Abstract

**Purpose:** With advances in pediatric health care, many adolescents with complex chronic neurological conditions live well into adulthood. As such, the movement toward adult health care services is an expected and desired outcome of pediatric care. When the young adult has an intellectual impairment in addition to a complex chronic neurological condition, parental involvement is critical in the transition process, as these young adults are unable to make informed decisions independently and require significant guidance from caregivers. Thus, the transition process should address not only the direct health care needs of the young adult, but also the needs and concerns of the parents who are instrumental in guiding that process. The objective of this study was to identify salient issues confronting these parents.

**Methods:** A qualitative interpretive design was used to gain an in-depth understanding of parents' perceptions of their young adults' transition process from a pediatric to an adult health care setting. Data were analyzed using the constant comparative method, in which interview data were simultaneously collected and analyzed throughout the data collection process. Purposeful sampling was used to interview 17 parents of 11 young adults who had transitioned to an adult health care setting.

**Results:** Findings suggest that parents perceived a tremendous sense of abandonment from the health care team during the transition process. They experienced a sense of loss, fear and uncertainty, as they navigated the transition of their young adult. Parents believed that what hindered the transition process was a lack of sufficient coordination within the health care system, the vulnerability of the young adult at the time of transition, the lack of appropriate resources in the adult health care system given the unique and multifaceted needs of the young adult, and their own tenuous health status. The transition process was felt to be facilitated by the parent's resourcefulness, family support and ability to establish new relationships within the adult health care setting.

**Conclusions:** This study has provided a greater understanding of parental perceptions of transition care for young adults with a complex chronic neurological condition. Parental involvement is essential in the transition process because these young adults are unable to make independent decisions and require significant guidance and support from caregivers. Transition processes should address not only the direct health care needs of the young adult but also the needs and concerns of the parents who act as key influencers during this transition. Understanding the parental experience and perception of the transition process is crucial in designing effective support systems for patients and families transitioning to adult health care.
Introduction

The challenges of transition care for young adults with complex chronic neurological conditions who have an intellectual impairment and their parents are considerable. This population is unique in that young adults who have an intellectual impairment require significant guidance from their parents for decision making regarding their care, and their reliance on their parents is unlikely to diminish over time. In view of the fact that these young adults cannot advocate for themselves, it is essential that we understand the challenges their parents are facing, from their own perspective.

Literature review

The health care transition process

With advances in pediatric health care, many adolescents with complex chronic neurological conditions live well into adulthood. As such, the movement toward adult health services is a normal, expected and desired outcome of pediatric care. The transition process of moving from pediatric to adult-centred health care is an important and necessary process in the lives of young adults with special health care needs. The optimal goal of transition is to provide health care that is uninterrupted, coordinated, developmentally appropriate, psychosocially sound and comprehensive (Blum, 1993). It is a gradual and purposeful process rather than a static event. One common misinterpretation is that transition is synonymous with transfer. In fact, transfer to adult care is one of many events in a much larger transition process (Callahan, 2001; McDonagh, 2003). The essence of transition care is that it starts early and it involves a commitment from the family and multidisciplinary team to move forward through assessment, planning, and the generation of interventions to optimize satisfaction (Blum, 1993; Sawyer, Blair & Bowes, 1997; McDonagh, 2003).

Differences in pediatric and adult approaches to health care

The Canadian Pediatric Society (CPS), in a position statement from the Adolescent Health Committee (2007), described pediatric- and adult-oriented health care as two different cultures. Pediatric care is family focused, relies on developmentally appropriate care with significant parental involvement in decision-making, and prescribes care within a multidisciplinary team. Adult care is patient-focused and investigational, requires autonomous, independent consumer skills, and lacks consistent multidisciplinary support. Adult health care differs significantly from pediatric care in the type and level of support, decision-making, the consent process and family involvement. Given these differences it is understandable that the transition from pediatric to adult health care is a complex one.

