflects that others still experience serious gaps in transition outcomes, meaning many find the new model does not meet their expectations, or does not fulfill their priority needs and then they may not fully integrate to the new service after transition. Those with more complex issues appear to have less positive transitions (Bloom, Kuhlthau, Van kleev & Knapp, 2012)

### **Interdependence**

The themes expressed for the essence of interdependence include: needing help getting things done from self-care to insurance/ referrals; parent/providers/ others have a role during and after transition and relationship is a priority consideration for provider fit. The transfer to independence and the need for parental support is reflected in Racine's (2012) observation of autonomy as a feature of successful transition, the coupling of decisional and physical autonomy, the influences of family and society on autonomy, the influence of healthcare professionals on autonomy and the need for preparation for autonomy. This reflects that autonomy is a process

that requires preparation and is influenced by familial and social norms and outside influences.

Parental role and parental involvement were presented in recent literature. Davies, Rennick, and Majnemer's (2011) study solicited parental experiences of the transition and discovered that parents felt a sense of abandonment from the health care team during the transition process, along with a sense of loss, fear and uncertainty, as they navigated the transition of their young adult. In that same study parents identified lack of sufficient coordination within the health care system, the vulnerability of the young adult at the time of transition, and the lack of resources in the adult health care system to meet the unique and multifaceted needs of the young adult, as the major issues they struggled with. This sentiment was also expressed in the narratives of young adults participating in this study.

The need for gradual transfer of care management from parent to child and the need for better communication between adult and pediatric services during the transition process were expressed in the study by Hess and Starub (2011). Similarities and differences in parental and young adult priorities for transition were explored (Maggs et. al, 2011); parental role and changeover to greater independence of the young adult through a gradual process were advised (Allen, Channon Lowes Atwell & Lane, 2011; van Staa, Jedeloo, van Meeteren, & Latour, 2011). Family involvement and preparation for transfer through a more formal means were tried in another study (Moons, Pinxten, Dedroog, Van Deyk, Gewillig, Hilderson, & Budts, 2009); and an educational manual for transition was piloted and showed promise for empowering the A/YA with special health needs to become more independent in managing their health care needs (Hess & Straub, 2011). The young adult with cerebral palsy comes from a family and that family should be considered in the transition process. As Annie, from the study asserted, "We are all somebody's kid."

## Accepting Less

The final essence of the structure of the meaning of the experiences of young adults with cerebral palsy transitioning to adult health care is accepting less. This essence is the culmination of the thematic expressions that discomfort with the situation -anxiety runs through it, new providers lack knowledge-disregard CP in routine care, and no transition planning-adult model not considering them. Much of the meaning units that clustered in this section were attached to narrative stories that related the individuals' disappointments with health care providers. In one of the encounters, reproductive care issues were not addressed and the underlying diagnosis of CP was refuted as a possible contributor to the individual's discomfort. In a recent study the topic of problems and challenges with sexuality in young adults with CP was raised. In order to prevent sexual difficulties and treat sexual problems, health care professionals need to proactively take the initiative to inform young people with CP about sexuality (Weigerink, Roebruck, Bender, Stam & Cohen-Kettenis, 2011). Key terms like proactive and initiative are repeating instructions directed at providers that have been captured in the literature review, indicating the expectation that providers should respond to the identified needs of transitioning youth.

Meeting the needs of patients during this transitional period, including the need for information, interventions that decrease the negative feelings associated with transition (e.g. distress, anxiety, uncertainty) (Al-Yateem, 2012) and the potential support of a structured service that focuses on supporting young adults with counseling for transition (Stoeck, Chang, Berry, 2012) were identified as potential improvements. Additional supports recommended in the literature for health care professionals involved with young adults in transition include initiating a specific transitional process or program (Stoeck, Chang & Berry, 2012) sooner (Young et. al,

2009) and providing more extensive support (Young Barden, Mills, Burke, & Boydell, 2009), using a more flexible attitude (McGrandles & McMahon 2012) throughout the transition process (Young et al, 2009).

In summary, transition to adult services for children and youth with special health care needs (CYSHCN) has emerged as an important event in the life course. There are many issues that interfere with efficient transition to adult health care. The interests and perspectives of stakeholders, age limits on pediatric service, complexity of health conditions, a lack of experienced healthcare professionals in the adult arena, and health care financing for chronic and complex conditions were highlighted in the report from Oswald, Gilles & Cannady (2012). The review of the literature provides hope that transition research is evolving in response to identified needs of the young adults with chronic illness who are experiencing the phenomenon. Challenges in transition, including: lack of access to health care; lack of professionals' knowledge; lack of information and uncertainty regarding the transition process (Young et al., 2009) resonate in the literature and throughout the study findings. Factors that have been noted to contribute to better outcomes are: collaboration between providers (pediatric and adult), young adults and their family; structuring services with the young adult's development and maturity in mind; approaching transition in a flexible way; and including support from nursing (McGrandles & McMahon 2012).

