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

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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.

Key words United Kingdom; organ transplant; identity; embodiment; corporeality; childhood; new ageing populations; qualitative;

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 themself. Felt identity, referring to how an individual thinks about themself as a person in the context of their daily life, or '*who I am'* (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 identify 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 & 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 & Lock 2006) or that organs are purely physical commodities (Fox & 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 (Philipson 2013).

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:

Esther Rantzen: Professor Calne says that Ben's chances of living a year now are 70 per cent.
Debbie Hardwick: That is lovely. But I can't let myself relax, because I can't be knocked over again. When he was a year old we hoped it was all going to be okay. Then we were told he'd die. So we can't relax now, because I couldn't take that sudden knock once again.
Esther: How soon do you think it will be before you dare think of the future?
Debbie: I don't know. When he goes home I suppose. I do have a sneaky view of it sometimes. I think that maybe he will go to school someday, and that sort of thing. But I try not to.
(Rantzen & Woodward 1985:125)

In the case of transplant for the more 'simple' problem of biliary atresia (the condition that Ben was diagnosed with), the procedure can now be seen as a solution where earlier surgery (a Kasai procedure, which removes blocked bile ducts and replaces them with part of the small intestine) has failed, with follow-up problems focused on monitoring of immunosuppression and its side effects. For those with more complex conditions such as cystic fibrosis or Alagille syndrome transplanted subsequently, liver transplant deals with an acute problem in early childhood, yet the underlying condition will persist in adulthood. These recipients have therefore grown up with a body that had never become as wholly 'well' after transplant as was initially hoped. Nevertheless, childhood liver transplant potentially enabled this early patient group to survive into young adulthood and beyond, albeit with an unknown and uncharted future ahead of them.

In terms of appearance, children in liver failure are most notably jaundiced with yellow skin and eyes, may have a swollen abdomen, or may have excess hair and overgrown gums as side effects of treatment. In the first decades of the paediatric liver transplant operation, the typical surgical incision (and subsequent scar) was an inverted 'Y' that crossed the abdomen just under the ribs, referred to as a 'Mercedes' incision after the manufacturer's distinctive marque. These children therefore not only had chronic illness but also new corporeal markers of bodily difference that could be hidden or displayed and commented on by others, or play a semiotic role. Hence both the corporeal and embodied nature of identity has consequences both for the understanding of normalcy or difference and for a person's feelings of inner worth (Shilling 1993; Sharp 1995; Kaiser 2008). Significantly, as Gilleard and Higgs (2014) point out, it is important to be aware that the corporeal is often that which is seen as private while the embodied is seen as that which is social and out in the world. The capacity of the disability movement to move the issues resulting from the effects of disablement to the public sphere can be seen as an example of the value of this distinction (Thomas 2012). The way the body is represented and the contexts in which it is either publically or privately located signifies what type of a person is present; the body itself being used to generate meaning in a number of complex ways:

> 'Its physical character, inspected and controlled in the environments where people move; its social character and value, constructed through interactions with others; individuals' personal perception of their body is revised in response to these experiences in a range of social environments and with a range of people.' Mayall (1998b:135)

In the context of childhood organ transplant, the corporeal body can therefore be seen as the site of a reflexively organised project that is chosen or constructed from a complex multitude of choices offered by high modernity (Giddens 1991). Situated at the very centre of the nature/culture and biology/society dichotomies, it is ‘an unfinished biological and social phenomenon which is transformed, within certain limits, as a result of its entry into, and participation in, society.’ (Shilling 1993:12). However here again adults, not children, have been the focus of social scientists’ theorising. Where attention has been turned to embodied identities in childhood contexts of health and illness, this has been most commonly focused on severe or complex disability where children fit ‘outside’ the standardised lifecourse, with extreme health needs, or on common childhood conditions, such as asthma. Research conducted with healthy schoolchildren has shown that bodily experiences and bodily differences function as important signifiers for social identity (Prout, 2000). Height, shape, appearance, gender and performance are corporeal and embodied aspects of identity found to have particular significance, each acting as flexible and fluctuating resources in children’s interactions, identities and relationships (James 1993).

