



# University of HUDDERSFIELD

## University of Huddersfield Repository

Kola, Susanna, Turner, J. and Dhingra, Katie

Challenging lives: An Exploratory Qualitative Study of Quality of Life in Young Adults Living with a Chronic Neurological Condition

### Original Citation

Kola, Susanna, Turner, J. and Dhingra, Katie (2015) Challenging lives: An Exploratory Qualitative Study of Quality of Life in Young Adults Living with a Chronic Neurological Condition. *International Journal of Developmental Disabilities*, 61 (3). pp. 156-165. ISSN 2047-3869

This version is available at <http://eprints.hud.ac.uk/id/eprint/19307/>

The University Repository is a digital collection of the research output of the University, available on Open Access. Copyright and Moral Rights for the items on this site are retained by the individual author and/or other copyright owners. Users may access full items free of charge; copies of full text items generally can be reproduced, displayed or performed and given to third parties in any format or medium for personal research or study, educational or not-for-profit purposes without prior permission or charge, provided:

- The authors, title and full bibliographic details is credited in any copy;
- A hyperlink and/or URL is included for the original metadata page; and
- The content is not changed in any way.

For more information, including our policy and submission procedure, please contact the Repository Team at: [E.mailbox@hud.ac.uk](mailto:E.mailbox@hud.ac.uk).

<http://eprints.hud.ac.uk/>

Challenging lives: an exploratory qualitative study of quality of life in young adults living  
with a chronic neurological condition

Susanna Kola<sup>1,2</sup>, Joanne Turner<sup>1,2</sup> and Katie Dhingra<sup>1,3</sup>

<sup>1</sup> University of Huddersfield, UK, <sup>2</sup>Department of Behavioural and Social Sciences,  
Queensgate, UK, <sup>3</sup>Business School, Queensgate, UK

**Corresponding author:**

Susanna Kola, Department of Behavioural and Social Sciences, Queensgate, Huddersfield

HD1 3DH, United Kingdom

Email: [s.kola@hud.ac.uk](mailto:s.kola@hud.ac.uk)

## **Abstract**

**Objective:** The transition from adolescence to young adulthood is traditionally a time of self-discovery, career establishment, and the development of relationships. However, for young adults with a chronic illness this time in life can be very challenging, and the management of the transition is crucial for these young adults to reach their potential. The purpose of this study was to explore the lived experiences, perceptions, and challenges of young adults with a chronic neurological condition undergoing the transition from adolescence to adulthood. The Quality of Life model was used to inform the interview schedule and explored two specific areas: identity and condition.

**Methods:** Six participants with chronic neurological conditions (age 18-25 years) took part in the study. Audio-recorded semi-structured interviews were transcribed verbatim and analysed using Interpretive Phenomenological Analysis.

**Results:** The findings revealed a number of interlinking superordinate themes across the participants: 'condition', 'support', 'strive for independence', and 'transition'.

**Conclusions:** The findings of this exploratory study provide a visible indication of the specific needs of the participant group, including informational and social support needs, and removal of barriers for successful participation. They also highlight holistic service requirements and the interlinking relationships of the direction of support which could be provided to meet these needs.

**Key words:** Health Care, Users' Experiences; Illness and Disease, Chronic; Interpretative Phenomenological Analysis (IPA); Lived Experience; Neurology; Young Adults

The period of adolescence is one of transition, including physiological, psychological, and environmental transitions (Bryon and Madge, 2001). Medical advances in early detection, diagnosis and management have resulted in increased survival rates for children with neurological diseases (Tuffrey and Pearse, 2003). For example, over 70% of children with cerebral palsy will survive to adulthood (Stevenson et al., 1997), significantly more than 50 years ago (Strauss et al., 2008). Some, neurological conditions, such as cerebral palsy, are problematic and static in childhood but progress in adulthood (e.g., mobility deteriorates). Others, such as epilepsy, might remit in childhood, yet have persistent effects on adult social functioning, leading to unemployment, social isolation, or depression (Camfield and Camfield, 2011). Similarly, dyslexia can significantly influence educational attainment, job status, and social mobility, in addition to perceptions of intellectual ability and academic competence in adulthood (Boetsch et al., 1996).