Preparation for transition to adult services should start early and focus on strengthening adolescents' independence without undermining parental involvement. Building bridges between services, gaining trust and investing in new personal relations are emphasized in the literature, and transition is characterized as responding and bonding (van Staa, et. al., 2011). A consistent and systematic approach may improve transitions and more programs are being piloted in order

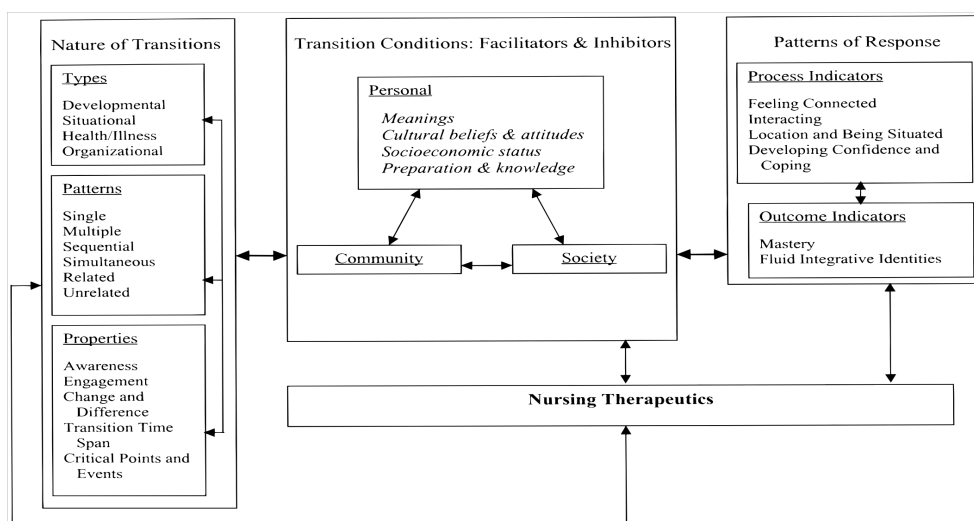
to gain some consensus of what successful transition should look like and how best to foster success. It has been suggested that while transition programs appear to improve patient satisfaction, perceived health status, and independence, they do not appear to decrease patient anxiety during this stressful period (Chaudhuury, Keaton & Wasr, 2012).

Further long-term studies are needed to inform best practices in transition care and at least one, the Longitudinal Evaluation of Transition Services (LET'S), is underway with outcomes on the horizon. (Tsybina, Kingsnorth, Maxwell, Bayley, Lindsay, McKeever, Colantonio, Hamdani, Healy & MacArthur, 2012).

### **Reflections Using a Nursing Model**

Meleis' Transition Theory (2000) provides a framework (Figure 1.) for further reflection of the essential components of the transition experiences from this study. This theory is the result of the evolution of Meleis' initial research to develop role supplementation as a nursing therapeutic that could help patients make healthy transitions. Role supplementation was defined by Meleis as any deliberate process through which role insufficiency or potential role insufficiency can be identified by the role incumbent and significant others. Role supplementation involves both role clarification and role taking. In these interactions the nurse guides individuals who, because of transitional stress or illness, are unable to fulfill their role or are unclear about their role. Clarifying the role may be used to re-establish the person in their role, or re-define the role, which involve modifying the role to a level they can better manage. It can be likened to helping individuals set realistic goals and expectations in their time of crisis. Throughout her studies using role supplementation theory, Meleis began to question the nature of transitions and the human experience of transitions.

**Figure 1.** The Midrange Transition Theory. (From Meleis, A. I., Sawyer, L. M., Im, E. O., Messias, D. K. H., & Schumacher, K. [2000]. Experiencing transitions: An emerging middle range theory. *Advances in Nursing Science*, 23[1], 12-28



The Mid- range Transition Theory illustrated above expresses the multidimensionality of transitions including the Nature of Transitions, Transition Conditions, Patterns of Response and Nursing Therapeutics within that Transition framework. This theory has been used to guide the development of research and the analysis of data in multiple qualitative studies in a variety of transitions. This framework was considered alongside the data compiled in this study and the structure of the meaning of the experience of transition that was conceived from this investigation.

### **Nature of Transition**

The types of transitions include developmental, health and illness, situational and organizational. Patterns of transition include multiplicity and complexity; that is more than one transition may be experienced at a given time and they may overlap or occur over different time intervals. The nature of transition involves both type and patterns of transition. The young adults with CP transitioning from pediatric to adult health care providers within this study are involved in a situational type of transition; the transfer from one provider's service to another.

Multiple transitions were highlighted in this study and noted in the experiences of participants who were initiating new careers, switching schools and changing living circumstances during the transition period. Additionally the patterns were both simultaneous in the case of the college students, and sequential in the case of the graduates now in and/or entering the work force. Transition properties as prescribed by Meleis were reviewed within the context of this study.

