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# Accepted Manuscript

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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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**1 Abstract**

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

21

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

24

25

## 26 Introduction

27 Modernity, it has been widely recognised, has led to many changes in everyday social life that are far-  
28 reaching, all encompassing, and have important implications for individuals (Giddens 1990). Three of  
29 the most noteworthy changes have been the expansion of medical activity through medical innovation  
30 in a whole variety of new areas such as childhood organ transplantation; the subsequent possibility of  
31 survival from historically fatal conditions; and the transformation of the idea of identity, a concept that  
32 has both a long history and a greatly increased significance in contemporary societies (Giddens 1991;  
33 Sharp 1995; Moran 2015). Together, these changes have led to the emergence of many new groups of  
34 individuals defined or defining themselves through their bodily experiences, diagnosis, and treatment,  
35 and present new and ongoing challenges for identity as these individuals grow older.

36

37 The concept of identity has been the subject of considerable debate within the social sciences (Jenkins  
38 2014). Self-identity, a personal understanding of one's own character, situation and experiences, can  
39 be seen as ambivalent, reflective and reflexive (Lawler 2014), with underlying health conditions and  
40 their treatment being highly influential in how an individual perceives themselves. Felt identity, referring to  
41 how an individual thinks about themselves as a person in the context of their daily life, or '*who I am*'  
42 (Lawler 2014:8), has historically received little empirical attention in the sociology of health and illness,  
43 but is now emerging as an important question for recipients of medical innovations living in diverse  
44 societies. In the context of organ transplantation anthropologists have offered useful perspectives for  
45 thinking specifically about the ways that receiving a donor organ might shape personal identity. For  
46 example, a transplant recipient may adopt new attitudes, behaviours, or imagined characteristics of the  
47 donor through believing that they have been acquired through the donor's organ (Sharp 1995; Crowley-  
48 Matoka and Lock 2006). Transplant recipients may also personalise their transplanted organs and  
49 weave these understandings into their perceptions of owners or inhabitants of a newly-assembled body  
50 (Sharp 1995).

51

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

65

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

76 individual change (Dyer 2015). In the context of increasing longevity, a future of survivorship is also  
77 now emerging for recipients of organ transplant, although there is so far little published work in this  
78 area.

79  
80 To date, sociological work on health and illness and anthropological work on transplantation focus on  
81 identity and survivorship in the context of adults, not children. Furthermore, although anthropologists  
82 consider notions of culture in public and private life, there has been little work from either discipline on  
83 how specific social settings shape identities of childhood transplant recipients. In the context of shaping  
84 identity in childhood, James (1993) notes the significance of cultures, structures and settings: identities  
85 at home and school being constructed in part through negotiation with both children and adults.  
86 Broadly, home and school offer contrasting social arenas for children, based not only on the character  
87 of their relationships with adults in each setting but also on adult ideas of what children are and how  
88 they should live their childhoods (Mayall 1998a). Here we argue that hospital is an important third arena  
89 for constructing and managing the identities of children undergoing organ transplantation, through their  
90 interaction with clinicians and other patients.

91  
92 If childhood is one neglected arena in the sociology of health and illness, then so too is the role of  
93 'bodily idiom'. Social identity is not only given meaning through information shared by an individual and  
94 others, but also through information transmitted through bodily appearance and physical expression  
95 (Lawler 2014:8). Again, anthropological work has shown how embodiment is significant in defining  
96 identity and its development, as it is through our bodies that the world is experienced, with the body  
97 being both a physical and symbolic artefact, located in a particular historical time (Scheper-Hughes &  
98 Lock 1987). As we have noted, a transplant recipient's sense of self-identity may be radically altered  
99 after another person's organs are transferred to them (Sharp 1995), for example through notions of a  
100 person 'living on through another' (Crowley-Matoka & Lock 2006) or that organs are purely physical

101 commodities (Fox & Swazey, 1974, 1992; Lowton 2003). Additionally, the symbolic meaning given to  
102 an organ may also have a profound effect on the transformation of identity, for example in the heart  
103 being considered the seat of emotions (Sharp 1995).