For adolescents with a chronic illness the transition to adulthood can be complex and difficult to negotiate. Many of the adolescent tasks, including successfully negotiating puberty, gaining autonomy, personal identity, sexuality, and making educational and vocational choices might all be affected by impaired physical or mental abilities, including pain, medical setbacks, involuntary dependence, and perceived prognosis of condition (Blum et al., 1993). Furthermore, for adolescents with neurological conditions these can negatively influence their self-esteem and sense of identity (Smith, 1998), and also other areas of life including schoolwork, sports, employment, and driving (Baker et al., 2005), potentially reducing quality of life (McEwan et al., 2004).

Quality of life (QoL) can be conceptualised as subjective general feelings of well-being, positive social involvement, and opportunities to achieve personal potential (Schalock et al., 2002). QoL issues are highly individual and perceptions of health outcomes cannot be determined by biomedical variables alone, thus highlighting the importance of considering

multi-dimensional factors (Ronen et al., 2011). As such, QoL provide a novel and useful framework for studying neurodisability-related issues, able to contribute to identification, development, and evaluation of supports, services, and policies for individuals with neurodisabilities (Schalock et al., 2002). McEwan et al. (2004) propose a model of QoL in adolescents with epilepsy in which good QoL is associated with adjustment to having epilepsy, which is predicted by successful identity formation and illness-related factors. Identity formation in turn is predicted by factors such as peer acceptance, development of autonomy, school-related issues, and acceptance of condition. Illness-related factors are predicted by medication issues, knowledge of condition, and perceptions and experiences of seizures. We were interested in how these issues of identity formation and those related to the condition influenced the experiences of living with a chronic neurological disorder.

At present little is known about adolescents and young adults with chronic neurological diseases, as much research to date has focused on other chronic illnesses (e.g., congenital heart disease). As the needs of adolescents and young adults with neurological diseases are likely to differ from those with other chronic illnesses this represents a significant gap in the literature. For example, adolescents with neurological conditions have been found to have more behaviour problems, less autonomous functioning, and poorer academic achievement than adolescents without neurological conditions (Howe et al., 1993).

Furthermore, while interest in transition research has grown worldwide, it can be difficult and might be inappropriate to rely on data from international studies when considering these findings in relation to transition guideline and policy development. UK educational and health systems differ from other countries (e.g., in terms of infrastructure and legislation), particularly for neurological services. Relative to some other countries there are fewer neurologists per head of population in the UK (e.g., one neurologist per 150 000 population in the UK compared with one per 20 000 in the Netherlands; [Bateman, 2011]). More

importantly, the organisation of UK neurology services, focused on large regional neuroscience centres providing periodic outpatient and ward consultation to one or more local district general hospitals, means that the local availability of outpatient care remains variable (Bateman, 2011). In terms of education, the majority of young people with a statement of special educational need (SEN; including needs such as specific learning difficulty, moderate learning difficulty, behavioural, emotional and social difficulty, physical disability) currently attend mainstream education (Maslow et al., 2011).

As the period of adolescence can be very challenging, especially for adolescents with a chronic illness, the management of transition is crucial to facilitate these young people reaching their full potential. In short, the increase in survival rates of childhood chronic neurological disorders highlights the importance of understanding these adolescents and their experiences and perceptions. It is essential to consider the unique experiences of adolescents and young adults as they are the ones that undergo the transition and are required to adapt to a new environment of care, education and/or employment. These subjective experiences of the transition process are likely to greatly influence outcomes such as adherence to treatment and successful participation in society (Lugasi et al., 2011).

Thus, the aim of this pilot study was to explore the lived experiences of adolescents and young adults living with a chronic neurological disorder, to explore the challenges they face in their day-to-day lives. In particular, the research was aimed at: a) Describing the experience of living with a chronic neurological disorder, b) Exploring the challenges of living with a chronic neurological disorder, and c) Exploring the challenges and aspects of care and support in the transitional period from adolescence to young adulthood. The findings from have the potential to identify the needs of this population which can inform the transitional process, by extending our understanding of aspects that facilitate a good transfer. A recent UK report (Royal College of Physicians, 2011) highlighted shortcomings in the organisation of

neurological health services and inability to meet patients' needs, so this study is topical and timely.