Optimizing the transition process for young adults who have an intellectual impairment

Promoting high-quality parent-team interactions may be one means to improve the delivery of health care transition for young adults with special health care needs and their families (Reiss, 2005; Scal, 2005; Betz, 2007). Integrated comprehensive transition services within network providers are paramount. As these young adults have complex care issues, interdisciplinary and interhospital collaboration are essential to optimize the best possible transition process. However, the vast majority of studies that examine transition care for young adults with special health care needs focus on their physical disabilities (Russell, 1996; Liptak, 2001; McDonagh, 2003; Kennedy, 2007). While these studies provide insight into the process that young adults with chronic conditions and their families engage in as they prepare for transition, important differences may exist when the young adult has an intellectual impairment in addition to a physical disability. Thus, the existence of an intellectual impairment in the young adult is an important variable to consider when examining transition. Parental involvement is critical in that these young adults are unable to make informed decisions independently and require significant guidance from caregivers. Thus, the transition process involves not only the direct health care needs of the young adult, but the needs and concerns of the parents who are instrumental in guiding that process.

Few studies have acknowledged family involvement in the transition process when a young adult has an intellectual delay, and parental perceptions and experiences remain relatively unexplored. A recent position paper (Camfield, 2011) discussed several models of transition/transfer for children with chronic neurological disorders. It suggested that few primary care settings cope well with multiply-handicapped children and concluded that the adult outcomes for young adults with chronic neurological disorders are often unsatisfactory. Reiss (2005) used a descriptive exploratory design to examine the transition experience of young adults with disabilities and special health care needs, family members and health care providers. Focus groups were conducted with 49 young adults, 44 family members and 50 health care providers. The transition process was described as being more complex and generally more difficult for those with more severe functional or intellectual limitations. However, participants in this study had many disabilities and diagnoses, and the impact of an intellectual impairment on the transition process was not explored. A systematic review by Freed (2006) concluded that young adults with severely impaired cognitive function relied heavily on the support and guidance of their families. However, the nature of parental involvement and parental concerns were not elaborated upon. A subsequent review by Betz (2007) found that parents who were most involved in transition programs were more likely to have positive expectations of their young adult’s future. While parents in both reviews were considered important in facilitating the transition process, there was no discussion of what parental expectations were regarding that process.

Purpose

Young adults with complex chronic neurological conditions who have an intellectual delay require significant guidance from their parents for decision-making regarding their care, and the reliance on their parents is unlikely to diminish over
time. Parental involvement is crucial. However, there is little understanding of parental perceptions regarding the transition process from pediatric to adult health care services. The salient issues confronting these parents are essential to enhance transition care. Thus, the research questions were: (1) What are parents’ perceptions of the transition of health care from pediatric to adult services for the young adult with a complex chronic neurological condition and who has an intellectual impairment? (2) What facilitated and/or hindered these parents’ and young adults’ transition from pediatric to adult health care?

Methods

Design

A qualitative interpretive design (Thorne, 1997; Sandelowski, 2000) was used to gain an in-depth understanding of parents’ perceptions of their young adults’ transition from pediatric to adult health care services. The aim of this design was to capture the contextual and unique nature of each parent’s experience while seeking to elucidate the shared realities of similar transition experiences of parents whose young adult has a complex chronic neurological condition and an intellectual impairment.

Sample

Purposive sampling was employed and 17 parents of 11 young adults with a complex chronic neurological condition and intellectual impairment were recruited. Five interviews involved the young adult’s mother, five interviews included the mother and the father, and one interview involved the young adult’s grandmother and foster mother. They ranged from 39 to 56 years of age. Nine parents were married and two were divorced. The young adults were between 18 and 21 years of age, had intractable seizures and, as per psychological evaluation, all had a severe intellectual deficit. Five of the young adults were non-ambulatory and did not speak, four required enteral feeding, and two had tracheostomies. These five young adults were dependent on their parents for all activities of daily living while the others required supervision. Ten of the young adults resided with their parents and one lived with a foster family. All had been followed in a pediatric neurology clinic in a university-affiliated hospital for more than 10 years, and had attended at least one appointment in the adult neurology setting. Nine of the young adults had one to five siblings. The siblings ranged in age from four to 24 years.