*Awareness* defined as perception, knowledge and recognition was apparent throughout all study participants; they were aware and recognized the transition as something they were going through. It was through that awareness that they were able to pick a story or engage in a memory for disclosure during the interview process.

*Engagement* refers to the degree of involvement in the transition. Participants in this study conveyed a high degree of engagement in the process of transition in their narratives. That assessment is implied from their level of active participation and involvement in dialoging at the time of the interview and the ease and energy they had in recounting experiences. It is possible that engagement was related to the interest in the dialogue experience and not solely to the topic of transition, as the young adult may have enjoyed being engaged in a discussion that focused on their experiences. The participants of this study were apparently engaged in the process of transition as evidenced through their ease in conveying the experience.

*Changes and differences* are another property of the theory, change in role, identity relationships and behaviors being appreciated both internally and externally are defining qualities of this property. Difference may be observed as feeling different, being perceived as different, or differences in expectation and reality. Change in role, greater independence was appreciated by study participants', differences in provider regard and being perceived as "child

like" and dependent where highlighted. Differences in expectations and reality were shared in every participant's narrative.

*Time span*, transition is marked by a specified span of time with an identified start from first expectation and moving through a period of instability, stress and confusion toward an eventual end. Many of the participants discussed the transition as a process, something they were moving through and in some cases something they were holding off.

*Critical points and events* are associated with increasing awareness of change or differences or more active engagement in dealing with transition. Critical points, markers in the process, were demonstrated in the narratives and actually generated the initial meaning units. A perfect illustration of a critical point is Elaine's comment, "That's when I knew I had hopped over a wall." when describing a feeling she experienced while she was working out her pain treatments through insurance.

### **Transition Conditions**

*Personal conditions* include meanings, cultural beliefs attitudes, socioeconomic status, preparation and knowledge. This study explored the meaning of the experiences of young adults with cerebral palsy; the narratives are rich with the conditions that have framed this transition experience for them. The study participants are technically vulnerable by nature of their diagnosis and their involvement in a transition. Their knowledge and experiences fortify them as they move through the transition. They are aware of their lack of preparation and support and have been frustrated by it.

*Community Conditions or Societal Conditions* that may impact transition experiences are included in the framework. For this study the major items of a change in systems of care, health insurance issues, provider knowledge and provider disregard, lack of options, lack of helpers in

the system and access issues all contribute and make up the sometimes "overwhelming" conditions of transition, as noted by Annie, Elaine, and Greg.

According to Meleis' model, assessment of individuals' readiness for transition includes evaluating the personal and communal and societal conditions of transfer. Through unstructured interviews with participants I was able to explore those facets. The essences of the study, *Evidence and Experience Based Expectations, Negotiating New Systems (effective/ineffective)*, and *Interdependence* have meanings that are congruent with the personal, community and societal conditions of the model.

### **Patterns of Response**

Indicators of health transition have been proposed by Meleis in both the process and outcome realms. *Process indicators* are indicators of healthy response that convey a movement of the clients in the direction of health or vulnerability. Feeling connected, interacting, being situated, developing confidence and coping are all indicators of a positive process. Lack of these indicators would suggest vulnerability of the client. In relation to the study, in retrospective review, glimpses of these indicators are apparent throughout the narrative expressions of the participants, which would indicate by definition that healthy progress was apparent in the study sample. Process is rarely linear. There may be movement back and forth among these indicators throughout the transition experience: regarding the challenge of care with a provider (of the type she had unlimited access to in her youth.

*Outcome indicators* are used to check if transition is healthy or not; these include mastery and fluid integrative identities. According to Meleis, the level of mastery of skills and behaviors needed to manage their new situations can determine the quality of a health transition. The promise of mastery and identity reformulation may be inferred from the narratives of the

participants in this study as illustrated through the processes they have negotiated and the examples of their successes over the transition period. The inferences made from the narrative experiences shared in this study illustrate progress toward a healthy transition in most of the study sample, according to the definitions of the theory. Even some of the instability stress and confusion are markers of process within the theory. Until there is more assured progress in supporting transition to adult health care in a systemic way, young adults transitioning to adult health care are still likely to encounter instability in systems and supports that may change their transition conditions.

Meleis' framework suggests an approach to transition that can support persons engaged with transitions. The components flow in a way that is similar to the outcome data from this study. Perhaps this model's greatest utility is the reflection that "Nursing Therapeutics" is part of the process and can be instrumental in supporting the individual experiencing a transition, enhancing transition outcomes. This is a natural progression as nursing is concerned with person's response to health issue or illness. The nursing process starts with assessment.