## **Method**

### **Design**

This was a qualitative study involving open-ended semi-structured interviews. The interview schedule, consisting of open-ended questions, was informed by the Quality of Life model (QOL; ;McEwan et al., 2004), with specific focus on issues of identity and condition. Identity explored issues of autonomy, acceptance, peers, education, and employment opportunities. Condition explored perspectives regarding the participant's medical condition, including questions around medical, legislation, knowledge, and awareness issues.

All interviews were transcribed verbatim and subjected to interpretative phenomenological analysis (IPA; Smith, 1996). IPA is particularly relevant to this study as the aim was to explore the lived experiences of the participant in order to examine how individuals with chronic illness deal with challenges and issues within their day-to-day lives.

### **Participants**

Participants were purposefully sampled from a post-16 educational centre in the Northwest of England. Inclusion criteria included (a) presence and diagnosis of a chronic neurological condition with minimum duration of 12 months, (b) age between 18-25 years, and (c) fluent in spoken English. Six participants were recruited in total. All participants had decisional capacity and cognitive ability to provide informed consent and participate in interviews. Participants ranged in age from 19 to 25 years, with a mean age of 20 years. The sample consisted of two females and four males. Both female Participants were living independently, or with a partner; while the four male participants were all living within their parental home. One participant had a diagnosis of epilepsy, a further participant had epilepsy

and cerebral palsy; three participants had dyslexia and one participant had quadriplegic cerebral palsy. Educationally, two participants had been through the mainstream education system. A further three participants were educated within a specialist educational setting and one participant had experience within mainstream and specialist education setting. At the time of this study, four participants were students of further education within a specialist educational setting; one participant was undertaking part time employment; and one participant was at home with two small children.

The relatively small sample size reflects the general principles of conducting IPA research, where the emphasis is on engaging with the richness of data from the participants' accounts and in detailed examination of convergences and divergences within the sample. It has been noted that there is no objective finite sample size for an IPA study, thus such research is characterised by small, homogenous samples (Smith and Osborn 2008).

## **Procedure**

Ethical approval was gained from the relevant institutions, and young people who expressed an interest were given more information about the study and the opportunity to have any questions answered before agreeing to participate. All young people who expressed an interest met the inclusion criteria, and agreed to participate. Consent to be interviewed and for the interviews to be recorded was obtained prior to interview, and the interviews lasted between 30-60 minutes, with an average duration of 40 minutes.

## **Data analysis**

Data were analysed using IPA (Smith, 1996). The analysis involves two stages of interpretation: the meaning of their experiences attributed by the participant, and the researchers interpretation of the participants' accounts of their meaning-making (Smith and Osborn, 2008). Thus, the findings reflect both the participants' accounts of their experiences



and perceptions, and the researchers' interpretation of the participants' cognition, affect, and behaviour reflected in what they communicate and how it is expressed.

Smith and Osborn's (2008) recommendations for IPA were followed to analyse the data. First, each transcript was read independently by the first author who conducted all interviews, and coded in a free textual analysis. Emerging themes were analysed for connections and the interpretations made underpinned the development of higher-order themes that were given relevant titles. A table of codes and themes was created based on the analysis for each participant. The second author independently read and coded each transcript and built on the list of themes. The emerging themes were then grouped together to form superordinate themes which were corroborated between the authors. Where there was disagreement between the authors, we went back to the original transcript and discussed the coding to reach agreement. The table of themes was used to code similar meanings in the same categories, and was expanded to incorporate new ideas as they emerged. Once this process had been completed for all transcripts, each transcript was re-read by both authors to ensure that all themes were coded consistently. The themes were then written into a narrative form to provide an accurate illustration of each theme using quotations taken directly from the transcripts.

### **Findings**

Four main themes emerged from the analysis: 'condition', 'support', 'strive for independence', and 'transition'. Notwithstanding the varied individual expression of these themes, comparable parallels in participants' accounts allowed some important insights into the experiences and challenges associated with living with a chronic neurological condition. Although distinct, the themes are interrelated and inevitably overlap, reflecting the biopsychosocial nature of living with a chronic illness. Further elucidation of the themes, with verbatim illustrative data excerpts, is presented below.

## **Condition**

The first theme reflected the day-to-day challenges faced by participants around aspects relating to their condition, including how they understand their condition, how they developed this understanding, and how they experience living with the condition. Three subthemes are reported here: Understanding the condition, medication, and adjust and adapt.