Bringing together discourses surrounding organ transplant, survivorship, the body and notions of identity we can see that the construction of identity in the context of what, for others, was a life extension and an unanticipated survivorship sheds light on both biomedicine and on identity. For this group the impact of their health condition is central to both individual and social concepts of self from early life. Adult survivors of childhood liver transplantation have had to continually negotiate the expectations of social and biological normality that rarely include living with the long-term consequences of transplantation, both in terms of the pharmaceutical regime and the physiological consequences of growing up post-operatively. Moreover there are emotional and psychological issues connected to the life/death nature of survivorship, as ‘normal’ before transplant could only have led to childhood death as the natural outcome of the liver condition.

However, the effects of medical innovation on both identity and survivorship have to date focused on young adults and those in midlife who, as Fox & Swazey (1974) noted early in the history of transplantation, are able to construct new biographies or extend and enhance existing ones, rather than those who receive innovative life-saving medical care as young children and have little or no prior developed sense of personal identity or indeed awareness of receiving a donor organ. In contrast, the emphasis of pioneering paediatric organ transplantation was to save lives through the application of new medical and surgical techniques; little anticipation was given by clinicians or society at that time to the effects of such medical advances on children as they grew up to become adults. For the same reason they have also been termed a 'new' ageing population (Lowton & Higgs 2010); even though they cannot be conceived as 'old' in conventional terms, these early childhood transplant recipients represent new pathways through life that societies have not hitherto experienced.

This paper reports findings from a study that aimed to gain a deeper understanding of how the now-adult survivors of the pioneer cohort of UK childhood liver transplant recipients thought about who they were as they were growing up and how this relates to both the effects of the medical intervention and its effects on the processes of embodiment. We show how their membership of a new ageing population has had a number of effects on both their experience of life and on the development of their identity. Specifically, we examine how identities were shaped in three core social settings; what we show to be the private contexts of home and hospital and the more public context of school. We explore how felt identity was experienced in terms of recipients' understandings of their 'normality' and difference to childhood others.

Methods

Data collection

We sampled the first ten years of the paediatric liver transplant programme (1984-1994) at Addenbrooke's hospital, Cambridge, where it began in the UK, and at King's College Hospital, London, which had strong ties to Addenbrooke's and also began liver transplant surgery during this time. The London-Camberwell St Giles NHS Research Ethics Committee granted ethical approval. We included those who had had a liver-only transplant at age 13 years or younger, as we were interested to talk to adults who had lived the majority of their life as a transplant pioneer and who had not reached adolescence at the time of their surgery. Letters of invitation and study information were sent by the two hospitals to eligible patients, who were asked to contact the study team if interested. All participants were assured anonymity and confidentiality. Consenting participants were interviewed at a venue of their choice using a topic guide formulated from clinical and social science literature plus [author's] early experience as a nurse caring for the initial liver transplant recipients at Addenbrooke's hospital. Briefly, interviewees were asked how they were currently, with emphasis on their health, then invited to tell the story of their transplant and associated treatment, and how they perceived and experienced their own life in relation to others. All interviews were audio recorded with participants' permission, transcribed verbatim and coded using NVivo.

Data analysis

For the purposes of understanding how childhood identity was formed and shaped, we were interested in understanding participants' recollections of this time. Participants predominantly discussed these in the three primary contexts of home (i.e. before leaving their parental home), school (before leaving compulsory education) and hospital (before hospital transition to adult services). However, we acknowledge the problems inherent in determining when childhood ends; in reality the transition from child to adult is fluid and may last for many years. The purpose of our analysis was to understand, in their most familiar public and private contexts, how the interplay between corporeality and embodiment shaped the identity of these young pioneer liver transplant recipients. Here we do not focus on planned disclosure of transplant status to others, or on romantic relationships or employment, which were generally reported when recipients were adult.

We read closely each transcript, using open coding to mark any text that referred to these three primary contexts, and noting the key issues that participants raised in these and other contexts concerning their identity or relationships with others. We used a constant comparative process to note similarities and contrasts between participants' accounts and the possible reasons for these. During the interviews and our first coding of transcripts we were struck by how often participants recollected comparing themselves to their peers, or having their bodily appearance commented upon by others. We therefore re-read the transcripts, searching for and coding all accounts of feeling 'normal' or 'different', expressed most often through comparing characteristics, feelings, or experiences to others.

Our analysis followed a grounded theory approach (Charmaz 2006). As well as paying particular attention to the contexts in which childhood and meanings surrounding it were recalled, we were mindful of the ways in which each participant had 'remembered' their story, for example through newspaper clippings, photographs and stories that had been told to them by their parents, and their own memories of salient events. We use pseudonyms here for each participant, but as they form a very small, potentially identifiable group, we present minimal detail about them.