Meleis' "Nursing Therapeutics" include assessment of readiness for transition; preparation for transition through education; and role supplementation. The premise of role supplementation incorporates the nurse as facilitator, assesses the level of function in usual roles and assists the individual to meet role functions. The nursing processes of this theory are similar to the usual approach to a health promotion projects. First, during the assessment phase the transition nurse specialist determines baseline transition readiness, capabilities and internal and external conditions. Once that assessment is made a plan of support can be developed. Finally, using education for preparatory support and role supplementation as a secondary tool for skills acquisition the nurse can facilitate the live components of transition.

### **Reflections of the Researcher**

It is my nature to be a helper, teacher, coach, and having to keep my usual manner from spilling over into this project was, at times, exhausting. Journaling is an essential tool of qualitative research and a means of identifying personal biases and keeping them apparent but apart from the phenomenological unfolding. Journaling and reflection were used throughout the interview process, data analysis and synthesis in order to reinforce my orientation to the fundamental question of the lived experiences of the study participants.

It was my good fortune to work with experienced faculty, who have embraced this methodology and demonstrated the interpersonal practice of nursing in research without tainting their studies. From these models I understood how the qualitative nurse researcher does not remove herself so far from the participant that she is absent. It is apparent from the body of this discourse that I was attending, present, trusted, interested and accepted by participants. Their stories compelled me to reaction, but the practice of phenomenological exploration quieted me toward inaction and attention, while embracing the apparent issues, themes and contexts of the stories.

At the conclusion of each interview, after the digital recorder was turned off, was a time that, as a trusted receiver of information, I was able to converse further with participants about what the experience of talking about transition meant to them and what it meant to me. In all cases I took time to reflect the utter sense of honor I felt in sharing the glimpses of their experience. I acknowledged the letdowns and shared their disappointment in the "way that it is" and also cheered their creativity and perseverance in how they challenged or at least considered challenging "the way that it is". I coached them to troubleshoot and shared with them what I

knew from practice and had learned so far from others through my study interviews. I felt the weight of their concerns long after our time together and I needed time to debrief, often.

Journaling is a critical tool for debriefing in the qualitative research environment. Journaling or "ranting writing" (my term) was both cathartic and salve throughout this process; it enabled me to quiet myself after experiencing the stories of the participants. It freed me from the trepidation I felt after my clumsy introduction to the world of physical disability; i.e. overlooking 'movement' as a factor prior to my first interview with a wheelchair-using participant. Reflection through journaling reduced the sting of critique and provided me a place to speculate and reflect on the fundamental meaning of those lived experiences.

Reviewing the journal entries after the study enhanced my understanding of the findings and actually helped me come to truly know the action and influence of the nursing interventions proposed in Meleis' theory. My intuition/constitution to be helper, teacher coach was verified in the role supplementation essentials of role clarification, role development and role support. An example of the nursing interventions prescribed by my experience and aligned with the essences of this study is provided alongside the concepts of Meleis' Theory in Table 4 (page 89).

My impression is that more work is justified in the area of transition as a phenomenon that may be reached through nursing intervention and engagement. The nurse as educator and/or administrator can use the YA-CPs' transition insights along with a model such as Meleis' to author effective adolescent health education and promotion programs. Reflection throughout the research experience truly illuminated the meanings of the lived experiences of transition to adult health care and highlighted a role for nursing intervention

**Table 4.** *Nursing Interventions Related to the Transition Model*

<b>NURSING INTERVENTIONS PROPOSED FROM REFLECTION OF THE ESSENCES</b>		
<b>CONCEPTS OF MELEIS' THEORY</b>	<b>NURSING INTERVENTION</b>	<b>ESSENCES FROM STUDY</b>
Nature of Transitions	<b>Assessing Readiness</b> <b>Education</b> <b>Strength based plan</b>	<i>Expert Novices</i> <i>Experience/Evidence Based</i> <i>Expectations</i>
Transition Conditions	<b>Orientation</b> <b>Troubleshooting</b> <b>Problem solving</b>	<i>Negotiating New Systems</i>
	<b>Coaching</b> <b>Explaining</b> <b>Reflecting</b>	<i>Interdependence</i>
Patterns of Response	<b>Modeling</b> <b>Empowering</b> <b>Testing/Evaluation</b>	<i>Accepting less than expected</i>

### **Limitations of Study**

This study was conducted in order to illuminate the meaning of transition to adult health care for young adults with cerebral palsy. Since I as the researcher was the instrument, the responses both from the participants and myself were very individual and related to the connections that we made. Participants in this study represent a cross- section of young adults

with cerebral palsy experiencing transition from pediatric to adult health care. Although many of the participant experiences were related to CP specific issues such as, mobility and long term care needs, there were a fair number of routine considerations such as needing more assistance or guidance in negotiating systems of care and more information about how to access care when it is needed. These issues may apply generally to young adults in transition to adult health regardless of underlying diagnosis. That generality may allow for applicability of findings across different demographics in the 19-25 year old age range. Participants in this study were accessed through a center in a metropolitan area, which may result in a demographic that is better advised, or more multidisciplinary focused. Additionally, participants of this study were, for the majority, actively pursuing higher education degrees and therefore differences in motivation between this cohort and a less accomplished one may limit generalizability. This cohort's high level of expectations for functional achievement may not resonate across other study pools and the essence of "accepting less than expected," may not resonate in differently served communities.