**Understanding the condition.** Most participants were well informed about their condition. However, some described not understanding their condition, which contributed to feelings of fear, anxiety, and dependence, as well as an unwillingness to disclose their condition to others.

Participants who expressed feelings of fear and anxiety, or not having accepted the condition described many perceived restrictions and limitations to academic, employment, leisure, and social life, including social isolation:

I'm not confident with anything to be honest. It's because of my epilepsy.

Because I'm always too scared to try like new things, because I'm scared that if I try something it's going to trigger something. You know like shaking or trigger a fit.

However, participants with an optimistic outlook, perceived both challenges and opportunities rather than simply viewing the condition as a continued burden, and described ways in which they strive to overcome challenges.

**Medication.** For participants requiring medication to control their conditions, differences regarding their knowledge and understanding of their conditions, as well as their relationship with their health care providers, were found to influence how they plan and manage this aspect of living with a chronic condition. A lack of understanding and a poor

relationship with health care providers were linked to failure to manage adherence to medication:

I'm on the highest dose on one of the tablets I'm on, but like I'll take some in the morning and then like if I start feeling funny during the day then I'll take more. I mean the doctors don't know, I'll just take them and if I do then I feel alright.

However, participants' perceptions of their care as collaborative and their health care providers as knowledgeable, flexible and trustworthy influenced adherence to medication and other therapeutic treatment regimes.

**Adjust and adapt.** Participants were found to differ in how they approached day-to-day challenges, and the extent to which they had adjusted and adapted in order to live independently and to their full potential. Some talked about availing of opportunities that presented themselves to build experience and confidence: "I am doing some work helping out as a youth worker at a couple of the youth clubs too".

Many participants described the wish and the certainty that despite their conditions they can contribute to society and be as good and as useful as any individual without a chronic illness. In addition, many had incorporated strategies for coping with everyday living, including stocking the freezer with cooked food, or socialising at home rather than going out to pubs and clubs.

## Support

The second theme reflects participants' perceptions of available support, three sub-themes are reported here: structural support, functional support, and perceptions of lack of support.

**Structural support.** The importance of support networks was a consistent finding within all participants' accounts. Much support was obtained within the core family unit, and perceptions of available social support from family, friends and wider support network were highly valued by the participants. Many expressed feelings of empowerment associated with good family support, which contribute to increased autonomy:

My dad, it was actually him that made me come to this school, because he felt that with me being in a mainstream school I wouldn't progress as far as I could do in life. . . That's why I ended up coming here, to get better self-esteem and build my confidence in my abilities. My dad has given me a great push in the right direction.

Findings relating to support networks within school and educational settings were mixed across the participant group. Many reported mutual trust, and being respected and treated as individuals, capable of making adult decisions, which contributed to feelings of self-esteem, confidence and being a valued member of society: "At the end of the day they are not just my teacher, they are my friends as well and you can actually trust in them and they won't blurt it out to everyone".

Where participants reported good relationships with health care professionals, these were considered a valuable source of support, and increased participants' satisfaction with the health care environment: "My old GP was really good, he had an interest in epilepsy and was

really good. Whenever I needed more information about something to do with my epilepsy he would explain things clearly for me”.

**Functional support.** Participants reported receiving various forms of support from family and friends, as well as from medical practitioners, school, and employers:

The company have put things in place to make sure I am safe when I am at work if I have a seizure and that. The team I am working with know what to do if I have a seizure while I am at work.

The participants’ accounts outlined how perceived and received support had assisted in greater participation in academic, employment, leisure, and social activities, which was related to increased autonomy, independence, and opportunities to become fully functioning adults.

**Perceived lack of support.** Many participants reported feeling let down by the health care providers that they had encountered, and disappointment with the lack of care and support received:

They have done nothing for me. They just give me these tablets and changed them a couple of times, said they might work they might not but they haven’t done nothing since. I mean, I have been to the doctors, they know I have had fits and they are getting worse since I have had the kids. But they are doing nothing.

Access and waiting time to see health care professionals were significant challenges for participants, and further demonstrate perceptions of lack of support:

It was the same with the first miscarriage, I actually rang the consultant because I needed to speak to them about being pregnant and my epilepsy but I couldn't get an appointment for three months. It was too late by the time I actually got to see the consultant I had already had the first miscarriage.

