

## Young people and healthcare. Part 2: Experience of long term health conditions

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## **Abstract**

The aim of this study is to provide a qualitative perspective of young peoples' experiences of long term illness. Three young people were interviewed and participated in making film diaries about their experiences of living with a long term illness. The interview transcripts were then analysed using thematic analysis. Four main themes were identified to represent common shared experiences across participants. These related to coping, the impact of illness on various aspects of life, experiences of healthcare, and transitions from pediatric to adult services. While significant efforts are being made to increase knowledge and understanding of the experiences of long term illness within the child and adolescent population there is still much to be learned, as is evident from this direct account of young peoples' experiences. We identify implications for clinical practice and suggestions for future research in light of listening to the young peoples' stories.

**Keywords:** young people; long term health conditions; experience; qualitative.

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## **Introduction**

Some 10-15% of children under the age of 16 years of age are affected by chronic, long term health conditions (Weiland, Pless & Roughman, 2007). Chronic diseases are characterised by their long duration and the fact that they cannot be cured. In other respects they vary greatly. The prevailing medical point of view suggests that all diseases are different and have different and specific implications for treatment. However, the alternative perspective stresses that many similarities hold across different conditions and that families with a child with a chronic disease are confronted by a series of stressful situations. These include major life stresses such as adjustment to diagnosis, hospitalization and depletion of financial resources and daily hassles such as having to make special arrangements for transport and attending multiple appointments with a number of health professionals (Eiser, 2003).

Assumptions are made that adjustment difficulties or coping resources are purely a function of the disease and independent of developmental processes. It has only recently begun to be acknowledged that a young person's appraisal of their situation, their resources to cope with the disease and its consequences, and their capacity to utilize external resources changes throughout childhood (Kazak, 2002). Thus it is important to take into account the impact of chronic illness on a young person and their family across the age range (Quittner, 1992). In addition, diseases themselves follow a developmental course. On diagnosis, families must deal with their shock and disbelief about what has happened, assimilate vast amounts of illness information and learn how to care for their child (Eiser, 2003). These challenges change during the course of treatment. Families must learn how to integrate treatment demands with everyday work and social activity, keep hopeful and define limits to the child's behaviour which take into account the child's need to attain independence while balancing constraints imposed by the disease (Eiser, 2003).

Research has shown that young people with chronic health conditions tend to experience higher levels of depression and anxiety compared to their healthy counterparts (Eiser, 2003). In addition, young people may suffer from higher levels of stress as they try to manage a disease that can often be difficult to control while at the same time trying to fit in among their peers. Due to these factors, their quality of life may be lower than their healthy peers. A crucial factor related to how young

people cope with the disease is their family. As well as there being an impact on a young person's mood, aspirations, family and peer group, a chronic disease brings with it long term interaction with the world of healthcare and into contact with a network of health professionals (Bradford, 1997). There is a need to investigate such experiences through the eyes of young people in order to inform service delivery and development.

There is now increasing recognition of the importance of qualitative enquiry, and the contribution it can make to the field of psychology and to clinical research within health settings (Smith, 1996; Turpin et al, 1997). For example, Van Houdenhove (2002) identifies the value of listening to the story of the patient, suggesting that such a biographical account can often provide crucial etiological and therapeutic clues. The aim of qualitative research is to understand and represent personal experience, by attempting to capture the meanings that particular phenomena may have for the individual. There are clear indications that understanding of the impact on young people of long term illness is relatively poor, and the RCPCH guidelines (2004) recommend amongst their research priorities for both quantitative and qualitative studies. A review by the British Psychological Society (2003) criticises the tradition for children to be seen as passive rather than active health care consumers, and also emphasises the potential for accessing children and adolescents' own views in research as a rich and valuable resource.

Within childhood chronic illness literature more generally, qualitative methodologies appear to have been employed with success, and studies, though somewhat scarce, have included descriptions of young peoples' experiences of alienation, of missing out on social and educational development (Sartain, Clarke & Heyman, 2000); and of life as being both physically and emotionally more difficult (Woodgate, 1998).

It is therefore the aim of this study to adopt a similar line of enquiry, using semi-structured interviewing and the analysis of video diaries using the qualitative method of thematic analysis, to explore young peoples' experiences of long term illness. In accessing and listening to young peoples' unique perspectives within the long term illness population, it is hoped that the researcher might gain a fuller and more meaningful understanding of their experiences of these conditions and draw similarities. Furthermore, it is hoped that this study will identify themes that have implications for clinical practice.