### **Summary of Discussion**

The purpose of this qualitative inquiry was to explore the experiences of young adults with cerebral palsy transitioning from pediatric to adult health care in order to give voice to their subjective experience. Giorgi's Phenomenologic Method was applied faithfully throughout the interviews and the reduction so that an essential structure relevant to the discipline of nursing could be realized. The structure of the lived experiences of young adults with cerebral palsy as they transition to adult health care as expressed from the data is *expert novices with evidence and experience based expectations, negotiating new systems (effective/ineffective) interdependently (parents peers and pediatric provider support) and accepting less than was expected*. This

statement conveys the essences revealed through dialogue and provides a glimpse of the experience for consideration in the nursing perspective.

The qualitative format resulted in rich descriptions of actual experiences in the voice of the participants. A literature review confirmed that many of the issues brought up through this study are both universal and recurring considerations for this population. All participants identified challenges in transition, including: lack of access to health care; lack of professionals' knowledge; lack of information and uncertainty regarding the transition process (Young et al., 2009). This study illustrates the need for a considered approach to support the transition to adult care for young adults with CP. Two solutions were identified in the review of literature (Young, et al., 2010): early provision of detailed information and more extensive support throughout the clinical transition process.

At the time of this study healthcare reform was paramount on the political agenda and its implementation is progressing. The Patient Protection and Affordable Care Act promised and may provide improved access to all; however, specialized populations such as those aging into adulthood with CP with special health care needs to assure their future health and functioning cannot afford to be blended into the whole when considering reformations and redistribution of services. At the time of this writing, an article by a panel of disability policy experts analyzed the proposed elements of the act and reported that approximately 2 million persons with disabilities will be newly insured; however, they also find a probable unintended consequence that some persons with disabilities will lose their current Medicaid coverage (Gettens, Henry & Himmelstein, 2012). Those authors reflected that the newly eligible or non-categorical Medicaid participants; those who are not currently eligible for the state's Medicaid program under the December 1, 2009 eligibility rules (SSA, 2010a), will be covered in much greater proportion

than current Medicaid eligible participants, creating a disparity (Gettens, et al., 2012). The authors further assert that the disparity will change financial incentives for state Medicaid expansions, which may lead to changes in level of services, provided by states to currently eligible disabled Medicaid participants (Gettens, et al., 2012).

It has been noted throughout this study that YA-CPs have had the experience of having to defend cerebral palsy as a valid disability with serious and progressive health implications that require special and often repetitive services. These YA-CPs and their family members already encounter resistance and disparity in securing necessary care; care that they are entitled to within the current funding level, so the possibility of further disparity in coverage suggested in the analysis is worrisome. Vigilance about the potential changes and the implications these changes may have for YA-CPs like those in this study is essential as the program is rolled out. The momentum of the roll out has stalled somewhat and much of the initial health care reform initiative has been postponed until after 2014 (Gettens et al., 2012) so there may still be time for action and advocacy to eliminate the disparities and assure best possible outcomes for transitioning young adults with cerebral palsy.

### **Implications for Nursing**

Nurses are in a key position to develop and implement new models of practice, training and research (Betz, 2008). To date the focus for health care transition has been medical and the unique skill set and perspective of nursing as facilitator is missing from the process (Betz, 2012). The nurse's improved understanding of the phenomenon of transitioning to adult health care may inform nursing care practice that facilitates and optimizes the individual's response to the transition process and acquisition of skills in adult self-care abilities. Nursing has a role as advocate, mentor and guide. The elements of that skill set can be instrumental in easing the

transition process for the individual and facilitating larger systems in formulating processes for this emergent health care shift.

It has been my experience that health care organizations undergoing financial difficulties often eliminate the facilitator, mentor educator role of the nurse in practice as a non-critical service. Nurse educators and advanced practice nurses working in adult and pediatric services are in a prime position to assess the transition issues at hand and provide individualized assessment and support for adolescents and young adults with chronic health issues such as cerebral palsy and their family members and plan for, and negotiate the transition either into or out of the service. Nurse led programs should acknowledge that transitioning young adults with cerebral palsy and any other chronic condition or disabilities, who are transitioning to adult care, may still want to have the support, input, and presence of a parent, peer or family member. That is the team they have come to know and rely on during the course of their development in the health care experience.

The individuals' experiences of provider disregard, ill-prepared systems and provider lack of preparedness that were shared in the interviews depicted multiple provider types, including nurses. It is very important that nursing responds to the assessment that we have been inconsiderate of the YA-CP's circumstances and insensitive to the stressors involved in getting things done in a new and different system. A "patient first" consideration should be applied in all practice settings. Nursing curriculum review and revision must include interpersonal nursing care that promotes awareness of the personal dignity embedded in individuals' autonomy, mobility and functioning.