Procedure

The study was approved by the institution’s research ethics board. Potential participants were contacted by the nurse in the epilepsy clinic of an adult hospital and asked if they were willing to be contacted by the researcher. Although the epilepsy clinic was not specifically chosen for recruitment of participants, the vast majority of young adults with complex chronic neurological disorders and intellectual impairment who require transition to adult neurological care have a seizure disorder. Once verbal consent was obtained, the researcher contacted the parent by telephone, explained the study, and arranged a time and place for an interview. Parents themselves decided who would participate in the interview. They were asked to participate in one interview, with the possibility of a follow-up phone call at a later date. All parents referred by the nurse agreed to participate. Although the researcher had previously provided care to 10 of the 11 families in the pediatric setting, her role as a researcher was clearly differentiated from that of the young adult’s current health care provider, and any clinical issues that arose during the course of the interview were referred to clinicians at the adult health care setting. The researcher met with four families at their homes, two at the pediatric hospital, four at the adult hospital and one parent at her office. At the time of the interview the study was explained again and written, informed consent was obtained from all parents.

Data collection

Data were collected from in-depth semi-structured interviews (see Appendix A, page 39) with the parents of the young adults. Semi-structured interview questions were used to ensure that various dimensions of parents’ perceptions were explored, while allowing parents to freely describe their own unique experiences (Morse & Field, 1995). Data were collected over a period of eight months. Interviews lasted approximately 60 minutes. All interviews were audio-taped and transcribed verbatim, and field notes were written at the completion of each interview. Confidentiality was maintained by keeping consent forms in a locked cabinet and by removing identifiers from the data and replacing them with a code number.

Data analysis

Data were analyzed using the constant comparison method (Burnard, 1991), in which interview data were simultaneously collected and analyzed throughout the data collection period. Line-by-line coding of the data from each interview was done and, during subsequent interviews, the codes were checked and verified with parents to verify the authors’ interpretation of the data. Categories of parental perceptions were identified, including perceived facilitators and barriers to transition.

Evaluation of rigor

Confirmation of preliminary interpretations was sought through member checking. Member checks took place through a follow-up telephone phone call to five parents who had participated in the interviews and with the parents of subsequent interviews. Triangulation was used to draw conclusions about what constitutes the truth (Loiselle & Profetto-McGrath, 2004), through the use of field notes, transcriptions, member checks and review with the authors. An audit trail of all interview transcripts, field notes, data reduction and documentation on working hypotheses were systematically collected to ensure dependency of the study (Polit & Beck, 2004).

Results

Perceptions of transition care

Parents perceived numerous challenges associated with the transition process of the young adult with a complex chronic neurological condition and an intellectual impairment from a pediatric health care setting to an adult health care setting.

Sense of abandonment by the health care system

Parents felt they had received little, if any, preparation for the eventual transition from the pediatric health care setting to the adult health care setting. There were limited discussions about the process in the year preceding the transition, and it was generally only at their young adult’s last appointment in the pediatric setting that future care was discussed. Some pediatric services provided referrals to specialists in the adult setting while others did not. When a specific referral was not provided, the parents felt abandoned, as the onus was on them to locate adult specialists. One parent said, “I was very nervous and upset at the (pedi-
Fear and uncertainty during transition

Parents were fearful of the unknown in relation to the availability of appropriate services to address the multifaceted needs of not only the young adult, but the needs of the family, as well. All parents reported that through the years they had developed a trusting relationship with the health care team in the pediatric system and learned how to navigate that system. They were confident that when their young adult required care, the team was available. They felt they had developed a partnership with the pediatric health care team, and their opinions were welcomed and valued. They also felt that not only were the needs of the young adult addressed, but the needs of the whole family were of importance. At the time of transition they were uncertain as to whether their expertise would be appreciated, especially in light of the young adult’s intellectual impairment. As one mother stated, “Sometimes I would call the (pediatric) hospital when I felt overwhelmed. Now I don’t know if anyone would care about how I feel or what I need. Would they help me?” The parents also perceived that their young adults were unique and complex, and while care had previously been adapted to meet these needs, they were not convinced that this would be a priority in the adult health care setting. For example, one father stated, “She is petrified of needles. They (pediatric hospital) figured out how to make her comfortable. Since she has changed hospital we don’t do them (blood tests) anymore. We just go by how she is doing. Will they give up on her?”

Facilitating transition from the pediatric to adult health care system

Establishing relationships within the adult health care setting

Parents felt a tremendous sense of relief following their first appointment with the adult health care professional. They felt reassured that they had begun the process of developing new relationships. One parent stated, “He (neurologist) took his time with us. It was very reassuring. He listened. Even though we are still not sure what we would do in an emergency, we felt better. We can at least say there is someone who knows us.” Five parents reported having a positive experience following a timely response after requesting assistance from a health care professional in the adult health care system, which, in turn, enhanced their confidence in the system. As one mother reported, “I am happy that when I left the nurse a message she called me back. Even though she could not give me an answer right away, she said she would call me back and she did.”