Perceptions and experiences of lack of support appeared to negatively influence treatment adherence, leading to feelings of dissatisfaction, anger, alienation, confusion, and anxiety. Some participants reported that they have received little information from their health care providers, and that they have actively sought information themselves. In some cases, this had led to feelings of increased autonomy and empowerment, with the participant perceiving more control and assertiveness when discussing their condition with their health care provider. For others, it has had the opposite effect, including increased dependence and fear.

### **Strive for independence**

The third theme concerned participants strive for independence, and wishes for autonomy and the ability to live as independently as possible. Three sub-themes were identified: Seeking independence, barriers to independence, and facilitators of independence.

**Seeking independence.** A consistent theme throughout participants' narrative was the desire to become independent: "I know that in the next few years I want to be able to move and live independently – live my own life". It was clear from their accounts that they wished to have opportunities to participate autonomously and fully in academic, employment, leisure, and social life. Participants expressed frustrations when this was denied them,

including feeling like they were letting themselves down by not being able to do something independently.

**Barriers to independence.** Some participants reported perceived barriers to independence, including over-protective parents, lack of financial support and funding, the educational systems not aligning with their needs, and practical barriers, as well as perceived prejudice: “When they place jobs and colleges, they don’t place it so it’s easy for people with disabilities to get into it”. These barriers to independence appeared to contribute to feelings of frustration and perceptions of having to work much harder than individuals without chronic neurological disease to achieve the same level of independence and autonomy.

Many participants spoke of attitudinal barriers: not being seen or heard as individuals, where they had experience of being patronised, ignored, avoided, or assumed to be stupid by the general public as well as by health care professionals: “I do find that sometimes some of the doctors will even now talk over me directly to my mum”. These experiences appeared to contribute to feelings of frustration and exclusion, and were linked to stereotyping and prejudice, which many participants described encountering.

**Facilitators of independence.** Participants explored the various factors they perceived as facilitating independence and autonomy, including financial independence, supportive family and friends, educational and employment structures, independent travel, and adapted housing:

The house has been adapted with a digital box which allows me to answer the phone, switch the lights on or off, answer the intercom at the door and even let people in after I have confirmed their identities. I think this is a good step forward in supporting the move to helping me live independently.

The facilitators of independence were valued and participants expressed appreciation of opportunities to become independent, autonomous, and gain skills to deal with everyday life.

## **Transition**

The final theme concerned participants' experiences and perceptions of the transition from adolescence to adulthood, including transitions from paediatric medical services to adult services, and from school to college education. Four subthemes were found: making the transition, support, perceived barriers, and suggestions for service improvements.

**Making the transition.** Prior to making the transition, participants expressed the wish for greater autonomy over their health care and acquiring a sense of control: "I'm hoping that I will be given more options and choice in my care within the adult service – but I still think that the doctors will talk over me to my mum rather than me".

Successful transitions were those where the participant was now independently making their own medical appointments and managing their own health care responsibilities. Despite valuing being in charge of their own health care, some participants reported that they choose to bring a parent with them to medical appointments for further support:

When I was a teenager my mum would always come with me, whenever I go to the consultant mum will usually still try to be available to come with me.

Sometimes it's better for her to be there, she will often ask other questions which I don't think of asking, and between us we are able to cover everything I wanted to find out.



Transitions with less success were reported by participants who were more fearful and dependent, with a lack of preparation for increased autonomy before the transfer. This appeared to contribute to feelings of abandonment and lack of support.

**Support.** Participants were found to value the support offered by their families and their wider support networks: “I was lucky that I have such a good relationship with my parents the transition was a lot smoother for me but for people who don’t have parents who are as involved then they must really struggle”. However, the experiences of support differed between participants, which could be reflective of whether they were from a mainstream or special educational background. Participants from a special education background appeared to have been given more help and support in their transitions relative to those from a mainstream educational background: “I use the Connexions lady upstairs – she helps us complete forms and things for college”.

**Perceived barriers.** Some participants reported barriers to successful transition, including concerns and lack of knowledge about funding. In addition, individuals from a special educational background appeared to have restricted access to college education because of lack of coherence between mainstream and special educational systems, contributing to feelings of frustration:

Me dad’s like a bit wound up about this, he spent the last couple of years trying to find out what qualification I would get to see if it would be good enough for me to get into college...