### **Implications for Future Research**

This study explored the meaning of the experiences of young adults with cerebral palsy transitioning to adult health care. The study uncovered insights from young adults about the processes and preparation that they experienced as well as some of their impressions of the systems. Future research should include replication of this study in a way that would be inclusive of participants with different cognitive and communicative abilities, in order to assure the full perspective of the young adult with cerebral palsy transitioning to adult health care, is voiced.

A study that concentrates on the parental perspective of the transition experience should be conducted as a follow up to this study. Information about the experience of parenting a child who is a young adult with CP transitioning from pediatric to adult health care would enrich the knowledge base and likely drive the discussion of the next steps to make things work better. Perhaps the parental experience of being in between and on the precipice of transition to "independent" adult health care will add a new and different perspective to the conversation.

Further research with the aim of developing and defining nursing therapeutics within Meleis' framework is also suggested. Definition and dissemination of nursing therapeutics that are responsive to and supportive of the transition experience are essential for nursing to become activated and tuned into the current state of transition for young adults with chronic conditions, like cerebral palsy. Practical application of this model may inform nursing practice and curriculum to develop standards of nursing care sensitive to the negative elements of transition that can cause individuals to become vulnerable and experience negative health outcomes.

### Summary

The reflective process of this final chapter included a reiteration of the structure of the meaning of the lived experiences of young adults with cerebral palsy transitioning from pediatric to adult health care. The structure of that meaning was reflected against the current literature that concentrated on qualitative study of transition to adult health care in young adults with chronic health issues. Next, the outcome data and the structure of the meaning were considered through the framework of *Meleis' Transition Theory*. A consideration of the subjective iterations of the researcher as data was also offered as relevant in the carryover to the Nursing interventional impetus of both the model (Meleis) and the practice of phenomenological nursing science. A summary of the findings, implications for nursing and considerations for future research was shared.

**APPENDICES**

**Appendix A**  
**Research Flyer**

## OPPORTUNITY TO PARTICIPATE IN A RESEARCH STUDY

I am a Doctoral Nursing Student at The Graduate Center of the City University of New York (CUNY). I am conducting a research study designed to improve the health care transition of teen-agers and young adults to adult health care. I am interested in hearing about experiences of young people as they age out of pediatric care and transfer to care with adult providers.

If you are between the ages of 18 and 25 years, you can contact the email address below or call the number below to find out if you are eligible to participate in the study.

The study involves completing an interview over the course of 90 minutes that will be tape recorded for use in the research study. **A gift card (value \$50)** will be given to all participants as compensation for their time.

If you are interested, please email Ellen Carroll at [ECarroll@gc.cuny.edu](mailto:ECarroll@gc.cuny.edu) or call at (877) 726-2534. Ellen will contact you to see if you are eligible.

Thank you!

ECarroll@gc.cuny.edu (877) 726-2534	Carroll@gc.cuny.edu (877) 726-2534	ECarroll@gc.cuny.edu (877) 726-2534	ECarroll@gc.cuny.edu (877) 726-2534	ECarroll@gc.cuny.edu (877) 726-2534	ECarroll@gc.cuny.edu (877) 726-2534	ECarroll@gc.cuny.edu (877) 726-2534	ECarroll@gc.cuny.edu (877) 726-2534	ECarroll@gc.cuny.edu (877) 726-2534	ECarroll@gc.cuny.edu (877) 726-2534
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## Appendix B

### Research Postcard

#### OPPORTUNITY TO PARTICIPATE IN A RESEARCH STUDY \$50 Reward

My name is Ellen M. Carroll and I am a doctoral student in the Doctorate of Nursing Science (DNS) Program at the Graduate Center of the City University of New York (CUNY) and the principle investigator of the project **"the lived experience of the Adolescent/Young Adult with Cerebral Palsy (AYA-CP) transitioning to adult health care."**

The study involves completing an interview over the course of 60-90 minutes that will be tape recorded for use in the research study. **A gift card (value \$50)** will be given to all participants as compensation for their time.

I am recruiting 10 to 15 participants for this study. If you are between the ages of 18 and 25 years, have cerebral palsy and are willing to be interviewed, please contact  
Ellen Carroll at **[ECarroll@gc.cuny.edu](mailto:ECarroll@gc.cuny.edu)** or call at **(877) 726-2534**. Thank you!

