Understanding the role of scars in adults' narratives of childhood liver transplantation: a sociological perspective

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Abstract

For sociological and anthropological scholars alike, the body is both a physical and social entity as well as a project to be worked on by the self and by others (Tamari, 2020). However, scholars’ conceptual work in organ transplantation and the body has tended to overlook the resultant surgical scars, yet these are borne by all transplantation recipients. For example, in understanding biomedicine’s intervention in the body through the skin Shildrick (2008) uses the term ‘corporeal cut’ conceptually rather than focus on the flesh that is cut and the scar that subsequently forms. In this way body flesh has become abstract; cut but unmarked, with transplantation scars being an ‘absent presence’ in these disciplines’ thinking. In this paper we attempt to develop a more nuanced understanding of how organ transplantation shapes both the corporeality of the body and the embodiment of the self through considering the concept of a transplant scar in three ways. First, through transplantation scars' dynamic physical appearance across their lifecourse and their symbolic meaning for their bearer. Second, how scars’ coded messages are framed for ‘stranger’ audiences in the context of their little experience of organ transplantation; and third, through the scars’ display and storytelling in the context of more intimate relationships.

Interview data from 27 adult survivors of childhood liver transplantation, who bear either ‘Lexus’ or ‘Mercedes’ transplantation scars, are drawn upon to illustrate these concepts. Awareness of the meanings associated with the scar as well as others’ reactions, imputed or not, to the physicality of the scar point to the significance of the body as a corporeal marker of personal narratives and negotiations. It also indicates the polysemic nature of the scarring and the way in which inventive narratives can play a positive as well as negative role in the lives of organ transplant recipients.

Key Words

Scar, surgery, organ transplantation, embodiment, qualitative, signs, audience, UK
Introduction

The use of the word ‘scar’ is widespread in sociology but rarely refers to its physical presence on individual bodies. ‘Scarring’ is used as a metaphor to describe the negative impacts of historical events or processes which leave their impact on the lives of individuals (see for example Bell, Bindler, & Machin, 2018; Fervers, 2021). Where scars are understood as being physically present instead of being discursive devices, they are studied in terms of their role in promoting narratives of identity (see for example Weitz, 2011) rather than as issues of embodiment. We argue that this has led to an absence in sociological accounts of this important aspect of lived experience; particularly for those whose scars result from medical procedures. The proportion of people who bear scars is impossible to know, but by adulthood most people have some skin scarring, whether through accidental injury, self-direction (e.g. body modification or self-harm) or (un)planned surgical incision. We wish to concentrate on this latter area. Large surgical scars are commonly perceived as ‘unsightly’, with clinicians seeking to make incisions (and therefore the subsequent scars) as small as possible, and if able, positioning them out of sight, for example in taking a skin graft from the upper thigh. Once formed, scars can be cosmetically revised but at the time of writing cannot not be erased. An ever-increasing biomedical reach coupled with historically improved surgical survival rates suggest that even if the size of a surgical incision can be reduced through biomedical advances, for example keyhole surgery, more people are living with scars, including the relatively large scars following organ transplantation.

Research on surgical scars is broadly located in medically- and psychologically-informed reductionist approaches which posit the scar as potentially problematic and work towards ‘fixing the problem’, covering issues such as visibility and psychosocial distress (e.g. Brown et al, 2010); quality of life (e.g. Brown et al, 2008); and effects on body image and self-esteem (e.g. Zimbrean, 2015). Using surveys and rating scales to measure a single point in time relatively soon after scar formation, these largely quantitative studies fail to capture fully the personal and social meanings and impact of scars over the lifecourse, although they do acknowledge that the bearer’s
interpretation of the scarring may often differ from that of clinicians (e.g. Brown et al 2010), and objective assessment (e.g. Powers et al, 1999).

While clinical management may address patients' cosmetic appearance and psychological adjustment, scars following surgical procedures have wider significance outside medical appraisal. Being one of the largest possible surgical scars, childhood liver transplantation scars present a noteworthy case example given that the scarring not only represents a physiological surface phenomenon but also potentially reveals the organ transplant underlying the surgery. Transplantation is usually performed with parental consent for surgery, with bearers growing up in societies increasingly focused on perfecting the body’s appearance. This paper therefore presents a sociological understanding of organ transplantation scars and draws on a study researching the experiences of adults who had undergone liver transplantation in the UK as children. As part of our study, we sought to understand how recipients conceptualised the physical scar; its meaning; and its display to others, both materially and in the stories about it that its bearer told.

The term for the standard incision for liver transplant was coined by Sir Roy Calne, its pioneer, as the ‘Mercedes’ incision (Llado & Figueras, 2004); extending right across the upper abdomen and up to the sternum it resembles the German car manufacturer’s iconic marque. A later inverted J-shaped incision, named for its creator Masatoshi Makuuchi, has a double meaning. Alongside its reference to the surgeon, Makuuchi translates literally as ‘behind the curtain’, referring to a private waiting area in early sumo wrestling for the most highly-ranked contestants. UK clinicians extending the marque analogy commonly refer to it as a ‘Lexus’ incision; together, the Mercedes and Lexus incisions reference the marques of two distinctive and prestigious motor cars, noted for their superior engineering. These resulting scars remain a significant size across the torso on the bodies of those operated on and usually appear together with additional scars, for example those caused by intravenous lines, drains, and other surgical interventions.
In developing our approach, we draw on anonymised in-depth interview data from a study of now-adult childhood liver transplant recipients in the UK (Lowton et al, 2017). We sampled from children who underwent surgery in the first decade of this transplant programme (1984–1994) at Addenbrooke's hospital, Cambridge, and King's College Hospital, London. 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 with a transplant and who had not reached adolescence at the time of their surgery. Twenty-seven recipients (16 women and 11 men) participated, representing about half the cohort now living as adults. 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 at interview (median 27), they were 6 months-13 years (median 6 years) at first transplant. At time of interview, survival since first transplant ranged from 15-28 years (median 22). This cohort, a pioneer generation, has had no cultural tradition to draw upon in disclosing their scars or status as liver transplant recipients and as such during their interviews they variously reported their scars as being wilfully displayed or carefully covered; this occurred both within and across participants’ accounts of their lives post-surgery. The interviewers did not ask to see participants’ scars although were spontaneously invited to do so by many. Four recipients reported remaining unclear about the underlying condition that required them to undergo liver transplantation, with others having learned about their diagnoses as adults. As a small, ‘rare’ group of people, we protect their anonymity by assigning new pseudonyms, detailing interview age by decade and the age when liver transplants were received by 5- or 10-year age bands.