104

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

112

### 113 **Background**

114 Although the first 'successful' adult kidney transplant took place in the late 1950s, paediatric liver  
115 transplant did not begin in the US and UK until the early 1980s (Starzl 2000; Otte 2002; Williams 2009),  
116 when immunosuppression, surgical technique and public willingness to consider children as potential  
117 organ donors allowed such transplants to be considered for children who had missing or blocked bile  
118 ducts (biliary atresia) or metabolic damage arising from rare or complex syndromes. In the UK in 1984,  
119 BBC Television's *That's Life* popular consumer programme lobbied for British paediatric liver  
120 transplants to commence through the entreaties of Debbie Hardwick, mother of two-year-old Ben. Ben  
121 subsequently became the UK's first recipient, but died just over one year later following a second liver  
122 transplant. His surgeon, Professor Roy Calne, had been instrumental in developing the  
123 immunosuppressant cyclosporine to prevent rejection of donor organs (Starzl 2000), thus enabling  
124 transplant to be perceived as a treatment rather than an experimental procedure. At this point children  
125 could still be conceptualised as a biological 'project' of the transplant surgeons who were concerned



126 with repairing a non-functioning body. The focus was on rescuing the child and on surgical success,  
127 with the transplant programme placing children in a passive position relative to medical intervention and  
128 parental consent. Yet in the early years of the transplant programme not only were there no long-term  
129 survival data, there was also no knowledge of the life the child would be able to lead or, if they survived,  
130 what they might grow up to become, as the excerpt from *That's Life*, transmitted after Ben's first  
131 transplant, illustrates:

132

133 *Esther Rantzen*: Professor Calne says that Ben's chances of living a year now are 70 per cent.

134 *Debbie Hardwick*: That is lovely. But I can't let myself relax, because I can't be knocked over again.

135 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  
136 relax now, because I couldn't take that sudden knock once again.

137 *Esther*: How soon do you think it will be before you dare think of the future?

138 *Debbie*: I don't know. When he goes home I suppose. I do have a sneaky view of it sometimes. I think  
139 that maybe he will go to school someday, and that sort of thing. But I try not to.

140 (Rantzen & Woodward 1985:125)

141

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

150 potentially enabled this early patient group to survive into young adulthood and beyond, albeit with an  
151 unknown and uncharted future ahead of them.

152

153 In terms of appearance, children in liver failure are most notably jaundiced with yellow skin and eyes,  
154 may have a swollen abdomen, or may have excess hair and overgrown gums as side effects of  
155 treatment. In the first decades of the paediatric liver transplant operation, the typical surgical incision  
156 (and subsequent scar) was an inverted 'Y' that crossed the abdomen just under the ribs, referred to as  
157 a 'Mercedes' incision after the manufacturer's distinctive marque. These children therefore not only had  
158 chronic illness but also new corporeal markers of bodily difference that could be hidden or displayed  
159 and commented on by others, or play a semiotic role. Hence both the corporeal and embodied nature  
160 of identity has consequences both for the understanding of normalcy or difference and for a person's  
161 feelings of inner worth (Shilling 1993; Sharp 1995; Kaiser 2008). Significantly, as Gilleard and Higgs  
162 (2014) point out, it is important to be aware that the corporeal is often that which is seen as private  
163 while the embodied is seen as that which is social and out in the world. The capacity of the disability  
164 movement to move the issues resulting from the effects of disablement to the public sphere can be  
165 seen as an example of the value of this distinction (Thomas 2012). The way the body is represented  
166 and the contexts in which it is either publically or privately located signifies what type of a person is  
167 present; the body itself being used to generate meaning in a number of complex ways:

168

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

174

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

188  
189 Bringing together discourses surrounding organ transplant, survivorship, the body and notions of  
190 identity we can see that the construction of identity in the context of what, for others, was a life  
191 extension and an unanticipated survivorship sheds light on both biomedicine and on identity. For this  
192 group the impact of their health condition is central to both individual and social concepts of self from  
193 early life. Adult survivors of childhood liver transplantation have had to continually negotiate the  
194 expectations of social and biological normality that rarely include living with the long-term  
195 consequences of transplantation, both in terms of the pharmaceutical regime and the physiological  
196 consequences of growing up post-operatively. Moreover there are emotional and psychological issues  
197 connected to the life/death nature of survivorship, as 'normal' before transplant could only have led to  
198 childhood death as the natural outcome of the liver condition.

199

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

211

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

221

## 222 **Methods**

223 *Data collection*

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

239

#### 240 *Data analysis*

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

249 disclosure of transplant status to others, or on romantic relationships or employment, which were  
250 generally reported when recipients were adult.