We interviewed twenty-seven now-adult survivors: 16 women and 11 men. Eighteen participants had had one liver transplant, eight had required two and one participant had had three at the time of interview. Aged 19-36 years (median 27), they were 6 months-13 years (median 6 years) old when they underwent their first transplant. At time of interview, survival since first transplant ranged from 15-28 years (median 22 years). Early hospital data for the cohort is patchy, as many pioneer recipients have been lost to follow-up, although from discussion with clinicians we believe we interviewed around half of the 1984-1994 surviving UK cohort; around 60 were known to fit our criteria at the time of recruitment. Interviews took place most commonly in participants' homes and lasted on average 82 minutes (range 20-163 minutes). Around half reported biliary atresia as the reason for transplant, with the remainder reporting a range of rare or complex syndromes; this broadly reflects current indications for needing liver transplant in childhood. From their interviews, 12 participants stated they were completely unaware of their need for surgery at the time of their first or only transplant; this group received a donor organ before they were five years old. Sixteen participants, who had received a transplant aged between 5-13 years, could remember events connected to at least one of their transplants, for example being spoken to by a surgeon or a long stay in hospital. Only one participant fitted into both groups, having received transplants aged 2 and 9 years old. All continued to attend regular outpatient appointments at specialist liver clinics and all reported co-morbidities that had developed after transplant including epilepsy and brittle bones. At interview, 18 participants reported being in employment or further/higher education. Two had become wheelchair users as adults.

Findings

Reflections of childhood identity and to what extent participants had considered their childhood self to be 'normal' emerged during all interviews and are presented below in two parts. First, we consider briefly how participants recalled conceptualising themselves as children and how their bodies and transplant had influenced this. Second, we consider how identities were constructed and shaped in the private spaces of home and hospital wards and the more public space of school.

Conceptualising identity in early childhood

Participants recounted that in early childhood they had formed few reference points of what was 'healthy' or indeed that they were, or were soon going to be, the recipient of a donor organ. In these early years, before being able to conceptualise, articulate, or compare health and illness experiences with peers, participants reported thinking it was 'normal' for people to be unwell, to visit the doctor regularly and be admitted to hospital, and to have regular blood tests and other investigations. They did not understand where the boundaries of 'health' and 'illness' might lie, or that their bodies might appear different to those of other children. When very young they did not conceptualise themselves as an 'ill child', nor, when they were slightly older, understand how serious their illness was:

> I think I was aware that there was something wrong, but I probably didn't understand the magnitude of how ill I was. …. There was no part of the first seven years where two years I was OK. …. I didn't actually know, up until when I came out of hospital [post-transplant], what was right and what was ill. (Barry, 32, transplant aged 7)

All participants reported being ill during their school years, but in primary school (aged 4-11) not being particularly aware of the illness or transplant itself as something they should be worried about. For example, Joseph, aged 34 at interview and 8 at transplant recalled, 'not being really concerned, ever, because I didn't really know what to be concerned about.' As they grew into their teenage years and attended secondary school (aged 11-18), most participants stated they became more aware that something was physically wrong with their body yet they still did not equate this to being 'ill', question why they might be ill, or attempt to evaluate how poor their health was. Additionally, although they knew as young children that they had to take medicine daily for their liver disease or transplant, for many it did not act as a clear signal that their health might be 'out of the ordinary'.

Although details of donors are kept confidential, by their teenage years most participants knew at least the gender of their donor and, for some, the circumstances of their death. However, the extent to which those who had had a transplant before their teenage years understood themselves to be a recipient of a donor organ was variable. For example, Helen, aged 34 at interview, recalled understanding at age 10 that she needed a new liver, but not that it would come from another person. Similarly, those who had grown up from a very young age with surgical scars, either from a Kasai or transplant operation, conceptualised these corporeal markers as 'just part of me.' The ambiguity of normality in the context of health and illness, having little idea of the transplant procedure and that another person's organ would be transferred to them, and the scar being a constant part of their body, meant that for those who received a transplant as a young child there was no 'before and after' in conceptualising who they were, for example in integrating a donor's identity into their own.