**Suggestions for service improvements.** Within this subtheme, participants reported very similar suggestions for improving the transition experience:

I think that similarly with the community specialist there should be one for adults and one for children, but there should be more support from age 16 through the handover to the adult consultants. It's like you just become an adult overnight.

Thus, participants' accounts related to access to specialist community nurses, regular contact with a health care and/or educational professional known to the adolescent or young adult, and different care depending on age to facilitate the transition process. It would, therefore, appear that access to information and support were particularly valued by participants.

### **Discussion**

To date, few studies have directly examined the lives of young adults with chronic neurological disease. Consequently, this study provides an important step in bridging this gap. This was an exploratory study, and qualitative methodology was specifically employed to explore the diverse lived experiences and perceptions of individuals and to gain further understanding of the day-to-day challenges that they face.

The findings of this study highlight a number of crucial areas of concern for young people with chronic illnesses within the core areas of their lives; management of condition, social support, strive for independence, and transition. The findings of this study are consistent with issues highlighted in prior research for young people with chronic illness, such as independence, higher parental dependency, and social isolation (Beecham et al., 2008, Reiss and Gibson, 2002).

The importance of being informed and understanding the condition is highlighted, as this influences bio-psychosocial trajectories and quality of life. For example, participants with a better understanding of their condition were able to acknowledge the limitations to activity associated with their condition but were also able to develop strategies to maximise

activity and participation in education, employment, and social life. These participants were more optimistic, more autonomous, with self-advocacy abilities for their own medical care. In contrast, participants with less understanding of their condition were anxious, pessimistic, and dependent, and reported poor adherence to prescribed treatments. These findings support those of other studies which have found that informed patients tend to have better outcomes, and patients who are more knowledgeable about their symptoms are able to better interact with their health care provider which leads to enhanced shared-decision making (Ford et al., 2003).

From our participants' accounts, it is clear they receive a vast amount of support within their family unit, and also from their immediate social network. It would appear that social support constitutes an important protective factor in these young people's lives. These findings are consistent with prior research which has found that young people with chronic illness have higher social dependence, competence and social adjustment needs than their healthy peers (Jalava et al., 1997, Kyngas et al., 2000). However, a balance is required as over-protective parents might lead to over-dependency and reduced autonomy during young adulthood (Seiffe-Krenke, 2006).

In addition, perceptions of lack of support and care negatively influenced participants, and contributed to feelings of dissatisfaction and abandonment. This might in turn be associated with poor adherence to prescribed treatments (Pai and Ostendorf, 2011). There is widespread under-recognition of the needs of young adults with chronic illness by health care professionals. Other studies have similarly found that young people feel challenged within the medical environment and are dissatisfied with the level of care that they receive (Farrant and Watson, 2004, Kyngas et al., 2000, Reiss and Gibson, 2002).

The accounts of the participants of living with chronic neurological disease highlights the importance of individualised care, access to information and support, and preparation for

increased autonomy before transfer to adult health care services. Overall, the findings of this exploratory study suggest that young adults with chronic neurological conditions have holistic service requirements. It is evident that they require additional support and guidance to aid them through the transitional period. Within the context of most medical encounters, the focus is on the alleviation of patient symptoms. Consequently, many of the broader social issues and circumstances faced by individuals with chronic neurological conditions remain unspoken. Although active examination of an individual's psychosocial adaptation, their understanding of their condition, and experiences of service delivery may be beyond the scope of a health care professionals' responsibility, some awareness of the lived experiences of individuals living with varying chronic neurological conditions is needed in order for them to provide, or direct individuals to, support services, and ensure treatment adherence.

Furthermore, the findings of the present study suggest that the interlinking of medical, community, and support networks, particularly familial support, is required, to provide care and support that allows for full and active participation in society. One recent review highlighted that only two out of five families receive transitional support (Park et al., 2011). Undoubtedly, an integrative approach for these young people is a key element in aiding the successful transition from childhood to adulthood (Kraus de Camargo, 2011). There is an apparent need for the provision of an adolescent service to bridge this transitional period, providing coordinated care for all adolescents. It is essential that relevant support is provided encompassing medical, developmental and social aspects. Additional specialist community support might be required for those who need a more integrated approach throughout the transition period, such as young people with chronic illnesses. The heterogeneity in lived experiences also indicates the importance of professionals seeing people with a chronic neurological condition as individuals in relation to their condition, support needs, desire for autonomy, and transitions. From a UK perspective, it is will be interesting to see how far the

Children and Families Bill 2013 goes to address some of these issues. The focus of the Bill is to provide consistent support to children and young people with special educational needs, including improving cooperation between all supporting services. The similarities and differences between participants' narratives suggest that it is possible for researchers to construct models of chronic neurological conditions to assess outcomes (transitions, support needs, transition experiences, and so on), between, and within, neurological conditions, in order to better help those with chronic neurological conditions participate in their chosen life domains, adapt better to life-long challenges, and function to the best of their abilities. .