Parental resourcefulness

Seven parents spoke about their informal support network that they used to help guide them through the process of transition. They spoke with other parents of young adults with similar impairments, as well as teachers, friends, and neighbours who had experience with adult health care. Two parents spent a considerable amount of time independently preparing for the transition of their young adult. They did so as they felt their present health care team was not proactive enough and were worried about the availability of future services. One parent described her experience:

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Several months before A. turned 18, I wrote to the (pediatric hospital) requesting a copy of her chart, and requested that it be sent to (adult neurologist). About four months later, I called the secretary and said that I need an appointment. I didn’t say that she is a new patient, but asked her if she got the file and when would her appointment be. Everything went well.

All parents spoke about the amount of time and effort required to locate new services once their young adult was no longer able to receive care in the pediatric setting. They spoke of this time as being incredibly difficult, but all were persistent in attempting to locate new resources. Some parents were successful while others were still trying to find services for their young adults. One father said, “I spent a lot of time on my days off and lunch hours looking for doctors on the internet and then calling for appointments.” One mother described the efforts of trying to find a specialist through contacting a former student nurse who had previously worked with her son at his school. This person was able to assist the family with locating the specialist they needed.

While all parents felt they had been able to successfully navigate the pediatric health care system (although several parents reported that it took many years to become confident), only half of the parents reported gaining some confidence in navigating the adult health care system, and the rest found it extremely difficult. For those who had gained some confidence, they felt it was because of their perseverance. One parent explained, “I have been doing my best for her for 18 years, and I’m not going to stop now. I will keep calling until I get the answers that I need.” Another parent stated, “I have a file for her at two hospitals. It took me a while to coordinate everything, and make sure that everyone was okay with this, but this way we get the services that we need.”
Family support system
The availability of others within the family to share household responsibilities was perceived as important by all parents. They spoke of how the care for their young adult within the family had evolved over the years, and during the process of transition these shared responsibilities for care remained stable. While three parents reported that their relationships within the family had become strained during the transition period, they had coped with much stress in the past with the care of a child with multiple needs and, as a result, felt these current difficulties were temporary. For four families there were two parents who were equally involved in the management of the care involved in the transition process, and for seven families there was one parent who was primarily responsible. However, all parents spoke about the importance that their families had in supporting them during this process. As one mother simply stated, “I don’t know what I would have done without my sister. She is my rock.” Another couple stated, “There is so much to do when your child turns 18. It is such a heavy load, but we are fortunate to have each other.”

Factors perceived to hinder transition from pediatric to adult health care
Inadequate resources
Parents perceived a termination of existing well-established health care resources and expertise, without the establishment of new services. They felt there were few resources available to meet the complex needs of their young adults. Although they may have had a referral to an individual specialist, they felt an interdisciplinary team approach was required, yet this was not available to them. As the parents themselves reached out for resources they met numerous obstacles. Several parents reported a lack of basic expertise and resources to assist with the general care of their young adults. As one parent described in her quest for assistance when her young adult developed a fever:

I called our local hospital and they refused to see her. They said she was too complex and to bring her to (university hospital). But that hospital is far from our house. I called several doctors and they said they were not taking any new patients. They said that they do not have a place for B. They told me that they did not have specialized care. So I took her to the clinic. They asked me to bring her back three times before finally saying she is too complex and they do not know what to do. They said she is better off at the hospital, but the local hospital said they do not know what to do.

Another parent related a similar experience:

I took him to an adult ER, but they really did not understand. They said who is his doctor? I said that he doesn’t have one. The next time he was sick I changed his medications on my own and hoped for the best. I tried to get a doctor, but everyone said they were not taking new patients. I called back the (pediatric hospital) and they said call the CLSC (community clinic). The CLSC said he is too complicated. I knew he would eventually have an appointment in neurology, but I was on my own for everything else and no one seemed to care.