During their interviews all respondents acknowledged some degree of 'not feeling normal' in their childhood social contexts. Much of their feeling about who they were and to what extent they were normal came from their embodied interpretations of how they looked, how they behaved, and how aware they were of others' responses to them. Their own responses to the appearances and experiences of others, not only in the context of transplant, but also in their wider childhood social context, were also influential. Medical intervention for some had come at the expense of other areas of life that children would routinely take part in, as Jaime explained:

> My life has always been mostly the medical kind of thing. I think it was just because of that focus, I didn't really have that kind of social life that my friends had. I mean, I did have friends, and I did have a lot of family support all round me, but I couldn't say that – people went off to sleepovers, or they stayed out some nights. I can't say "oh, I've done that, and all that kind of stuff". (Jaime, 27, transplant aged 8)

These concepts of corporeal and embodied identity are explored further below in the three social environments of home, hospital and school.

Shaping identities in public and private spaces

Home

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' (Stainton-Rogers 1991), 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. Parents' accounts and photographs were drawn upon in all participants' stories of their childhood, these being reported to have helped construct and fill gaps in their early memories. Many of these accounts appeared to have been used to tell participants' childhood selves about who they were and what medical interventions they had undergone, thus becoming a very early part of their identity. Here, rather than wider stories of the transplant process, their corporeal childhood body was made central, through stories of procedures performed upon it and photographs taken of it in hospital. Additionally, newspaper articles reporting their stories and scrapbooks made by their parents were important in telling the story (both to themselves and others) of who they were:

> I remember my mum showing me videos of when I was on TV on local programmes. And my mum's got four ring-bound scrapbooks of paper clippings and magazine clippings and stuff, of when I was in the paper and that, pre- and post-op [transplant]. (Edward, aged 28, transplant aged 2)

Parents were reported to act as case managers, delivering ongoing care and having oversight of hospital appointments; if not possessing medical expertise, then at least following closely the medical direction for their child (Craig and Higgs 2012). As one participant recalled, her reaction to her mother telling her she needed a liver transplant aged 9 was: ‘If my mum told me, then that was that.’ Many participants spoke about not understanding until adulthood how seriously ill they had been as children and the trauma that their parents had experienced. Indeed, the uncertainty over their future that their parents would have been managing at that time was spoken of in only one account:

> When I was recovering [post-transplant], I said to my mum one day, “If I never had my liver transplant, I would still be sick.” And my mum said, “No, you wouldn't be sick, you would be dead” [laughs]. (Jaime, aged 27, transplant aged 8)

However, juxtaposed to a ‘body as machine’ approach, most participants also reported that their parents treated them in the same way as their healthy brothers and sisters; either through explicitly telling them that they were just like their siblings or through being grounded, slapped, or given chores, yet always believed, supported, and cared for when ‘poorly’. In this way, home life became enshrined as a family ‘normal’, even for families who had more than one sick child:

> I think it [liver disease] was very normal in our family, because of my sister [who has also had a liver transplant]. We’d always been going back and forward to hospitals since being babies, so I literally didn’t know any different. So it was kind of normal for me…But I think it was how my mum and dad were…I think because they never allowed us to feel like, oh! We’re ill. We’re sick kids. We just never did. (Isobel, aged 27, transplants aged 8 and 13)

Home was most often recalled as a safe, private, ‘backstage’ environment where bodily differences and treatment could become a normal difference or a domesticated idea of ‘normal for me’. One illustration of how their donor organ had shaped their identity here was shared by many participants, not through any notions of inheriting the donor’s characteristics, but in the way that their parents and close friends and family celebrated their transplant and survival akin to an anniversary or extra birthday, seen also in North American adult recipients (Sharp 1995):

> I always used to get a little present on my – basically a very small birthday. Didn’t have a party or anything. It was just something for them [his parents], because it’s bigger to them than it is to me. Really. And it’s so hard to find a card saying, Happy Transplant Day! [Laughs.] (David, 22, transplant aged 1).

Of note, siblings and other young family members were reported to work to protect these private notions of normality outside the home, most commonly by standing up to bullies. However, parents appeared to maintain ‘normality’ in a different way, through urging their child to conceal their bodily differences in public and to not discuss their health condition and treatment with those they did not know well.

Hospital

With regard to time spent in hospital, all participants referred to at least one parent being present. The only visitors recalled were close family members, and interactions with people other than hospital staff were limited to other young inpatients with liver disease. Somewhat surprisingly, interactions with doctors did not feature extensively in participants’ accounts of their childhood, despite none having been discharged from specialist centre oversight and those with rare or complex conditions acknowledging long periods of admission. While the hospital ward might seem to be a ‘front stage’, public space (Goffman 1963), these features, plus participants conceptualising hospital admission as ‘normal’ for them, suggested it to be a more private, backstage environment.