## Method

### *Participants:*

Participants in this study were three young people between the ages of 12 and 18 who were experiencing a variety of long term illnesses including muscular dystrophy, diabetes and cystic fibrosis. Participants had already made a film documentary, in association with the 'Stepping into Shoes' Project (<http://www.realideas.org/real/work/stepping-into-shoes>) as funded by Cornwall & the Isles of Scilly Primary Care Trust and Real Ideas Organisation) prior to the research taking place. The film documentary aimed to explore the impact of a long term health condition on a young person, as well as the subsequent interactions with the health care system and the impact of this on their lives and families.

### *Data Collection and Analysis:*

Data were collected through individual semi-structured interviews developed in accordance with Smith & Osborn (2003). All participants were interviewed on camera as part of their video diary. The interview schedule was constructed in collaboration with the Stepping into Shoes project team, clinicians working within the pediatric health field, and with reference to existing literature. There was general agreement on these points of reference which were felt to be of particular pertinence to young people with long term illness. In particular, the impact of long term illness on everyday living (including educational, social and family based aspects), coping with long term illness, and the experience of health care.

All interviews were recorded and transcribed in full. Each transcript was subjected to thematic analysis by the interviewer, following the guidelines in Smith and Osborn (2003). This involved several readings of the transcript, noting initial thoughts and then tentatively identifying initial themes, or summary phrases, from these notes. Emergent themes were listed and then progressively organised into clusters as possible connections between them were identified. Throughout this process the researcher revisited the transcript a number of times to check that connections identified within the data made sense and did not detract from the essence of the primary source material.

Remaining clusters were named, representing superordinate themes, which were then organised in a table with accompanying supportive themes.

## Results

In spite of anticipated differences between participants, there were also a number of consistent responses in the young peoples' experiences of long term illness. These have been represented within four themes. Within each theme, there was a diversity of thoughts, feelings and behaviours. Each theme will be described in turn, and substantiated with the use of excerpts of text from the transcripts.

### Theme 1: Impact on life

This first theme aids in understanding the far reaching consequences of long term illness on a young person's life. The areas identified as being affected include school, social life, mood, family and hobbies. Long term illness can affect school either by missing out on school due to treatment or missing out on particular aspects of school due to perceived disability.

*'{...}Miss a lot due to hospital appointments and going into respite... (this then makes me worried).'*

*'{...}I get...left out of PE...so have to go on computers...there's no reason why I should be left out.'*

However, some methods for overcoming these difficulties were identified by participants such as the school training a worker to provide treatment in-house, such an intervention reduces the impact of the condition on the young person's schooling :

*'{...}Genuinely doesn't interfere unless have to do into hospital for two weeks for IV antibiotics...I have physio at school..Teaching Assistants have learnt how to do it.'*

The impact of long term illness on the young peoples' social life and friends appeared to be profound, with participants perceiving that their peers were frightened of their illness (due to lack of education) and that this led to them often being left out of peer activities and being unable to engage with activities 'normal' for the age group:

*'{...}' Friends at school find my disability awkward...easier to talk to friends at Activ8'*

*'{...}Harder to have a sleepover due to feed..I'll go to the odd one where I won't have it as a treat'*

*'{...} Affects going out with friends as you have to keep on the straight and narrow..'*

Furthermore, hospital appointments were found to interfere significantly with participants social activities:

*'{...}Appointments affect social situations'*

*'{...} Sometimes I can't go because of my hospital appointment'*

Meeting with other young people with long term illness and engaging in activities together was perceived to significantly reduce the negative impact of illness on the social life:

*'{...}Friends at [regional children's hospice offering respite care] keep me upbeat'*

*'{...} I am more friends with people at [local activity group for young people with physical disability] than at school'*

*'{...}Friends at school find my disability awkward...easier to talk to friends at [local activity group]'*

*'{...}At MD holiday I meet my best friends'*

The impact of the young person's illness on the family was quite extensive, with parents taking a key caring, organisational and advocacy role in the young person's life:

*'{...} My family are supportive if I'm having a bad day...we'll do something nice'*

*'{...} My family sometimes have to take time off work to take me to appointments'*

*'{...}My parents do a lot of caring'*

*'{...} Mum comes to appointments as I'm not confident at the moment'*

Participants identified that living with a long term illness has a profound impact on mood, however



this could be generally overcome by seeking appropriate support and keeping a positive attitude:

