# Adult survivors of childhood liver transplant: personal narratives of an emerging 'new' ageing population

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## Background

Alongside the profound social and economic changes brought about by general population ageing, the past half century has seen the emergence of what have been termed ‘new’ ageing populations (Lowton & Higgs 2010). These populations have come into being through rapid medical progress in tandem with changes in social attitudes to the issues surrounding disability, which have led to increasing numbers of people with rare and/or complex disease or disability surviving into adulthood and living considerably longer than would have been possible in the past. Previously fatal childhood conditions such as cystic fibrosis (CF) or congenital heart disease (CHD) are now routinely modified in early life, leading to new challenges and opportunities for this group of patients as they grow into adulthood. While many aspects relating to clinical presentation and healthcare delivery that arise from these developments have been well documented, ontological and existential issues for those living with or beyond the expectations of a condition have not been studied so extensively. Surviving a condition while simultaneously attempting to live an ‘ordinary’ life is difficult for most patient populations; adding the normal preoccupations of growing up to this mix creates new and different pressures. If additionally a patient is a pioneer of a ‘new’ ageing population they can face issues that have never before been encountered, either by themselves or by the professionals leading their treatment and care. This element of uncertainty could potentially place more pressure on individuals to reflexively negotiate rapidly changing clinical and social contexts.

Adult Survivors of Childhood Liver Transplant (ASCLT) constitute one such ‘newly ageing’ group. Not only are they survivors of a major organ transplant but they are also a group of adults who have lived their whole lives in the context of their then experimental or innovative surgery. They have had to deal with being children who have had a transplant; being adolescents who have had a transplant; and being adults who have had a transplant. In so far as this has been the case they have had to live their whole lives within the context of their body as a project. While this may chime with contemporary cultural themes which resonate in the term ‘somatic society’, their experiences are much more because their whole lives have been seen as a vindication of the power of bio-medicine and the advances that come from innovative medical and surgical techniques.

When the first liver transplants in young children were performed in the United States in the late 1970s and early 1980s it was not clear if it was at all realistic to expect these children to reach adulthood (Otte 2002). In 1984, 2 year old Ben Hardwick received the United Kingdom's first publically acknowledged paediatric liver transplant at Addenbrooke's Hospital, Cambridge. As in the US, surgeons at Cambridge had successfully pioneered *adult* liver transplants in the late 1970s but it was still an experimental intervention, novel in children. The public interest stimulated by the BBC TV series ‘That’s Life’, which broadcast Ben’s story in response to a plea from his mother, provided the impetus for a children’s service to begin. Although Ben died 15 months later, soon after receiving a second liver transplant, further paediatric liver transplants were performed in Cambridge, with paediatric medical support to the surgical programme from King’s College Hospital in London. By the early to mid nineties new centres were open at Birmingham and Leeds and the original Cambridge surgical programme had transferred wholly to King’s College Hospital.

Over the subsequent 25 years, experience has proved that up to 80% of children are likely to survive at least ten years following liver transplant (Otte 2002), and that more children are receiving transplanted livers who in future years will survive for longer. Like young people with CF considering or undergoing organ transplant (Lowton 2003), uncertainty, risk and hope are likely to have been key features forparents and medical specialists at the time of each child’s surgery and beyond, but little attention has focused on the broader experiences of the recipients of the transplanted livers as they mature into adulthood.

The research examined the lived experiences of the now adult Addenbrooke’s and King’s College Hospital paediatric liver transplant patients and the transplant clinicians who continue to care for them. Studying the first UK cohort of child liver transplant patients not only generated knowledge about how a particular section of a ‘new’ ageing population has dealt with the health and social implications of living with transplanted livers from a very early age, but also the wider existential questions of having had such transforming surgery.

## About the study

Unusually for a study of this type, the entire surviving patient cohort was identifiable and contactable. At the time of application to ESRC (January 2011) there were around 65 individuals still alive who had survived at least 10 years since receiving their first liver transplant in childhood. Of those, 45 were potential participants for our study as they had passed their eighteenth birthdays. The cohort of 45 includes 19 men and women for whom it was twenty years or more since their first liver transplant and 7 of them were under five when that happened. Sixteen of the 45 had had more than one transplant.

Initial access to potential recruits was secured in principle through Dr Alexander Gimson, Consultant Hepatologist at Addenbrooke’s Hospital, subject to the usual ethical approvals. As this population had not been studied before in this way there were no datasets on which to base our study, however basic demographic, personal and surgical details of the entire transplant patients at Addenbrooke’s were available to aid sampling. This ‘new’ ageing cohort had by then either passed through or was in the tail end of the transitional phase from adolescent to adult.

We recruited a purposeful sample of the oldest ASCLT we could, to ensure that men, women, single and multiple transplant recipients and those transplanted under five years of age were represented as well as they could be, given the number of possible patient recruits.

Interviews with 27 patient participants were conducted in a place of each participant’s choice amongst as many as possible of the longest surviving men and women. By approaching the longest surviving individuals, we were able to gather rich data from participants both with significant experience of liver transplant survivorship and as an adult attempting to live a ‘normal’ life.

The semi-structured interviews investigated patients’ thoughts, feelings and experiences in the past as a person with a liver transplant, how they felt now and how they perceived their future. The interviews developed over time, as themes were identified and pursued. Each interview gathered the patient’s narrative in the order they found most comfortable, although the interview began by seeking a summary of the participant’s present situation to establish rapport, and then asked about the past through a simple invitation to tell the researcher about their liver transplant. Returning to the present for more detail on their current lives the researcher continued to invite the participants to explain their challenges and successes with a liver transplant and then move on to how they saw their future.

In addition eight interviews with professionals were undertaken. The focus of these was on how the management of ASCLT is seen as a professional as opposed to a personal challenge, though the personal was not excluded.

## Our findings

Our findings span the clinical, sociological, policy, and public interest spheres. We have presented a range of papers at national and international conferences and have begun to write up our findings for publication. Papers include:

* Shark Bites and Surgery: Personal and Social Meanings of a Scar for a ‘New’ Ageing Population
* Understanding 'Normal' and Different for Pediatric Liver Transplant Recipients: Qualitative Study of the UK's First Now-Adult Survivors
* The Limitations of Biographical Disruption Approaches: The Case of Adult Survivors of Childhood Liver Transplant
* Moral Obligations and Expectations of Adult Survivors of Childhood Liver Transplant: Deserving or Undeserving Recipients?

Additionally, we submitted written evidence to the All Party Parliamentary Hepatology Group’s Inquiry into progress in improving outcomes in liver disease, and in 2013 were called to give oral evidence the Health Select Committee’s about the concept of ‘new’ ageing populations and implications for their care, as part of their inquiry into the management of long term conditions.

We have worked with NHS Choices Video to produce a series of six short videos about growing up and growing older with a paediatric liver transplant which can be viewed here:

<http://www.nhs.uk/livewell/donation/pages/childhood-liver-transplant.aspx>

We also worked with Simon Crompton, a highly respected health journalist, to produce a feature article on the adult survivors of childhood liver transplant:

<http://www.telegraph.co.uk/health/10566984/After-Ben-Hardwick-a-bittersweet-legacy-living-with-a-new-liver.html>

More information about all of our findings to date can be found here:

<https://researchoutcomes.rcuk.ac.uk/grants/RES-062-23-3363/details>