Participants recollected their clinicians talking more with their parents than with them; minors who could not consent but could join in some conversations about liver transplant to some extent. These children were also too young to articulate themselves as organ transplant recipients to others or to develop counter-narratives around their surgery, such as to imbue their donor organ with the personality of the donor and so, perhaps as transplant was so innovative at this time, these families followed closely the medical narrative that objectified the donor organ (Sharp 1995). Of importance here in the context of shaping identity is the reinforcement of the concept of the body as a machine, the absence of the notion that anything of the donor's self may be transmitted with the organ (Crowley-Matoka & Lock 2006) and positive comparisons with other young 'different' children who participants felt were most like them.

The hospital appeared instrumental in shaping parents' focus on their child's corporeal body as a machine that could be 'fixed'; prioritising bodily function over appearance and emulating a medical way of thinking. For example, Kim reported how her father explained why she needed a liver biopsy performed soon after her transplant:

> I had to have a biopsy done, because something weren't quite right. And I says to me dad, 'Why? Why me? Why do I have to have another problem?' And he said, 'Now listen to me. You know when you get a new car and you put the bonnet up and summat's not quite right, you have to find out don't you? Well, think about your body. A new car part you've had – summat's faulty on it. So we need to find out why it's faulty'. And I said, 'I'm not a car, Dad'. He says, 'I know, but that's how we work it out. Once your new part's fitting in properly and everything's all right you can go back home.' (Kim, aged 36, transplant aged 13)

Except for their scar, participants recalled doctors and their parents discussing objectively their body function much more than their appearance, for example in 'sizing them up' for a transplant. In the context of the scar, for participants old enough to remember, many recalled being shown a teddy bear with a zip (zipper), which some took literally to mean that they too would be fitted with a zip. Others recalled for example being promised stitches and receiving staples in surgery, or finding they had a scar shape different to the one that had been indicated. Here they were not in a position of control to challenge this unexpected appearance of their body post-transplant, with their body aesthetics not appearing to be a priority for adults.

In the context of other young liver unit patients, the most common recollection was of forming deep friendships while inpatients. However, these friendships were rarely continued outside the hospital, possibly because children would have been referred nationally or parents were too busy with their treatment to arrange meetings. Participants also reported hospital friends as being much sicker, needing more liver transplants, or dying through complications of surgery or what they later learned to be a lack of donor organs.

Recalling being in hospital with a group of five children with liver problems, David, now aged 22, reported being the only one who 'made it' to adulthood. David described his mainstream school experience as 'extremely difficult' through his felt difference to other students. As a result of feeling settled in hospital school during an admission aged 11, and finding it 'too hard' to return subsequently to mainstream school, he reported moving to a school for children with special needs, where, through everyone's difference, his confidence grew and he created for himself a new normality (Jones and Higgs 2010):

> I went to a hospital school, for a short time, where everyone had something wrong with them… And I had a vague memory of not wanting to go back to [mainstream] school. I wanted to stay there [in hospital school]. Because at that point in my life I knew. Ha! Wow! Everyone's got something wrong; I finally fit in here. Everyone's normal back home. And it was very hard to go back [to mainstream school], because I'd made friends and these friends were in some way like me. (David, 22, transplant aged 1)

We next explore how these children experienced the more public environment of school, where liver transplants were largely unknown and fellow students were generally in good health.

School

Our group of participants comprised 12 who had had their first transplant before they started school (aged 6 months-3 years, median 2 years); all bar one participants with biliary atresia were in this group. Fourteen had lived with liver disease for a number of years before undergoing their first transplant while at school (5-13 years, median age 9 years), and one participant whose liver condition was thought to be 'fixed' by transplant aged 2 needed another in primary school; these participants were more likely to have a rare syndrome or complex condition. School was reported as a significant context in the young lives of all participants, and despite the challenges of educating a chronically ill child, only one participant reported being held back a year educationally. It was in school, through interaction with 'healthy' children and teachers, that bodily actions and appearances appeared more salient, and where social identity was negotiated and more often held in contention than in the private spaces of home and hospital.