Insufficient coordination
Parents perceived very limited coordination in the transition of their young adult’s care from a pediatric to adult health care setting. They felt there was a lack of communication among health care professionals before and after the transition process had begun. Parents spoke of their frustrations at the lack of coordination and preparation of the transition in the months before their young adult turned 18. One parent angrily stated, “She is not a child where she broke her arm and one day it will get better. Her problems are for life. So it should not be any surprise that when she turned 18 she would need the same care as she did at (pediatric hospital). So why could her transfer not have been better organized?” Many parents assumed that their young adult’s health records and summaries would be available to the adult health care professional. They believed that this process would be automatically completed by the pediatric setting. However, all but one parent reported that at their young adults’ first appointment in the adult setting, no information, except for a referral sheet, was available to the adult service. In the words of one mother, “At our first appointment, the doctor did not have any information. We had a referral with two sentences on it. Two sentences does not explain 18 years of care. We told him our story, but he needed test results. We had to reschedule our appointment. We thought that the file would have already been transferred.”

Parents reported a fragmentation in care, as the young adult transitioned from one setting to the other. They perceived the gap in care, ranging from two months to two years, was directly related to insufficient planning and coordination. For those parents who experienced a gap between their young adult’s last appointment in a pediatric setting and their first appointment in an adult setting of greater than five months, there was a tremendous sense of anxiety and stress. As one parent sadly stated, “The gap was so long. It was the most stressful time of our lives.” Another tearfully stated, “We were so scared. It was the first time in our lives that we felt completely alone.”

The majority of parents reported that given the complex nature of their young adults’ needs, their care was no longer available at one location; rather, it was divided among many specialty services located in a variety of settings. They perceived this was not only detrimental to their young adults’ care, but also placed considerable burden on them to coordinate and communicate care among the specialty services. As one parent eloquently stated, “He is now being followed for his pieces and no one looks at him as a whole, as a person.” They also perceived that the likelihood that the various health care members would work as a team would be minimal, and that their young adults would suffer in terms of a lack of comprehensive care. In their experience, they believed that communication within a health care setting was often difficult and, thus, perceived this difficulty would be exaggerated by dealing with multiple settings. Although they perceived that they were strong advocates for their young adults, they felt the onus was now on them to coordinate the care and this was too much of a responsibility and caused great turmoil. One mother described her feelings about this burden:

He is now followed in four different hospitals. When he has GI problems it affects his seizures, and when he has seizures it affects his breathing. Who do I call first? GI, respiratory or neurology? When I finally reach someone, and if they make a medication change, then it might affect his other medications. Then what? I want to be his mother, and that is sometimes very hard. How can I be expected to do everything else?

Compromised parental health
The majority of parents perceived the process of transition as an extremely stressful time in their lives. These parents spoke of the fact that they themselves had less energy than when they were younger to cope with the stress. They felt that at the beginning of their young adults’ lives they required a tremendous amount of
energy to cope with the initial understanding of their child’s needs. Through the years there were many times of stress. However, they had reached a certain amount of stability, which they now felt they had lost. They spoke of how this impacted their personal emotional and physical well-being. Five parents reported that since the process of transition began, they themselves had been diagnosed with significant medical illnesses. Parents also perceived that given the competing demands intrinsically involved in being a parent to a young adult with complex needs, they were also the parent of that young adult’s siblings, as well as a wife/husband and daughter/son, and they were tired. As one mother stated, “My husband got sick, then my mother. Then I got sick. And you keep going, but your body is giving you signals and you don’t listen to it. I don’t have it in me anymore. I do it because I have no choice. But it is hard. You know, you get older and you don’t have that energy anymore.”

Vulnerability of the young adult

Parents perceived that the instability of their young adults’ health status was not truly appreciated by the pediatric services during the process of transition. Three young adults were not stable in the months prior to transition and required admission to an adult hospital during the process. One parent reflected on the belief that decisions made regarding the care of their young adult may have been different if they had been guided by the pediatric team who had known their young adult over the years: “His breathing problems started to get worse. He was taken to (community hospital). He was in the ICU. He needed a trach, so they put one in. It was very hard. There was no one who knew us, to help us decide what to do. Maybe we would have made a different decision if he had been taken to (pediatric hospital).”