*'{...}I get...grumpy about getting up early for treatment'*

*'{...}The illness affects me with nervousness and worry''*

*'{...}Usually it doesn't affect my mood, but on a bad day I can't do anything'*

*'{...}It feels like a rollercoaster..really good times and really difficult times, focussing on fun things and being positive helps''*

*'{...}Generally you can fight it or live with it. You can't fight it so it's better to live with it!''*

*'{...}Try and think on the positive side'*

### Theme 2: Coping

All young people identified people, activities and support systems that enabled them to cope more effectively with the impact of long term illness. The key points were that involvement with activities with other young people with disabilities was important and it was felt that there was an inherent understanding of their condition without feeling restricted by this. This involvement was felt to facilitate positive peer relationships as well as making the disability feel positive, for example, by playing power chair football. Receiving care and treatment in the community was felt to be an aid to coping as it was felt that treatment impinged less on the young person's life, furthermore a positive relationship with health professionals was felt to be beneficial.

*'{...}Activities with others is very important...it helps me to forget and just be me.'*

*'{...}Concentrating on fun helps to forget bad hospital appointments'*

*'{...}Getting involved in groups so that you don't feel alone is helpful'*

*'{...}My friends at [regional children's hospice]*

*'{...}A positive attitude and getting on with it helps'*

*'{...}Mike (Physiotherapist) knows me well and my family life...they're really good...and must cost a lot!'*

Furthermore, the young people were able to identify factors that impeded their coping which is also crucial to our understanding in order to enable effective coping in young people in the future. Lack of NHS resources was felt to impede coping as was the feeling of being different to peers both in a school and social context. A particularly pertinent issue was that the support networks that facilitate activity and friendship amongst young people were only funded on a time limited basis, thus when this runs out coping is impeded.

*'{...} Hydrotherapy and physio....sometimes they don't have the equipment that I need locally'*

*'{...} I get left out of PE and have to go on computers, why should I?'*

*'{...}I don't get invited to friends birthday parties'*

*'{...}I need to take half an hour off school per day for physio'*

*'{...}The support networks/local activity group etc are only funded for two years..... when this runs out there will be a big hole in my support'*

### Theme 3: Experience of Healthcare

All the young people reported having significant interactions with the healthcare system, seeing a network of health professionals, including consultants, nurses and physiotherapists. The young people have both appointments at hospital; including local and specialist, community based appointments and a daily home-based treatment regimen. Participants were able to identify factors that improved their experience of healthcare as well as those that impeded the experience.

Factors that were helpful in creating a positive experience for the young person were when the

hospital staff addressed them as the patient and not just their parents. The outcome of such an interaction would be that the young person felt more in control and informed. Having a positive

relationship with health professionals was important, as was consistency in seeing the same people and their positive attitude towards treatment and outcome. Flexibility in the delivery of care was deemed important, for instance being treated in the community and reduced travel was seen as a

positive as it reduced the time needed for each appointment.

*'{...}The hospital help out...try and look at different ways, make it more exciting....like changing my everyday routine'*

*'{...}They talk to me about it rather than parents....I understand more if they tell it to me'*

*'{...}The travelling I have to do is {...} not too far so doesn't take up too much more time'*

*'{...}A positive attitude from them (health professionals) helps me'*

*'{...}It helps if I'm involved in care...if I can choose parts of my care'*

*'{...}One physio who I see all the time is nice'*

*'{...}I feel involved in my programme of care, there's a lot of contact over the week with me at home via phone, it's not like they forget about you,(they're)always there to help, you can get in contact if you need to'*

*'{...}Everything is out in the open and relaxed and great'*

*'{...}My nurse has the personal touch, you can ring and talk about anything... (she's) on my level'.*

Factors identified as making the young peoples' experience of healthcare difficult were when there was inappropriate or lack of suitable equipment for the patient's needs and treatment or when there was poor communication with and between health professionals. When large amounts of time were required for appointments and travel this was deemed particularly unhelpful as it adversely impacted on school and other activities. There was also anxiety related to attending hospital appointments.