School, as a public place, gave participants the opportunity to compare their bodies with others'. This practice illustrated their difference, predominantly by skin colour pre-transplant or body shape:

> I didn't really notice [an enlarged abdomen] until I think maybe aged five or six when, as a kid in the playground, my stomach was actually quite big and it was quite firm. It wasn't like jelly. It was quite hard. And my skin of course was yellow, which is kind of weird, 'cause I was looking at my friends [thinking], "Why have you got pink skin? And I'm yellow?" (Jaime, 27, transplant aged 8)

Children could do nothing to hide these specific corporeal differences of shape and skin colour, which were experienced in the context of usual worries about body image, for example in comparing oneself unfavourably to those who had already experienced puberty. Participants who received a transplant while at school additionally recalled strong feelings about their scar, for example in 'being convinced nobody would like me because I had a scar' (Becky, aged 28 at interview and 6 at transplant), or imagining their future self as a person that nobody would want to marry.

School brought bodily activities into public view that in other contexts would be considered private, such as getting changed for physical education (PE) lessons, when classmates could potentially see the scar. When it was the only bodily sign that its bearer was 'different', the scar was unique in that it could be kept hidden, and thus identity managed. For example, participants reported trying to find a corner or facing the wall in getting changed, or positioning a towel over their abdomen. Explanations for why participants had not wanted to show their scars in this context were summed up by Helen, who had had three liver transplants while at school; 'because I wanted to be accepted for who I was'.

Participants experienced additional ways in which their bodies caused them to feel different, most prominently by ill-health meaning they were lagging behind educationally. Many had missed long periods of schooling and shared peer experiences, had ongoing learning difficulties, or had felt they had no reference point for where they should be educationally. Felt isolation and stigmatisation for some meant they were not confident in contributing to class discussions and could be targets for bullying, as Keith described in the context of both his appearance and ability:

> My writing is terrible. And my maths isn't what it should be…They got me a teacher that used to come round classes with me, which really didn't help. Given what I know now...they were trying to flog a dead horse in my opinion, but you can't blame them for trying… It really wasn't a help when I had this old woman sat next to me for - when you're a teenager, self-conscious already, and this old woman's following you around every class. It didn't help. (Keith, 31, transplant aged 3)

Prolonged absences from school meant it was difficult to make or sustain friendships. When re-joining school, these participants reported being identified by their peers as the sick child, and having to work hard in trying to re-join friendship groups that had developed both their educational and social learning in their absence; as Becky, who underwent transplant aged 6 noted, 'I was like the new girl again'. Primary school was generally reported as being a more unpleasant environment than secondary school for constructing a positive embodied identity, as the corporeal marks of liver disease or transplant were more evident and participants had few resources on which to draw. A dominant theme of bullying and teasing ran through most respondents' narratives, despite not being an explicit area of our questioning. In terms of their appearance, participants reported being bullied because of their distended abdomen, appearance of teeth or hairiness, or their short stature. For very young children, not being aware of their bodily differences meant that name-calling - most commonly ‘witch’, ‘alien’, ‘freak’ and ‘weirdo’ - was only understood in retrospect by their older selves. Some participants also reported being bullied about their behaviour, for example in not having learnt to ride a bicycle because of sickness and parental concerns of injury. Of note, the transplant itself did not often appear to be the focus for bullying, most likely because other children would not have possessed any sophisticated knowledge about the procedure at this time. Only two participants, both women who had received a liver from young boys, reported bullying in this context, taunted for being ‘half boy’ or having ‘a bit of boy inside you.’

What appeared to help create and protect a ‘normal’ identity was being first known to other schoolchildren as a friend, fellow student, or healthy child, before needing time away from school or being noticed for bodily differences. In this context, friends’ reactions to, for example, the new transplant scar, were positive and influenced strongly participants’ own attitudes towards it. However, when they felt or feared being stigmatised or disadvantaged, participants reported adopting strategies to try to maintain what they believed to be a ‘normal’ social identity, most commonly by not doing anything that might mark them out as different, for example not using a wheelchair at school, or burying in the garden hearing aids prescribed for hearing loss caused by their underlying medical syndrome. However, despite their best attempts children could always be discredited, either through their scar or through the actions of a teacher, as Penny explained:

> ‘There was this one time I couldn’t take part in sport, and people were saying, ‘Why?’ And she [the teacher] had to tell them, and I was like, you didn’t need to tell them why. You could have just said I was ill or something.’ (Penny, 20, transplant aged 2)

Deliberately changing school or college in order to not be known as the child with the liver transplant – what we term ‘narrative restarts’ – was reported by some participants who had felt particularly bullied or teased. These were focused specifically around new education environments and their school peers:

> I was looking forward to going secondary school, because obviously, apart from [two friends], nobody else knew my background, my history. They didn’t know me as the witch [laughs]. (Becky, 28, transplant aged 6)