## Appendix C

### Letter of Collaboration Primary Site



**David P. Roye Jr., M.D.**  
Director of Pediatric Orthopaedic Surgery  
Morgan Stanley Children's Hospital of New York  
St. Giles Professor of Pediatric Orthopaedic Surgery  
Columbia University  
College of Physicians & Surgeons

3959 Broadway, CH 8N  
New York NY 10032  
Tel: 212-305-5475  
Fax: 212-305-8271  
dpr2@columbia.edu

September 12, 2011

Re: Letter of Collaboration

This correspondence serves to recognize that the Division of Pediatric Orthopaedic Surgery at New York-Presbyterian Morgan Stanley's Children's Hospital agrees to collaborate in Ms. Ellen Carroll's protocol entitled "The Lived Experiences of Imminent Transition to Adult Healthcare in Adolescents and Young Adults with Cerebral Palsy."

Ms. Carroll is a Doctorate of Nursing Science candidate at The Graduate Center of the City University of New York and this is her dissertation study. Our role will be to help identify patients for her to recruit and to provide identified patients with her recruitment flyer.

Sincerely,

A handwritten signature in black ink, appearing to read "D. Roye Jr.", written in a cursive style.

David P. Roye, Jr. MD

## Appendix D

### Letter of Collaboration Second Site

educate | innovate | advocate



Westchester Institute  
for Human Development  
Cedarwood Hall  
Valhalla, NY 10595-1681

[www.wihd.org](http://www.wihd.org)

March 16, 2012

Re: Letter of Collaboration

This correspondence serves to recognize that the Westchester Institute for Human Development's Article 28 Diagnostic & Treatment Center agrees to collaborate in Ms. Ellen Carroll's protocol entitled "The Lived Experiences of Imminent Transition to Adult Healthcare in Adolescents and Young Adults with Cerebral Palsy."

Ms. Carroll is a Doctorate of Nursing Science candidate at the Graduate Center of the City University of New York and this is her dissertation study. Our role will be to help identify patients for her to recruit and to provide identified patients with her recruitment flyer.

Sincerely,

A handwritten signature in black ink, appearing to read 'T. Mehnert', is written over a light blue horizontal line.

Thomas Mehnert  
Director, Health Services

## Appendix E

### Consent Primary Site

CUNY UI - Institutional Review Board	
Approval Date:	<u>December 14, 2012</u>
Expiration Date:	<u>December 13, 2013</u>
Coordinator Initials:	<u>SL</u>



*Hunter-Bellevue School of Nursing*

#### Participant Information and Consent Form

My name is Ellen M. Carroll and I am a doctoral student in the Doctorate of Nursing Science (DNS) Program at the Graduate Center of the City University of New York (CUNY) and the principle investigator of the project entitled “the lived experience of the Adolescent/Young Adult with Cerebral Palsy (AYA-CP) transitioning to adult health care.” I am recruiting 10 to 15 participants for this study.

I would like permission to interview you about your experience in transitioning from the pediatric service to adult health services. Your participation in this study is completely voluntary; you can refuse to participate, or if you elect to participate, you may change your mind and discontinue your participation at any time. In either case, you may do so without penalty or loss of benefits to which you are otherwise entitled.

Although you received this flyer from your orthopedic provider’s office the study is not related to that program and your participation, or refusal to participate, will not help or hurt your relationship with the organization and the practice officers and providers will not know who did or did not participate.

Your participation in this study will involve an interview during which you will be asked questions about your experience since learning that you will be transitioning from the pediatric service to adult health services. With your permission, the interview will be audio recorded and transcribed, in order to capture and maintain an accurate record of the discussion. The interview will take approximately 90 minutes to complete. Upon completion of that interview, you will be compensated \$50 for participating.

Your name will not be used at all, all transcripts and audio recordings will be numerically coded; no names will be used. To preserve confidentiality, only the principal investigator, the professional transcriber and research committee members will hear the audio recordings. All the information gathered will be kept strictly anonymous and will be stored in a locked file cabinet in my office to which only I will have access.

The risks from participating in this study are no more than what you may encounter in everyday life. Should your participation in this study cause you anxiety, a physician or mental health professional will be available to talk to you at your request.

For any questions about the research, you can contact me at (877) 726-2534 or email me at [ecarroll@gc.cuny.edu](mailto:ecarroll@gc.cuny.edu), or my advisor Professor Carol Roye EdD, RN, CPNP at 212-481-4332 or [croye@hunter.cuny.edu](mailto:croye@hunter.cuny.edu). If you have any questions about your rights as a participant in this study you can contact the Hunter College Human Research Protection Program (HRPP) Office at (212) 650-3053 or [hrpp@hunter.cuny.edu](mailto:hrpp@hunter.cuny.edu)



*Hunter-Bellevue School of Nursing*

With your permission, I may publish the results of the study once complete. Names of people or any identifying characteristics will not be used in the publications. I would be happy to share the results of this study with participants, so if you would like a copy of the results please provide me with your address and I will send you a copy.

### Consent for Participation

**My signature means that I agree to participate in this study.**

**Audio recording is part of this research. Only the principal researcher and the members of the research team will have access to written and recorded materials. Please initial one:**

( ) I consent to be audio recorded

( ) I do NOT consent to being audio recorded

**Follow up research may arise from this study; All personal information will be kept locked and under supervision of the PI:**

( ) I agree to have my contact information kept on file for contact for future study or follow up research.