251

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

260

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

267

268 We interviewed twenty-seven now-adult survivors: 16 women and 11 men. Eighteen participants had  
269 had one liver transplant, eight had required two and one participant had had three at the time of  
270 interview. Aged 19-36 years (median 27), they were 6 months-13 years (median 6 years) old when they  
271 underwent their first transplant. At time of interview, survival since first transplant ranged from 15-28  
272 years (median 22 years). Early hospital data for the cohort is patchy, as many pioneer recipients have  
273 been lost to follow-up, although from discussion with clinicians we believe we interviewed around half of

274 the 1984-1994 surviving UK cohort; around 60 were known to fit our criteria at the time of recruitment.  
275 Interviews took place most commonly in participants' homes and lasted on average 82 minutes (range  
276 20-163 minutes). Around half reported biliary atresia as the reason for transplant, with the remainder  
277 reporting a range of rare or complex syndromes; this broadly reflects current indications for needing  
278 liver transplant in childhood. From their interviews, 12 participants stated they were completely unaware  
279 of their need for surgery at the time of their first or only transplant; this group received a donor organ  
280 before they were five years old. Sixteen participants, who had received a transplant aged between 5-13  
281 years, could remember events connected to at least one of their transplants, for example being spoken  
282 to by a surgeon or a long stay in hospital. Only one participant fitted into both groups, having received  
283 transplants aged 2 and 9 years old. All continued to attend regular outpatient appointments at specialist  
284 liver clinics and all reported co-morbidities that had developed after transplant including epilepsy and  
285 brittle bones. At interview, 18 participants reported being in employment or further/higher education.  
286 Two had become wheelchair users as adults.

287

## 288 **Findings**

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

294

### 295 **Conceptualising identity in early childhood**

296 Participants recounted that in early childhood they had formed few reference points of what was  
297 'healthy' or indeed that they were, or were soon going to be, the recipient of a donor organ. In these

298 early years, before being able to conceptualise, articulate, or compare health and illness experiences  
299 with peers, participants reported thinking it was 'normal' for people to be unwell, to visit the doctor  
300 regularly and be admitted to hospital, and to have regular blood tests and other investigations. They did  
301 not understand where the boundaries of 'health' and 'illness' might lie, or that their bodies might appear  
302 different to those of other children. When very young they did not conceptualise themselves as an 'ill  
303 child', nor, when they were slightly older, understand how serious their illness was:

304

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

310

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

320

321 Although details of donors are kept confidential, by their teenage years most participants knew at least  
322 the gender of their donor and, for some, the circumstances of their death. However, the extent to which



323 those who had had a transplant before their teenage years understood themselves to be a recipient of  
324 a donor organ was variable. For example, Helen, aged 34 at interview, recalled understanding at age  
325 10 that she needed a new liver, but not that it would come from another person. Similarly, those who  
326 had grown up from a very young age with surgical scars, either from a Kasai or transplant operation,  
327 conceptualised these corporeal markers as 'just part of me.' The ambiguity of normality in the context of  
328 health and illness, having little idea of the transplant procedure and that another person's organ would  
329 be transferred to them, and the scar being a constant part of their body, meant that for those who  
330 received a transplant as a young child there was no 'before and after' in conceptualising who they were,  
331 for example in integrating a donor's identity into their own.

332

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

340

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

347

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

350

### 351 **Shaping identities in public and private spaces**

#### 352 *Home*

353 At home, parents appeared to shape their child's identity through controlling tightly a daily medical  
354 regime focused on the concept of 'body as machine' (Stainton-Rogers 1991), celebrating their survival  
355 as a transplant recipient, yet at the same time socialising their child as a 'normal' child, albeit one who  
356 had a serious illness. Parents' accounts and photographs were drawn upon in all participants' stories of  
357 their childhood, these being reported to have helped construct and fill gaps in their early memories.  
358 Many of these accounts appeared to have been used to tell participants' childhood selves about who  
359 they were and what medical interventions they had undergone, thus becoming a very early part of their  
360 identity. Here, rather than wider stories of the transplant process, their corporeal childhood body was  
361 made central, through stories of procedures performed upon it and photographs taken of it in hospital.  
362 Additionally, newspaper articles reporting their stories and scrapbooks made by their parents were  
363 important in telling the story (both to themselves and others) of who they were:

364

365 I remember my mum showing me videos of when I was on TV on local programmes.

366 And my mum's got four ring-bound scrapbooks of paper clippings and magazine

367 clippings and stuff, of when I was in the paper and that, pre- and post-op

368 [transplant]. (Edward, aged 28, transplant aged 2)