For the majority of participants who did stay in mainstream secondary education, participants reported eventually being able to frame more positively their difference as children, through a growing understanding of transplant and their own treatment and care, and by drawing attention to themselves as unique or interesting and expressing their pride at being a transplant recipient. Although many reported they continued to be treated differently, for example being given ‘special’ awards in assembly, they noted this occurred within a positive context and was not inevitably problematic. At this point, children were generally not physically jaundiced and also started to become aware of others’ differences. Reactions from peers also became more positive, interested and supportive as children grew older; for example in nicknames such as ‘liver head’ being used as a term of endearment rather than a way to bully or intimidate.

Discussion

As Fox and Swazey note (1974; 1992), transplantation opens up new ground for understanding both the relationship between medical innovation, the body and identity, and the boundaries that define social relationships. While innovative liver transplantation allowed the children to live, as it had for adults before them, it also meant that their lives were of necessity highly reflexive projects in which their childhood corporeal bodies had to be 'worked at' in a much more deliberate fashion. These children as 'future people' (Ennew 1994) had an additional problem in that they had no template on which to base their experiences and expectations. People like them had never existed before, either as children with a future or as now-adult survivors of childhood transplant. Broadly, society had little occasion to react to or interact with these children in everyday life. There was little need to formulate any social or collective identity for them other than to fit them into, or exempt them from, the activities of a standardized lifecourse as 'sick' or 'well'. Through being 'rescued' by medical innovation and long-term supervision they have become a 'new' ageing population, and although there has been much clinical follow-up demonstrating how medicine has fundamentally altered their disease trajectories, there has been very little sociological or anthropological enquiry into how these children, who had not been anticipated to have a future, understood and experienced their social world or how they constructed their childhood identities.

In the 1980s and 1990s, 'child with liver transplant' was not merely a new identity or social category, but was one that could be claimed by only a small number of children, who had no recognised group identity outside of hospital care. Being a recipient of any organ at any age was also rarer than it is today. It is noteworthy then that peer-derived norms of what it might be like growing up after liver transplantation were remarkably absent from participants' accounts, and of note, only two of our participants reported knowing an adult who had also undergone this procedure in childhood. This is in contrast to adult transplant support groups where, for example, notions of being 'normal' or 'special' can be discussed (Sharp 1995). Instead, and although passive in the context of their surgery, these children were active agents in constructing their own personal identities – in effect shaping as well as being shaped by society (Prout 2000).

The awareness of difference, as we have shown, created anxieties not only about the body but also about being accepted for who they were, and affected the nature of the identities that emerged. It is important therefore to understand how these transplant recipients connected with the social world and how far they were seen as different or stigmatised. The most obvious context was the degree to which they could be seen by others as normal, for example by meeting milestones, accomplishing lifecourse events, or being accepted by their school peers. Normal can also be seen in relation to what is usual and expected of appearance and behaviour. Here Goffman's (1963) work remains important to thinking through the way that the corporeal and the embodied interact in the lives of childhood liver transplant survivors. While Goffman was writing about stigma at a time when transplantation was still largely experimental, he did address the notion of being discredited by corporeal difference such as scarring, by not achieving educational expectations, or through the conveying of private information to others. All of these were experiences common in this group.

It is important however to go beyond Goffman to understand the connections between the corporeal body and the embodied one. In part this insight has been facilitated by those working within the disability movement (Thomas 2012) who have challenged the individual standpoint of much of Goffman's work on stigma. Within our study we have seen the reframing or transcending of stigma experienced in secondary school and its replacement with a more embodied identity; for example in adopting nicknames such as 'liver head' through their being seen as a term of acceptance rather than rejection. Similarly the idea of a 'narrative restart' can be seen as part of the process of developing a sense of self-identity where the corporeal transplant becomes less significant than the embodied identity of someone who is not reducible to their biomedical past. This is not to underplay the challenges and difficulties of this cohort of children who had to deal with all the normal challenges of growing up but with the added context that there was little knowledge, expert or lay, to help guide them or provide reassurance.

We recognise that these accounts could be seen as ‘adults’ knowledge of children’s knowledge’ (Mayall 1998a), with understandings of past identity influenced by conceptualisations of present identity and multiple layers of reflection over time. Additionally, all memory is selective, however we believe the childhood feelings and events that are remembered and retold in these narratives are likely to be significant in shaping how each participant makes sense of themselves and those around them. Of course, people who did not consent to be interviewed and those who did not survive to adulthood may have different experiences of this time, and although being a liver transplant recipient is just one identity in the context of many we believe it is a significant place to start our sociological enquiry.