The findings from this study should be interpreted with the following limitations in mind. First, the qualitative nature of the study and the relative small sample size prevent generalizability to other individuals or populations. However, the ideographic nature of the study highlights the individuals 'lived experience' of day-to-day life with a chronic neurological disease rather than providing statistical generalizable results. Second, although no participant opted-out of answering any questions, the possibility of response bias due to participants not honestly answering or not fully answering questions is acknowledged. Finally, as the second author is the parent of a child with a chronic neurological disease, the possibility of researcher bias due to the closeness to the subject material, prior personal understanding, and life experience is acknowledged. However, the insight, empathy and perspective of the researcher facilitated the establishment of rapport in the interviews and aided the analysis process. In addition, the authors independently read, coded, and developed themes for each manuscript, before corroborating the findings, thus ensuring greater rigour in the analysis process.

Future research is required to ascertain whether the findings from this exploratory study generalise to other young adults living with chronic neurological conditions. The use of quantitative methods to assess levels of satisfaction with services and its influence on

engagement with services appears to be particularly pertinent for future research. Such research could have the potential to further inform and drive the implementation of the proposed changes contained within the Children and Families Bill 2013. There could also be scope to undertake a longitudinal study, to explore the impact of the proposed changes of the approach and service provision for these young people with special educational needs. It would also be interesting to consider if the suggested changes addresses the unmet needs of these young people as highlighted within this study and prior research.

In summary, the findings from the present study suggest that a considered integrative approach is required to assist adolescents and young adults in making successful transitions from adolescence to adulthood. There is overlap between physical, mental and social development, and for adolescents and young adults with chronic neurological disease failure to acknowledge this overlap might have serious consequences for quality of life, ability to live fully and independently, and ability to reach full potential in education, employment and social life. Future research is required to assess the generalizability of the study findings, assess levels of satisfaction with services, and determine the influence of service satisfaction on service engagement.

