

# Stories of a 'new' ageing population gathered for the first time

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Researchers at King's College London have called on politicians to review the cost of prescriptions for liver transplant recipients, who must take daily immunosuppressants to prevent organ rejection for the rest of their lives. For the first time a suite of personal narratives from an emerging 'new' ageing population have been gathered from the surviving members of the first cohort of paediatric liver transplant recipients, who received their transplant up to 30 years ago at Addenbrooke's or King's College Hospital.

The narratives have highlighted again the requirement for young adults living in England to pay ongoing prescription charges for their drugs, including vital immunosuppressants as well as other medications over their lifetime. Dr Karen Lowton, from the Department of Social Science, Health and Medicine, who led the study, said: 'The cost of prescriptions we believe is unjust for our participants and all others growing up and growing older with a transplant. The issue of exemption for people with long-term conditions in paying for the prescriptions has been raised before, most recently by Prof Ian Gilmore in his report for the Secretary of State for Health in 2009, but we were struck through the participants' stories by how government legislation has not caught up with how a small but significant part of our society live their lives.

'When the prescription exemption list for adults was drawn up in 1968, transplant expertise and [immunosuppressants](#) had not been developed, and children with rare and complex liver disease, who would have received free prescriptions when children, did not survive to adulthood;

there was no reason therefore to exempt them. Forty-five years later this is not the case for most adults receiving their post-transplant healthcare in England, despite their increasing numbers.'

The examination of the lives and experiences revealed insights into a 'new' population not previously expected to survive. The researchers were surprised to find that 90% of participants reported not knowing any other adult who had had the procedure in childhood, a contrast to the way other long-term conditions are managed in society.

Dr Lowton said: 'Talking to others in the same situation can be helpful to overcome feelings of isolation or 'being the only one', but this has not happened for these now-adult recipients. Patients who identify and converse with others with the same condition are able to share tips for living with rare and long-term conditions.'

As part of their study, the team from King's hosted a lunch for participants to enable them to meet other adults who share their liver-recipient status for the first time.

The collection of accounts from participants revealed lives lived within in bodies viewed as a physical and social 'project'. The adult survivors form a group of adults who have lived their whole lives in the context of their then experimental or innovative surgery. Whilst the study found participants recount many of the usual anxieties and challenges of growing up, the status of the participants as pioneers is clear as there is no cohort ahead of them who have had the same procedure to provide advice based on experience.

Other key themes to emerge from participants' narratives included 'the public's reaction', the use of alcohol, being 'different', managing uncertainty and using health services. The issue of the transplant arose in the stories of all participants. Early liver transplant surgery left

participants with a large scar; the incision made for today's paediatric liver transplants is now slightly smaller but is still a significant mark on the body.

Dr Lowton said: 'Surprisingly, current clinical practice guidelines for long term medical management of children post paediatric liver transplant do not refer to the scar at all, and instead focus on health-related considerations such as symptom monitoring, blood tests and immunosuppression. However, we found that this scar has a long and complex life and is of considerable significance to liver recipients.'

The most common significance of the scar was as a physical manifestation of what recipients had been through in terms of their health and treatment and as a reminder of how close they had been to death. Participants spoke in terms of heroic survival. They also spoke of their scar being a mark of respect to the donor who had given the 'gift of life' to them. Further, they expressed feelings of a moral obligation to not just observe life going by, but to live life 'well', although how this was interpreted differed between participants.

Dr Lowton said: 'The encouraging strand to emerge from [participants](#)' stories was what a full life all those who had received a liver transplant in childhood were living, despite quite a wide range of physical abilities and ongoing health problems. This research not only highlights the ongoing health and social concerns of those growing older with one of the first childhood [liver transplants](#) in the UK, but also the continuing need for donors for those waiting on the transplant list.'

Provided by King's College London

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