Our analysis examined three settings where children were placed in clearly defined social categories and where differences were likely to be experienced in a number of ways; as a child dependent on parents, as a hospital patient, and as a schoolchild. Nevertheless, these are not mutually exclusive categories or settings and many others would have existed where identity and feeling ‘normal’ or ‘different’ were experienced. We also did not focus on gender differences or impact of gender on embodiment for this analysis. However, by considering these three settings and categories, where children could be considered as ‘doubly minor’ to parents and those who deliver social policies (Mayall 1998a), we can begin to understand identity construction in both public and private spaces; not only of transplant recipients’ identities but also their perceived identities of others.

From our analysis we provide evidence for how social environments play a vital part in shaping identity whether it is the school or the family. Here we build on James’ (1993) work in children negotiating and constructing identity at home and school, and highlight the additional importance of hospital for those with life-threatening and complex conditions. We also acknowledge Sharp’s (1995) work on how adult recipients of donor organs experience the restructuring of their identity as a complex process that develops over time, and the importance of historical time in this process (Scheper-Hughes & Lock 1987). However, as we have shown, it is also important to be aware of the difference between the corporeal and the embodied self in the negotiations of childhood identity, especially so in a context where the personality or identity of the organ donor does not appear to play a significant role. What appears salient here instead are other-world identities such as ‘witch’ or ‘alien’, based on bodily appearance and bestowed by other children.

In part, identity work necessarily moves from the corporeal to the social as a normal part of moving through adolescence to adulthood. For all children and young adults the issues connected to the body can be crucial in dealing with the contexts of what is normal and what is different; this is all the more so with those whose lives we have considered here. Normative assumptions about childhood, adolescence and early adulthood provide the backdrop to everyone else’s lives and although understandings of the importance of culture are useful in understanding responses to transplantation (Crowley-Matoka & Lock 2006; Lock & Crowley-Makota 2008), these may not necessarily apply to a pioneer cohort of childhood transplant recipients. It is important to remember that the unspoken societal assumption behind transplantation was that having saved the child they would be able to go back to a ‘normal’ life that would be relatively undifferentiated from that of their peers. However as we have shown it is crucial to understand that there is no ‘normal’ life to be resumed. In recognising this, it could be that this group might be much more than just a pioneer cohort of those who had had organ transplants. It may also be that they are living the much more contingent lives of young people interacting in a much more reflexive society where assumptions about what ageing has become are much more conditional.

Conclusion and Implications

The continuing existence and growth of new ageing populations, as well as advances in biomedicine and society, challenge an understanding of the normal within discourses of ageing and reflect a new normativity of intervention (Jones and Higgs 2010). Adult survivors of childhood liver transplantation are exposed to these different discourses of growing older. Their experiences of normality and difference in the childhood arenas of home, hospital and school shape their narratives of identity and throw light on an underexplored aspect of the relationship between medicine and society. Significantly, as these distinctions become more blurred and confused in modern society (Jones and Higgs 2010), and as medical innovations such as face and hand transplantation become more widespread, we argue that such differences become another feature of the normativity of diversity (Beck 2007), rather than being the source of division and exclusion.

Today, around 100 liver transplants are carried out each year for children in the UK. These pioneering cohorts have rarely been the subject of sociological or anthropological enquiry, for example to what extent they challenge the theory that their lives have been biographically disrupted (Bury 1982), and, if so, whether childhood organ transplantation as a biographical disruption could be seen as a unique opportunity to develop the self (Bell 2012), or whether today's young organ recipients conceptualise their identities more in context with their donor (Sharp 1995). In addition, what opportunities exist for narrative reconstruction (Williams 1984), and what sort of social conditions might support and legitimate particular identities, are also areas that need to be examined. Here we hope to set an agenda for further work in the context of these 'new' ageing populations. We believe that sociology of health and illness needs to embrace medical innovation both in the early years of life and in pioneer cohorts to understand more fully the effects on individuals and society of medically altered illness trajectories.

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Research highlights

Medical innovation has created a future of survival for many people

Paediatric liver transplant creates new understandings of embodied identity

The interplay of corporeality and embodiment affects personal identity

Children and now-adult survivors straddle discourses of being ‘normal’ and ‘different’