



# Constructing embodied identity in a ‘new’ ageing population: A qualitative study of the pioneer cohort of childhood liver transplant recipients in the UK



Karen Lowton <sup>a, \*</sup>, Chris Hiley <sup>b</sup>, Paul Higgs <sup>c</sup>

<sup>a</sup> Department of Sociology, University of Sussex, United Kingdom

<sup>b</sup> Institute of Gerontology, King's College London, United Kingdom

<sup>c</sup> Division of Psychiatry, University College London, United Kingdom

## ARTICLE INFO

### Article history:

Received 16 January 2016

Received in revised form

8 November 2016

Accepted 10 November 2016

Available online 11 November 2016

### Keywords:

United Kingdom

Organ transplant

Identity

Embodiment

Corporeality

Childhood

New ageing populations

Qualitative

## ABSTRACT

Medical innovations have created a future of survivorship for many groups of people with a variety of conditions that were previously untreatable or untreated. This has led not only to an expansion of medical activity in a whole variety of new areas but also to the emergence of new groups of individuals defined or defining themselves through their experiences, diagnosis and treatment. Through analysis of in-depth interviews with 27 of the now-adult survivors of the pioneer cohort of children receiving liver transplants in Britain in the early 1980s and 1990s, this paper presents how this group not only illustrate the capacities of modern medicine and healthcare to transform the survival prospects of a more diversified population, but also create new narratives of embodied identity. Specifically, we examine how childhood identities were shaped in three settings; home, hospital and school. At home, parents appeared to shape their child's identity through controlling tightly a daily medical regime focused on the concept of 'body as machine', celebrating their survival as a transplant recipient, yet at the same time socialising their child as a 'normal' child, albeit one who had a serious illness. The hospital appeared instrumental in shaping parents' focus on their child's body, and offered a way, through other patients with liver disease, for children to feel 'normal' in their difference. It was in school, through interaction with 'healthy' children and teachers, that corporeality and embodiment appeared most salient, and where social identity was negotiated and more often held in contention. Adult survivors of childhood liver transplant straddle the different discourses of normality and difference as their embodied experiences shape their narratives of identity and shed light on an underexplored aspect of the relationship between medicine and society.

Crown Copyright © 2016 Published by Elsevier Ltd. All rights reserved.

## 1. Introduction

Modernity, it has been widely recognised, has led to many changes in everyday social life that are far-reaching, all encompassing, and have important implications for individuals (Giddens, 1990). Three of the most noteworthy changes have been the expansion of medical activity through medical innovation in a whole variety of new areas such as childhood organ transplantation; the subsequent possibility of survival from historically fatal conditions; and the transformation of the idea of identity, a

concept that has both a long history and a greatly increased significance in contemporary societies (Giddens, 1991; Sharp, 1995; Moran, 2015). Together, these changes have led to the emergence of many new groups of individuals defined or defining themselves through their bodily experiences, diagnosis, and treatment, and present new and ongoing challenges for identity as these individuals grow older.

The concept of identity has been the subject of considerable debate within the social sciences (Jenkins, 2014). Self-identity, a personal understanding of one's own character, situation and experiences, can be seen as ambivalent, reflective and reflexive (Lawler, 2014), with underlying health conditions and their treatment being highly influential in how an individual perceives themselves. Felt identity, referring to how an individual thinks about themselves as a person in the context of their daily life, or 'who I am'

\* Corresponding author. Department of Sociology, University of Sussex, Freeman Building, Brighton, BN1 9RH, United Kingdom.

E-mail address: [k.lowton@sussex.ac.uk](mailto:k.lowton@sussex.ac.uk) (K. Lowton).

(Lawler, 2014:8), has historically received little empirical attention in the sociology of health and illness, but is now emerging as an important question for recipients of medical innovations living in diverse societies. In the context of organ transplantation anthropologists have offered useful perspectives for thinking specifically about the ways that receiving a donor organ might shape personal identity. For example, a transplant recipient may adopt new attitudes, behaviours, or imagined characteristics of the donor through believing that they have been acquired through the donor's organ (Sharp, 1995; Crowley-Matoka and Lock, 2006). Transplant recipients may also personalise their transplanted organs and weave these understandings into their perceptions of owners or inhabitants of a newly-assembled body (Sharp, 1995).

Identity is also conveyed through understandings of oneself being bound and constructed in relationship with various other individuals and organisations (Williams, 1984). This is especially so for transplant recipients who work post-surgery to redefine and restructure their identities in public arenas; here transplantation creates new or complicates existing social relationships that affect how organ recipients assess their own worth (Sharp, 1995). However, numerous factors can undermine recipients' attempts to redefine themselves as 'healthy' (Sharp, 1995). For those with an ongoing health impairment, both the underlying condition and its treatment influence the degree of control possible over personal information and to what extent certain narratives or identities can be revealed or kept hidden. This has been most famously articulated in Goffman's (1963) notion that the 'discredited' have features that are immediately obvious to others and that the discreditable may be adept at 'passing' but always feel at risk of being publically exposed. Indeed, a recent systematic review of 18 qualitative studies of adolescent experiences post-transplant demonstrated that 'seeking normality' was by far the most common theme identified (Tong et al., 2009).