**Conflict of interest:** The authors declare that they have no conflict of interest.

## References

- BAKER, G. A., SPECTOR, S., MCGRATH, Y. & SOTERIOU, H. 2005. Impact of epilepsy in adolescence: A UK controlled study. *Epilepsy & Behavior*, 6, 556-562.
- BATEMAN, D. 2011. The future of neurology services in the UK. *Practical Neurology*, 11, 134-135.
- BEECHAM, J., SNELL, T., PERKINS, M. & KNAPP, M. 2008. After transition: Health and social care needs of young adults with long-term neurological conditions. *PSSRU Research Summary*, 48, 1-2.
- BLUM, R. W. M., GARELL, D., HODGMAN, C. H., JORISSEN, T. W., OKINOW, N. A., ORR, D. P. & SLAP, G. B. 1993. Transition from child-centred to adult health-care systems for adolescents with chronic conditions. *Journal of Adolescent Health*, 14, 570-576.
- BOETSCH, E. A., GREEN, P. A. & PENNINGTON, B. F. 1996. Psychosocial correlates of dyslexia across the life span. *Development and Psychopathology*, 8, 539-562.
- BRYON, M. & MADGE, S. 2001. Transition from paediatric to adult care: psychological principles. *Journal of the Royal Society of Medicine* 94, 5-7.
- CAMFIELD, P. & CAMFIELD, C. 2011. Transition to adult care for children with chronic neurological disorders. *Annals of Neurology*, 437-444.
- FARRANT, B. & WATSON, P. 2004. Health care delivery: Perspectives of young adults with chronic illness and their parents. *Journal of Paediatric Child Health*, 40, 175-179.
- FORD, S., SCHOFIELD, T. & HOPE, T. 2003. What are the ingredients for a successful evidence-based patient choice consultation?: A qualitative study. *Social Science & Medicine*, 56, 589-602.
- HOWE, G. W., FEINSTEIN, C., REISS, D., MOLOCK, S. & BERGER, K. 1993. Adolescent adjustment to chronic physical disorders - I. Comparing neurological and non-neurological conditions. *Journal of Child Psychology and Psychiatry*, 34, 1153-1171.
- JALAVA, M., SILLANPAA, M., CAMFIELD, C. & CAMFIELD, P. 1997. Social adjustment and competence 35 years after onset of childhood epilepsy: A prospective controlled study. *Epilepsia*, 38, 708-715.
- KRAUS DE CAMARGO, O. 2011. Systems of care: transition from the bio-psycho-social perspective of the International Classification of Functioning, Disability and Health. *Child: Care, Health and Development*, 37, 792-799.
- KYNGAS, H. A., KROLL, T. & DUFFY, M. E. 2000. Compliance in adolescents with chronic diseases: A review. *Journal of Adolescent Health*, 26, 379-388.
- LUGASI, T., ACHILLE, M. & STEVENSON, M. 2011. Patients' perspective on factors that facilitate transition from child-centred to adult-centred health care: A theory integrated metasummary of quantitative and qualitative studies. *Journal of Adolescent Health*, 48, 429-440.
- MASLOW, G. R., HAYDON, A., MCREE, A.-L., FORD, C. A. & HALPERN, C. T. 2011. Growing up with a chronic illness: Social success, educational/vocational distress. *Journal of Adolescent Health*, 49, 206-212.
- MCEWAN, M. J., ESPIE, C. A., METCALFE, J., BRODIE, M. J. & WILSON, M. T. 2004. Quality of life and psychosocial development in adolescents with epilepsy: A qualitative investigation using focus group methods. *Seizure*, 13, 15-31.

- PAI, A. L. H. & OSTENDORF, H. M. 2011. Treatment adherence in adolescents and young adults affected by chronic illness during the health care transition from pediatric to adult health care: A literature review. *Children's Health Care*, 40, 16-33.
- PARK, M. J., ADAMS, S. H. & IRWIN, C. E. 2011. Health care services and the transition to young adulthood: Challenges and opportunities. *Academic Pediatrics*, 11, 115-122.
- REISS, J. & GIBSON, R. 2002. Health care transition: Destinations unknown. *Pediatrics*, 110, 1307-1314.
- RONEN, G. M., FAYED, N. & ROSENBAUM, P. L. 2011. Outcomes in pediatric neurology: a review of conceptual issues and recommendations The 2010 Ronnie Mac Keith Lecture. *Developmental Medicine & Child Neurology*, 53, 305-312.
- ROYAL COLLEGE OF PHYSICIANS 2011. Local adult neurology services for the next decade. Report of a working party  
London.
- SCHALOCK, R. L., BROWN, I., BROWN, R., CUMMINS, R. A., FELCE, D., MATIKKA, L., KEITH, K. D. & PARMENTER, T. 2002. Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: Report of an international panel of experts. *Journal Information*, 40.
- SEIFFE-KRENKE, I. 2006. Leaving home or still in the nest? Parent-child relationships and psychological health as predictors of different leaving home patterns. *Developmental Psychology*, 42, 864-876.
- SMITH, J. A. 1996. Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology and Health*, 11, 261-271.
- SMITH, J. A. & OSBORN, M. 2008. Interpretative phenomenological analysis. In: SMITH, J. A. (ed.) *Qualitative psychology: A practical guide to research methods*. 2nd ed. London: Sage.
- SMITH, P. E. M. 1998. The teenager with epilepsy. *BMJ*, 317, 960-961.
- STEVENSON, C. J., PHARAOAH, P. O. D. & STEVENSON, R. 1997. Cerebral palsy - the transition from youth to adulthood. *Developmental Medicine & Child Neurology*, 39.
- STRAUSS, D., BROOKS, J., ROSENBLOOM, L. & SHAVELLE, R. 2008. Life expectancy in cerebral palsy: an update *Developmental Medicine & Child Neurology*, 50, 487-493.
- TUFFREY, C. & PEARSE, A. 2003. Transition from paediatric to adult medical services for young people with chronic neurological problems *Journal of Neurology, Neurosurgery & Psychiatry*, 74.