Although all of the young adults whose parents participated in this study had an intellectual impairment, four of them had some limited knowledge about the transition. The parents of these young adults spoke about how they attempted to prepare them for the changes. Parents perceived their young adults would realize the difference only once they began to meet the new health care professionals, and the routines developed throughout the years were altered. For three of these young adults, the transition was hard, as they had developed trusting relationships with the health care professionals who knew them well. As one mother said, “She got used to how things worked at (pediatric hospital). So, for her, the transition was very hard. Even though she cannot see, she knows she is somewhere different.”

In summary, parents of young adults who have a complex chronic neurological condition as well as an intellectual impairment perceived a tremendous sense of abandonment from the health care team during the transition from pediatric to adult health care services. They experienced a sense of loss, fear and uncertainty, as they navigated the transition of their young adult. Parents believed that what hindered the transition process was a lack of sufficient coordination within the health care system, the vulnerability of the young adult at the time of transition, the lack of appropriate resources in the adult health care system given the unique and multifaceted needs of the young adult, and their own tenuous health status. The transition process was facilitated by the parent’s resourcefulness, family support and the ability to establish new relationships within the adult health care setting.

Discussion

The purpose of this study was to enhance our understanding of parents’ perceptions of the transition process from pediatric to adult health care services when their young adult has a complex chronic neurological condition and an intellectual impairment. Results indicate that parents perceived the transition process to be an extremely difficult period of time in their lives. They felt an immense sense of loss, fear and uncertainty related, in part, to their belief that they had been abandoned by the pediatric health care setting. Despite having well established and trusting relationships within the pediatric health care setting, these were abruptly terminated at transition with little guidance for future care. The parents believed that the pediatric health care professionals had become a part of their family through the years. They felt let down by this extended family in one of their greatest times of need, and were extremely saddened and hurt by this lack of support.

Parents’ perceptions may have been associated with a pediatric system that promoted the transfer of care to an adult health care setting, rather than the transition of this care. Parents reported little, if any, discussion about future care services, and information about their young adults’ impending needs were discussed at their last visit in the pediatric setting. Much has been written in the literature (Blum, 1993; McDonagh, 2003; Callahan, 2011) about transition being a gradual and purposeful process rather than a static event. This study has revealed that when the transition process is minimized, the impact on parents is enormous.

Parents perceived several factors as hindering or facilitating the transition process. Health care resources available to parents and their young adult were felt to be inadequate in the adult system. Parents felt the ability of the adult health care setting to meet the needs of a young adult with complex care needs was limited by its subspecialty health care structure. While they felt relieved that individual adult health care specialists were excellent, the availability of an interdisciplinary team within the health care setting was found to be lacking. For some young adults, their care was now dispersed across various health care settings, limiting the potential for communication among the health care team members. This resulted in a tremendous sense of burden on the parent to be the coordinator of their young adult’s care. In the quest to find health care resources, some of these young adults were deemed too complex, and in other situations the services were simply not available. The multisystem complexity of these young adults and the lack of available health care resources were associated with parents’ perceptions of feeling overwhelmed and fearful for the well-being of their young adult.

Parents also perceived insufficient coordination from the pediatric health care team in preparation for the transition process. The literature supports the importance of preparing the young adult for the process of transition, (Greenen, 2003; Scal, 2005; O’Brien, 2006; Wong, 2010; Jurasek, 2010). However, there is limited understanding of the parental requirements during this process, as they are the ones who require preparation. Parents felt that they had received little guidance and that the onus was on them to learn to navigate the adult health care system without support. Some parents were very resourceful in their ability to locate and establish new resources, while others continued to struggle in this endeavour. When the pediatric health care service did provide a referral to a specific adult health care service, the appropriate accompanying documentation was lacking. Parents perceived this lack of coordination placed their young adults’ well-being at risk. In addition, the gap between the termination
of care in the pediatric setting and the introduction of care in the adult setting left the young adult vulnerable to not receiving appropriate care when necessary. Parents reported that it was during this period of time that they felt most distressed and alone. They felt they had to make health care decisions for their young adult without the guidance of a health care team.

The importance of appreciating the young adults’ overall health stability during the transition process is well documented in the literature (Betz, 2007; Freed, 2006; Wong, 2010). However, there is limited discussion about the potential for compromised parental health as an important variable in the timing of transition. Given the aging nature of this parental population, it is not surprising that parents reported serious personal medical and emotional issues. Parents spoke of their responsibilities in providing care for not only the young adult, but also themselves and other family members. This placed competing demands on parents who, at times, felt extremely overwhelmed. To cope with these challenges, family relationships were instrumental in providing support. For most parents, it was the emotional support they received from family members that was most highly valued.