369

370 Parents were reported to act as case managers, delivering ongoing care and having oversight of  
371 hospital appointments; if not possessing medical expertise, then at least following closely the medical  
372 direction for their child (Craig and Higgs 2012). As one participant recalled, her reaction to her mother

373 telling her she needed a liver transplant aged 9 was: 'If my mum told me, then that was that.' Many  
374 participants spoke about not understanding until adulthood how seriously ill they had been as children  
375 and the trauma that their parents had experienced. Indeed, the uncertainty over their future that their  
376 parents would have been managing at that time was spoken of in only one account:

377

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

381

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

387

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

394

395 Home was most often recalled as a safe, private, 'backstage' environment where bodily differences and  
396 treatment could become a normal difference or a domesticated idea of 'normal for me'. One illustration  
397 of how their donor organ had shaped their identity here was shared by many participants, not through

398 any notions of inheriting the donor's characteristics, but in the way that their parents and close friends  
399 and family celebrated their transplant and survival akin to an anniversary or extra birthday, seen also in  
400 North American adult recipients (Sharp 1995):

401

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

406

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

412

### 413 **Hospital**

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

422

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

432

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

437

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

446

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

455  
456 In the context of other young liver unit patients, the most common recollection was of forming deep  
457 friendships while inpatients. However, these friendships were rarely continued outside the hospital,  
458 possibly because children would have been referred nationally or parents were too busy with their  
459 treatment to arrange meetings. Participants also reported hospital friends as being much sicker,  
460 needing more liver transplants, or dying through complications of surgery or what they later learned to  
461 be a lack of donor organs.

462  
463 Recalling being in hospital with a group of five children with liver problems, David, now aged 22,  
464 reported being the only one who 'made it' to adulthood. David described his mainstream school  
465 experience as 'extremely difficult' through his felt difference to other students. As a result of feeling  
466 settled in hospital school during an admission aged 11, and finding it 'too hard' to return subsequently  
467 to mainstream school, he reported moving to a school for children with special needs, where, through  
468 everyone's difference, his confidence grew and he created for himself a new normality (Jones and  
469 Higgs 2010):

470

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

479

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

482

### 483 **School**

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

495

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

498

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

505

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

512

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

520



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

527

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

536

537 Prolonged absences from school meant it was difficult to make or sustain friendships. When re-joining  
538 school, these participants reported being identified by their peers as the sick child, and having to work  
539 hard in trying to re-join friendship groups that had developed both their educational and social learning  
540 in their absence; as Becky, who underwent transplant aged 6 noted, 'I was like the new girl again'.  
541 Primary school was generally reported as being a more unpleasant environment than secondary school  
542 for constructing a positive embodied identity, as the corporeal marks of liver disease or transplant were  
543 more evident and participants had few resources on which to draw. A dominant theme of bullying and  
544 teasing ran through most respondents' narratives, despite not being an explicit area of our questioning.  
545 In terms of their appearance, participants reported being bullied because of their distended abdomen,

546 appearance of teeth or hairiness, or their short stature. For very young children, not being aware of  
547 their bodily differences meant that name-calling - most commonly 'witch', 'alien', 'freak' and 'weirdo' -  
548 was only understood in retrospect by their older selves. Some participants also reported being bullied  
549 about their behaviour, for example in not having learnt to ride a bicycle because of sickness and  
550 parental concerns of injury. Of note, the transplant itself did not often appear to be the focus for  
551 bullying, most likely because other children would not have possessed any sophisticated knowledge  
552 about the procedure at this time. Only two participants, both women who had received a liver from  
553 young boys, reported bullying in this context, taunted for being 'half boy' or having 'a bit of boy inside  
554 you.'

555

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

566

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

571

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

575

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

579

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

590

## 591 Discussion

592 As Fox and Swazey note (1974; 1992), transplantation opens up new ground for understanding both  
593 the relationship between medical innovation, the body and identity, and the boundaries that define  
594 social relationships. While innovative liver transplantation allowed the children to live, as it had for  
595 adults before them, it also meant that their lives were of necessity highly reflexive projects in which their

596 childhood corporeal bodies had to be 'worked at' in a much more deliberate fashion. These children as  
597 'future people' (Ennew 1994) had an additional problem in that they had no template on which to base  
598 their experiences and expectations. People like them had never existed before, either as children with a  
599 future or as now-adult survivors of childhood transplant. Broadly, society had little occasion to react to  
600 or interact with these children in everyday life. There was little need to formulate any social or collective  
601 identity for them other than to fit them into, or exempt them from, the activities of a standardized  
602 lifecourse as 'sick' or 'well'. Through being 'rescued' by medical innovation and long-term supervision  
603 they have become a 'new' ageing population, and although there has been much clinical follow-up  
604 demonstrating how medicine has fundamentally altered their disease trajectories, there has been very  
605 little sociological or anthropological enquiry into how these children, who had not been anticipated to  
606 have a future, understood and experienced their social world or how they constructed their childhood  
607 identities.