Medical innovation itself has influenced identity through creating a stronger 'future of survivorship' for different groups of people with a variety of conditions that were previously untreatable or untreated. This is seen for example in the post-diagnosis longevity of those now surviving various forms of cancer (Trusson et al., 2016). Innovative cancer treatment has given rise to a public and professional discourse of survival as opposed to death, with a dominant view seeing survivorship as being an opportunity for individuals to strive to become something better than they were before diagnosis (Bell, 2012). In contrast, individual experiences of cancer survivorship underline alienation from this conceptualisation, e.g. through the threat of recurrence; having a less 'severe' cancer experience; or a desire to keep one's cancer experience private (Kaiser, 2008). Although the term 'survivorship' can be a contested concept, we use it here to indicate an important social transformation rather than simply marking an individual change (Dyer, 2015). In the context of increasing longevity, a future of survivorship is also now emerging for recipients of organ transplant, although there is so far little published work in this area.

To date, sociological work on health and illness and anthropological work on transplantation focus on identity and survivorship in the context of adults, not children. Furthermore, although anthropologists consider notions of culture in public and private life, there has been little work from either discipline on how specific social settings shape identities of childhood transplant recipients. In the context of shaping identity in childhood, James (1993) notes the significance of cultures, structures and settings: identities at home and school being constructed in part through negotiation with both children and adults. Broadly, home and school offer contrasting social arenas for children, based not only on the character of their relationships with adults in each setting but also on adult ideas of what children are and how they should live their

childhoods (Mayall, 1998a). Here we argue that hospital is an important third arena for constructing and managing the identities of children undergoing organ transplantation, through their interaction with clinicians and other patients.

If childhood is one neglected arena in the sociology of health and illness, then so too is the role of 'bodily idiom'. Social identity is not only given meaning through information shared by an individual and others, but also through information transmitted through bodily appearance and physical expression (Lawler, 2014:8). Again, anthropological work has shown how embodiment is significant in defining identity and its development, as it is through our bodies that the world is experienced, with the body being both a physical and symbolic artefact, located in a particular historical time (Scheper-Hughes and Lock, 1987). As we have noted, a transplant recipient's sense of self-identity may be radically altered after another person's organs are transferred to them (Sharp, 1995), for example through notions of a person 'living on through another' (Crowley-Matoka and Lock, 2006) or that organs are purely physical commodities (Fox and Swazey, 1974, 1992; Lowton, 2003). Additionally, the symbolic meaning given to an organ may also have a profound effect on the transformation of identity, for example in the heart being considered the seat of emotions (Sharp, 1995).

In this paper we discuss how the experiences of a 'pioneer cohort' of children who received liver transplant in the 1980s and early 1990s are examples of the capacities of modern medicine and healthcare to transform the survival prospects and create new narratives of identity of a more diversified population of organ transplant recipients in a world where the lifecourse has become more complicated. Consequently, in researching the lives of individuals who had liver transplants as children we not only need to be aware of its effects on self-identity but also that these same children were growing up in social and cultural environments that were also rapidly changing (Phillipson, 2013).

## 2. Background

Although the first 'successful' adult kidney transplant took place in the late 1950s, paediatric liver transplant did not begin in the US and UK until the early 1980s (Starzl, 2000; Otte, 2002; Williams, 2009), when immunosuppression, surgical technique and public willingness to consider children as potential organ donors allowed such transplants to be considered for children who had missing or blocked bile ducts (biliary atresia) or metabolic damage arising from rare or complex syndromes. In the UK in 1984, BBC Television's *That's Life* popular consumer programme lobbied for British paediatric liver transplants to commence though the entreaties of Debbie Hardwick, mother of two-year-old Ben. Ben subsequently became the UK's first recipient, but died just over one year later following a second liver transplant. His surgeon, Professor Roy Calne, had been instrumental in developing the immunosuppressant cyclosporine to prevent rejection of donor organs (Starzl, 2000), thus enabling transplant to be perceived as a treatment rather than an experimental procedure. At this point children could still be conceptualised as a biological 'project' of the transplant surgeons who were concerned with repairing a non-functioning body. The focus was on rescuing the child and on surgical success, with the transplant programme placing children in a passive position relative to medical intervention and parental consent. Yet in the early years of the transplant programme not only were there no long-term survival data, there was also no knowledge of the life the child would be able to lead or, if they survived, what they might grow up to become, as the excerpt from *That's Life*, transmitted after Ben's first transplant, illustrates:

Download English Version:

<https://daneshyari.com/en/article/5046782>

Download Persian Version:

<https://daneshyari.com/article/5046782>

[Daneshyari.com](https://daneshyari.com)