**Implications for practice**
The findings from this study suggest that current practice requires review in order to move forward in promoting and enhancing transition care. Nurses with expert knowledge about complex neurological conditions and family relationships have a unique and pivotal role in facilitating and guiding the process of health care transition for the parents and young adults.

Parents reported that they had received little, if any, preparation for the eventual transition from the pediatric health care setting to the adult health care setting. They felt the preparation for the process should begin two years prior to the transition to an adult health care setting. Parents spoke of the loss of trusting relationships within the pediatric health care setting and greatly missed these bonds. Thus, discussions should occur outside of formal clinic visits and include the opportunity for the parents to reflect on the end of care in the pediatric setting. Parents also spoke of the lack of concrete information available. Therefore, written information guides for parents would be beneficial to provide direction for the transition process. Although some parents were resourceful in seeking out information through their informal social networks, the information they obtained was largely inconsistent. Parent group meetings involving interdisciplinary professionals from the pediatric and adult health care services would be beneficial to provide parents with a comprehensive exploration of services in the adult health care setting, as well as an overview of tasks, including legal and governmental matters that require their attention prior to the young adult becoming 18 years of age.

As parents spoke of the tremendous sense of abandonment by the pediatric health care system, and the gap between appointments in the pediatric health care setting and the adult health care setting, it is crucial that the pediatric setting continue to provide care for the young adult until adult health care resources have been fully established. Furthermore, these pediatric health care professionals should remain available to the parents for assistance in guiding them with finding adequate resources and services within the adult health care setting. As well, referrals for subspecialty services should be arranged by the pediatric setting, including ensuring the arrangement of the first appointment in the adult settings and the establishment of a link with appropriate nursing resources. A summary of the young adults’ pediatric care should be completed prior to the transition and all pertinent information forwarded to the adult health care service to improve the continuity of care between settings. Finally, the timing of the transition should take into consideration the well-being of the young adults and the parents themselves, as the vulnerability of this population is considerable.

As parents were required to assume the role as coordinator of the young adults’ care, it suggests that a nurse coordinator is essential in the subspecialty setting of the adult health care milieu. The role of the coordinator would be to provide direct expert knowledge and support to the parents and young adults, and also to ensure ongoing collaboration and communication among all health care professionals involved in the care of the young adults.

Parents felt there were few resources available to meet the needs of the young adults, and that an interdisciplinary approach was required, yet not available to them. Thus, a dedicated group of adult health care professionals from various subspecialties, interested in the care of young adults with complex neurological disorders, should be clearly identified and available to provide ongoing care to these young adults. To improve the comprehensive care and reduce the fragmentation of care all attempts should be made to provide services within one institution and, when this is not feasible, to establish “expert” resources within the community. Where “expert” resources are lacking in the community, assisting with the establishment of these resources would be crucial.

**Limitations and implications for research**
The findings from this study are limited by recruitment from a single site. There was limited variability in the socio-economic status and cultural diversity of the parents, which may have biased the results. As well, the nature of the university setting of subspecialty adult health care institutions available for this population may limit the generalizability of the results, as compared to health care services available within one institution. The severity of the neurological disorder and the need for multiple specialty services varied among the young adults and this may have influenced parents’ perceptions on the availability of resources.

This study examined parental perceptions of transition for their young adults who were between 18 and 21 years of age. Further studies are necessary to explore whether parents’ perceptions change with time and experience in the adult health care setting. To provide a more comprehensive view of the impact of the transition process on the entire family, further research is needed on the perceptions and insight of siblings. Finally, the implications for clinical practice suggested in this study will need to be implemented and evaluated for effectiveness in facilitating the transition from pediatric to adult health care services.

**Conclusion**
This study has provided a greater understanding of parental perceptions of transition care for young adults with a com-
plex chronic neurological disorder who have an intellectual impairment. The emotional toll on the parent is tremendous and requires thoughtful consideration when planning the transition process for these young adults. Although all parents acknowledged the hardships and adversity they faced during the process were immense, they all felt that with better guidance and improved resources, the experience for future families could be positive and satisfying.

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