*'{...}Hydrotherapy and physio...sometimes they don't have the equipment that I need locally'*

*'{...}I see hundreds of doctors, OT's etc'*

*'{...}Respite in Barnstaple is a long way to travel'*

*'{...}Hospital care is a bit of a nuisance...missing time off school....some of the doctors are depressing because the only see the negative'*

*'{...}Appointments can be a whole day...I hate it'*

*'{...}Doctors are less like this (nurses) and feel like they are one step up on the hierarchy'*

*'{...}The doctor is a travel... I wanted to stay with old paediatric consultant as I know him'*

*'{...}Appointments make me nervous and worried'*

#### *Theme 4: Transition from Children's to Adult Services*

There was some anxiety around the transition from children's services to adult, in terms of the implications of different staff, different care and the fact that support from young people's groups stops. On the other hand, there was a sense of looking forward to this transition as participant's anticipated feeling more independent and in control of their own illness. They particularly looked forward to Doctors directly consulting with and addressing them as the patient.

*'{...}I'm now (at 15) starting to move into adult services to see what it's like...it's scary, like moving into the unknown'*

*'{...the local activity group} stops and makes way for the new lot after 2 years...Stops social interaction and support'*

*'{...}Don't like it when Doctor talks to parents instead of her which happens in children's services...expect that this will be different in adult'*

*'{...}As I get older then I go up to adult, they talk to me, I'm looking forward to'*

*'{...}Change to new doctor might be odd..and scary...but I think they will be fine and I'll get used to it...another learning experience of getting older'*

*'{...}Parents might find it hard cos they're used to it being told to them and not me but I'm looking forward to it'*

*'{...}I'm ready to take on more responsibility for medicines and stuff'*

*'{...}If they talk to me will be easier for me to understand'*

## Discussion

Analysis of the responses of participants with long term health conditions in this qualitative study identified four main themes: the impact of illness on various aspects of life; coping; experiences of healthcare; and transitions from pediatric to adult services. The thematic analysis identified that each of these themes could be expressed positively and negatively, reflecting their lived experience of growing up with a long term health condition.

Regarding *the impact of illness on aspects of their lives*, participants identified a positive range of ways that they were still able to take part in hobbies and sports. In some cases specialist provision such as a local activity group was available; in other circumstances their long term condition was not a barrier to participation in mainstream activities alongside peers. The negative impact of long term illness included absence from school, a sense that friends were frightened about their condition, and the negative impact on their own mood.

For *coping*, participants identified that other young people with long term health conditions understand their experiences, and were positive about opportunities to meet together. They also expressed how helpful it is when doctors and healthcare professionals attempt to understand their needs, and communicate directly with them rather than via their parents. Their negative experience of coping with a long term health condition included a basic lack of NHS support systems available to them in their local area, and the distancing they experienced from peers who were not able to understand their lived experience.

Their *experience of the healthcare system* was also expressed in positive and negative terms. All participants were positive about staff who understood and related to them well; yet all had also experienced the negative effects of poor communication. They perceived that the need to attend multiple hospital appointments had a negative impact in other areas of their lives, especially school.

Finally, participants reflected on their process of *transition from pediatric to adult services*. Although they anticipated some disruption to their established relationships with staff and the loss of youth-oriented support networks, there was also a positive sense of feeling more in control of and responsible for their own condition.

This study has identified some important implications for the care of young people with long term health conditions in a rural context. Firstly, services could be organised to deliver healthcare in community rather than hospital environments wherever possible, including at school. Community nursing services that visit young people at home significantly reduce disruption to everyday life; organisational barriers to providing services in this way should be challenged. Greater flexibility in the delivery of care in a rural setting through evening or weekend clinics and the use of telemedicine could reduce absence from school, as could improved liaison between educational and health services. The long term decline in the school health service in the UK appears to be an important negative factor for young people with long term health conditions.

Secondly, these results suggest that access to social and leisure activities (both ‘mainstream’ and specialist services) are highly valued by the young people, who are concerned about their ability to relate to peers not experiencing complex conditions. Provision and access to such services across a large a rural area presents a challenge, although the results here suggest that specialist groups and environments are highly valued.

Finally, the participants acknowledged that growing up with a long term condition had forced them to confront complex and emotive issues that separate them out from their peers. Further investment in peer group support and psychological services may help to support their positive coping; equally, relatively low cost initiatives in training all NHS practitioners in how to relate to adolescents in transition to adult services could make a huge difference to their experience of growing up with a long term health condition.

*In conclusion*, there are simple things that the NHS and staff can do to enhance care for young people with long term health conditions by improving communication; building strong relationships; ensuring communication between professionals; increasing patient choice for appointment times to reduce disruption to schooling; and offering more flexible community-based treatment services. Talking to young people directly in age appropriate language, helping them to be involved and voice opinion could help to improve their access to services. Creating a transition service and fostering links with existing services which allow young people to talk, find support with each other and get involved in leisure activities are recommended.

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