**Participant's signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Name (Please Print):** \_\_\_\_\_

#### Investigator's Verification of Explanation

Ellen. M Carroll (Researcher) certifies that I have explained the purpose and nature of this research to \_\_\_\_\_ (participant's name). He/she has had the opportunity to discuss it with me in detail. I have answered all of his/her questions and he/she provided the affirmative agreement (i.e. assent) to participate in this research.

Investigator's signature: \_\_\_\_\_ Date: \_\_\_/\_\_\_/\_\_\_

Thank you for your participation in this study. I will give you a copy of this form to take with you.

CUNY UI - Institutional Review Board	
Approval Date:	<u>December 14, 2012</u>
Expiration Date:	<u>December 13, 2013</u>
Coordinator Initials:	<u>SE</u>

## Appendix F

### Consent Extension site

CUNY UI - Institutional Review Board Approval Date: <u>December 14, 2012</u> Expiration Date: <u>December 13, 2013</u> Coordinator Initials: <u>SE</u>
---



*Hunter-Bellevue School of Nursing*

#### Participant Information and Consent Form

My name is Ellen M. Carroll and I am a doctoral student in the Doctorate of Nursing Science (DNS) Program at the Graduate Center of the City University of New York (CUNY) and the principle investigator of the project entitled “the lived experience of the Adolescent/Young Adult with Cerebral Palsy (AYA-CP) transitioning to adult health care.” I am recruiting 10 to 15 participants for this study.

I would like permission to interview you about your experience in transitioning from the pediatric service to adult health services. Your participation in this study is completely voluntary; you can refuse to participate, or if you elect to participate, you may change your mind and discontinue your participation at any time. In either case, you may do so without penalty or loss of benefits to which you are otherwise entitled.

Although you received this flyer from Westchester Institute of Human Development the study is not related to that program and your participation, or refusal to participate, will not help or hurt your relationship with the organization and that agency’s officers and providers will not know who did or did not participate.

Your participation in this study will involve an interview during which you will be asked questions about your experience since learning that you will be transitioning from the pediatric service to adult health services. With your permission, the interview will be audio recorded and transcribed, in order to capture and maintain an accurate record of the discussion. The interview will take approximately 90 minutes to complete. Upon completion of that interview, you will be compensated \$50 for participating.

Your name will not be used at all, all transcripts and audio recordings will be numerically coded; no names will be used. To preserve confidentiality, only the principal investigator, the professional transcriber and research committee members will hear the audio recordings. All the information gathered will be kept strictly anonymous and will be stored in a locked file cabinet in my office to which only I will have access.

The risks from participating in this study are no more than what you may encounter in everyday life. Should your participation in this study cause you anxiety, a physician or mental health professional will be available to talk to you at your request.

For any questions about the research, you can contact me at (877) 726-2534 or email me at [ecarroll@gc.cuny.edu](mailto:ecarroll@gc.cuny.edu), or my advisor Professor Carol Roye EdD, RN, CPNP at 212-481-4332 or [croye@hunter.cuny.edu](mailto:croye@hunter.cuny.edu). If you have any questions about your rights as a participant in this study you can contact the Hunter College Human Research Protection Program (HRPP) Office at (212) 650-3053 or [hrpp@hunter.cuny.edu](mailto:hrpp@hunter.cuny.edu)



*Hunter-Bellevue School of Nursing*

With your permission, I may publish the results of the study once complete. Names of people or any identifying characteristics will not be used in the publications. I would be happy to share the results of this study with participants, so if you would like a copy of the results please provide me with your address and I will send you a copy.

### Consent for Participation

**My signature means that I agree to participate in this study.**

**Audio recording is part of this research. Only the principal researcher and the members of the research team will have access to written and recorded materials. Please initial one:**

( ) I consent to be audio recorded

( ) I do NOT consent to being audio recorded

**Follow up research may arise from this study; All personal information will be kept locked and under supervision of the PI:**

( ) I agree to have my contact information kept on file for contact for future study or follow up research.

**Participant's signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Name (Please Print):** \_\_\_\_\_

Investigator's Verification of Explanation

Ellen. M Carroll (Researcher) certifies that I have explained the purpose and nature of this research to \_\_\_\_\_ (participant's name). He/she has had the opportunity to discuss it with me in detail. I have answered all of his/her questions and he/she provided the affirmative agreement (i.e. assent) to participate in this research.

Investigator's signature: \_\_\_\_\_ Date: \_\_\_ / \_\_\_ / \_\_\_

Thank you for your participation in this study. I will give you a copy of this form to take with you.

CUNY UI - Institutional Review Board	
Approval Date:	<u>December 14, 2012</u>
Expiration Date:	<u>December 13, 2013</u>
Coordinator Initials:	<u>SL</u>

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