

Young People Living with Liver Disease: A qualitative study of experiences of transitions

Background

Living with Liver Disease often involves maintaining a strict regime of medication and diet as well as regular assessment by specialist health professionals. In childhood, parents have full responsibility for issues around adherence although, as studies of other conditions have shown, children are still active agents in managing their health conditions (Williams et al. 2009). However, in adolescence responsibility for their condition will shift more towards the young person as they grow in independence. At the same time young people will make the move from child to adult services: a transition which has the potential for adverse health outcomes if not managed properly (Crowley et al. 2011).

Traditionally the impact of health conditions on children and young people were sought from adults around them such as parents. It has been increasingly recognised that if health outcomes are to be improved, young people's own understandings of chronic conditions must be taken seriously. The importance of taking young people's views seriously is incorporated into health policy (DoH 2004). Qualitative research is ideally suited to researching this as it allows young people to give accounts of what is important to them, without imposing a rigid framework on the research topic. Moreover, it is flexible in its operation, adapting and working alongside the varying needs of people with chronic conditions. Qualitative research has been extensively used to investigate conditions such as diabetes and cancer in young people, yet very few studies have qualitatively investigated the lives of children's liver disease. This is a significant gap in the research evidence.

Studies of young people with diabetes have illustrated the gaps in the provision of age-specific information (Dovey-Pearce 2005), the way that pressures of adolescence impact of managing their condition (Kay 2009) and how transition to adult services may leave young people vulnerable and their parents unable to support them (Allen et al. 2011). Studies of children with cancer have uncovered issues such as how children deal with the uncertainty of their condition (Stewart 2003) and their unmet needs whilst they are in hospital (Aldiss et al. 2008). Although these findings will all have resonance for children with liver disease, the different symptoms, treatments and prognosis mean that they cannot be directly compared, and as yet we know very little about the experiences and needs of young people with liver disease.

The one aspect of young people's experiences of liver disease that has been explored to date is the experience of liver transplants (Fredericks et al 2008). Wise's (2002) small scale study with nine paediatric patients in the USA found that post-transplant children strived to be 'normal', to do the same everyday things that other children of their age did, such as having friends and taking part in school events. Ongoing treatment was a barrier to being 'normal', as medication and frequent hospital visits could stop them participating or make them appear different. She found that certain aspects, such as taking medication, can more easily be incorporated into their lives, frequent or long periods of hospitalisation were disruptive to peer relationships. Wise also found that that some young people were reluctant to share health issues with their parents as they did not want to worry them about issues, and that parental vigilance could be a barrier to being 'normal'. Taylor et al. (2010) found similar concerns arising in their UK study with 14 liver transplant recipients. However, their findings also revealed a lack of communication and level of distrust between young people and health professionals. Whilst their data was limited in its discussion of the transition between child and adult services, what did emerge in a few accounts was a conflict between wanting to remain with the paediatric team that they know and a desire to be recognised as an adult. This is an important area to investigate further. Therefore, although these studies have given us some insight into young people's experiences of liver disease, both studies were small (9 and 14 participants) and focused solely on the experiences of transplant patients. Consequently more research is needed to broaden our understanding of these issues, and this project will seek to do so.

Methodology

This project will use in-depth semi-structured qualitative interviews with young people, parents/carers and young adults with liver disease to explore experiences during a time of transition. Qualitative methods are particularly suitable for research with young people as they do not see to test a specific hypothesis but instead allow participants to give their own in-depth accounts on issues that matter in their lives. In addition, the flexible nature of qualitative research means that it can adapt to fit around the lives of people with chronic illness, and be sensitive to their particular health needs at any given time.

Recruitment and selection

For the purposes of this study, young people are defined as aged 14-18 and young adults as aged 18-25. Recruitment of young people and parents/carers will take place through the membership Children's Liver Disease Foundation (CLDF). Information about the research will be sent to potential participants and an advertisement will be placed on the forum. The project will recruit 20 young people, 20 parents and 20 young adults. We will only recruit one member of each family in order to reassure potential participants that the interviews are confidential. Purposeful sampling will aim to achieve diversity in age, sex and ethnicity and diagnosis.

Participants will be asked to choose a convenient time and place for the interviews, and whether they would prefer for the interview to be face-to-face, via telephone or online. The venue could be in a private space at the hospital, at the University or at home depending on the preference of the participants. On-line interviews will use synchronous chat software and this is particularly useful for including participants whose geographic location could have otherwise excluded them (Jowett et al. 2011) .

Interviews

Exploring the perspectives of young people, parents and young adults will enable a more comprehensive picture of the issues to be uncovered. It will allow exploration of the current concerns for the immediate future and a retrospective account of the illness journey through adolescence and what worked and what could be improved through this particular transition. All the interviews will be semi-structured and although will have a list of key areas to be covered, will primarily use open question to ensure participants can give their own accounts. Whilst the range of topics will be refined following the extensive literature review in the first year of the project, they are likely to include the following areas:

- Illness journey (background of diagnosis and treatment)
- Managing (coping with the condition, adherence to treatment)
- Living with the illness (impact on wider social life)
- Transitions (growing into adulthood)
- Health Services (relationships with health professionals, transitions and changes in health services provision)
- Difficulties (unmet needs)

All the interviews will have similar forms, but questioning will vary depending on the informant. For example, young people will be asked about their needs now and what they think they might need in the near future whilst young adults will be asked to reflect back on this period of their lives. The interviews will be audio-recorded (with consent) fully transcribed and NVIVO will be used to facilitate the analysis. Discourse analysis will be used to identify patterns of experiences, attitudes and behaviours and also analyse the accounts in terms of their construction and function. Coding and analysis will be undertaken throughout the period of data collection so that analysis of early interviews informs the development of the interview schedule for later interviews.

Ethical issues

This project will gain approval from the National Research Ethics Service and the Aston University Ethics Committee during the first year of the project. Written patient information will be produced as part of this process and all participants will be asked to give written consent. In line with good practice, for young people under the age of 16, written consent from parents will be sought alongside the consent from the young people themselves. Potential participants will be informed that they can withdraw any time until publication of the

project findings. All researchers that have contact with young people will have a Criminal Records Bureau (CRB) and the project will adhere to the Child Protection Policy of the recruitment site (each hospital) or Aston University's Policy if young people are recruited directly.

All data will be held securely on the University's computers and will be anonymised at the earliest opportunity. Confidentiality will be maintained, except in cases where the informant discloses information which suggests there is a significant risk of harm to themselves or others (including child protection issues). In this case, the researchers will follow the relevant Policy guidance. Throughout, the research team will follow the British Psychology Society's Code of Ethical Conduct and the British Sociological Ethical Guidelines.

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