608  
609 In the 1980s and 1990s, 'child with liver transplant' was not merely a new identity or social category, but  
610 was one that could be claimed by only a small number of children, who had no recognised group  
611 identity outside of hospital care. Being a recipient of any organ at any age was also rarer than it is  
612 today. It is noteworthy then that peer-derived norms of what it might be like growing up after liver  
613 transplantation were remarkably absent from participants' accounts, and of note, only two of our  
614 participants reported knowing an adult who had also undergone this procedure in childhood. This is in  
615 contrast to adult transplant support groups where, for example, notions of being 'normal' or 'special' can  
616 be discussed (Sharp 1995). Instead, and although passive in the context of their surgery, these children  
617 were active agents in constructing their own personal identities – in effect shaping as well as being  
618 shaped by society (Prout 2000).

619

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

632  
633 It is important however to go beyond Goffman to understand the connections between the corporeal  
634 body and the embodied one. In part this insight has been facilitated by those working within the  
635 disability movement (Thomas 2012) who have challenged the individual standpoint of much of  
636 Goffman's work on stigma. Within our study we have seen the reframing or transcending of stigma  
637 experienced in secondary school and its replacement with a more embodied identity; for example in  
638 adopting nicknames such as 'liver head' through their being seen as a term of acceptance rather than  
639 rejection. Similarly the idea of a 'narrative restart' can be seen as part of the process of developing a  
640 sense of self-identity where the corporeal transplant becomes less significant than the embodied  
641 identity of someone who is not reducible to their biomedical past. This is not to underplay the  
642 challenges and difficulties of this cohort of children who had to deal with all the normal challenges of  
643 growing up but with the added context that there was little knowledge, expert or lay, to help guide them  
644 or provide reassurance.

645

646 We recognise that these accounts could be seen as ‘adults’ knowledge of children’s knowledge’ (Mayall  
647 1998a), with understandings of past identity influenced by conceptualisations of present identity and  
648 multiple layers of reflection over time. Additionally, all memory is selective, however we believe the  
649 childhood feelings and events that are remembered and retold in these narratives are likely to be  
650 significant in shaping how each participant makes sense of themselves and those around them. Of  
651 course, people who did not consent to be interviewed and those who did not survive to adulthood may  
652 have different experiences of this time, and although being a liver transplant recipient is just one identity  
653 in the context of many we believe it is a significant place to start our sociological enquiry.

654

655 Our analysis examined three settings where children were placed in clearly defined social categories  
656 and where differences were likely to be experienced in a number of ways; as a child dependent on  
657 parents, as a hospital patient, and as a schoolchild. Nevertheless, these are not mutually exclusive  
658 categories or settings and many others would have existed where identity and feeling ‘normal’ or  
659 ‘different’ were experienced. We also did not focus on gender differences or impact of gender on  
660 embodiment for this analysis. However, by considering these three settings and categories, where  
661 children could be considered as ‘doubly minor’ to parents and those who deliver social policies (Mayall  
662 1998a), we can begin to understand identity construction in both public and private spaces; not only of  
663 transplant recipients’ identities but also their perceived identities of others.

664

665 From our analysis we provide evidence for how social environments play a vital part in shaping identity  
666 whether it is the school or the family. Here we build on James’ (1993) work in children negotiating and  
667 constructing identity at home and school, and highlight the additional importance of hospital for those  
668 with life-threatening and complex conditions. We also acknowledge Sharp’s (1995) work on how adult  
669 recipients of donor organs experience the restructuring of their identity as a complex process that

670 develops over time, and the importance of historical time in this process (Scheper-Hughes & Lock  
671 1987). However, as we have shown, it is also important to be aware of the difference between the  
672 corporeal and the embodied self in the negotiations of childhood identity, especially so in a context  
673 where the personality or identity of the organ donor does not appear to play a significant role. What  
674 appears salient here instead are other-world identities such as 'witch' or 'alien', based on bodily  
675 appearance and bestowed by other children.

676

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

692

## 693 **Conclusion and Implications**

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

704

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

716



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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'