**Background**

Sociological and anthropological understandings of the body and embodiment are complex, encompassing a broad range of perspectives and interpretations. In the context of our work, a useful conceptualisation of the body is as both a physical and social entity (e.g. Scheper-Hughes & Lock, 1987; Shilling, 2003; Tamari 2020), with a continual exchange of meaning between the two kinds of bodily experience so that each reinforces the other. In a similar vein, this dualism is reflected by the body being conceptualised as both a ‘natural’ biological or material object while also being subject to social change, constructed by and constitutive of social relationships and
understandings of the body as products of economics, politics and historically developed cultural factors (Shilling, 2003). Further still, the body has been conceptualised as a site of lived experience and embodied agency, giving rise to notions of corporeality and embodiment (Gilleard & Higgs, 2014; Williams & Bendelow, 1998), with the onset of disorder or disease bringing a new body awareness, or its ‘absent presence’ (Leder, 1990). The body can also be conceived as a subject, object, or project to be worked on, such that biomedicine renders the body as a machine (Stainton-Rogers, 1991) or an ‘assembly of parts that may be arranged or transformed at will’ (Shildrick, 2008:34), with more recent work in this corpus of theoretical development of the body focusing on body modification (see for example Lane, 2017) and prostheses (see for example Tamari, 2017). With regard to the skin, anthropology has a long tradition of understanding it as a surface region upon which marks and symbols of culture and social structure are inscribed through ritual and scarification (Williams & Bendelow, 1998). In this way the inscribed body acts as a marker of identity in terms of gender, age, and political status (Schildkrout, 2004); processes that are also found in contemporary society (Crossley, 2005: Featherstone, 1999; Pitts 2003; Turner, 1999).

Conceptualising the body in the context of organ transplantation, work has centred around the displacement and transferral of internal organs, for example by considering the commodification of body parts (Sharp, 2000) and transfer of the donor’s personality alongside the organ (Sharp, 1995; Shildrick 2008; Youngner, 1996). Debates around two of the most significant concepts in transplantation, that organs are interchangeable ‘spare parts’ (Fox & Swazey, 1992) and that their donation is a ‘gift of life’ (Siminoff & Chillag, 1999), both focus on what is given (a donor organ) and what is replaced (a failed organ). In this work, aside from more recent face and hand transplantation, both are imagined: only those inside the operating theatre see removed and transplanted solid organs such as the human heart or liver (Young, 1997), and of course none can see the spirit of the donor, or the ‘gift of life’ itself. Social reminders of the transplanted organ, for example letters to a donor’s family or annual memorial services, keep the issue in the recipient’s mind (Poole et al, 2011; Shildrick, 2008), but transplantation scarring might also be considered a material form of reminding. Scars of all solid organ transplantations (heart,
lung, liver, and kidney) are confined to the torso, where bearers will see them daily, yet they will be to a large extent free to decide whether to conceal or disclose them, or to discuss them with various audiences. It is a surprising omission therefore that conceptual work has for the most part overlooked the resultant surgical scars of transplantation; their appearance, meanings and stories told about them across the bearer’s lifecourse.

Shildrick’s (2008) work is especially relevant here. She uses ‘corporeal cut’ in two ways: to denote bodies being increasingly bounded through their isolation from other bodies; and as a constructive act of biomedical intervention into the body through the skin, its boundary breached as it is treated, reorganised, and (re)normalised. In the context of biomedical intervention Shildrick suggests that it is ‘the end result of therapeutic cutting that we want to see, and not the process itself’ (2008:41, our emphasis), the ‘end result’ referring to the functioning body post-transplantation rather than the scarred skin. Here we suggest the ‘corporeal cut’ can also be understood in a third way, by focusing on the surgically-incised flesh and the scar that forms subsequently.

Anthropological work about general surgery scars also provides useful insights for thinking about the subject. Young’s (1997) ethnographic study of surgical interventions develops Shildrick’s notions of reorganising and (re)normalising the body through focusing additionally on the act of surgery in the context of scars and scarring:

‘Scars are the body tracks of the surgeon on the patient, the trail of one body’s passage across and into the terrain of another. They inscribe the body into the discourse of medicine, not effacing but adumbrating its instantiation as a social body. Surgery as a discourse overwrites the body’s inscription as a cultural text. Both inscriptions materialise as characters of a script into which we read personhood. So bodily inscriptions affect our deciphering of signs of presence in the flesh.’ (p86)
Surgical scars therefore signal to a body that remains accessible to re-modification (in liver transplantation one that is ‘behind the curtain’), yet are also reminders of previous biomedical intervention, evidence of which can be made public through bodily display. As markers of survival, they proclaim the body’s vulnerability, yet also its recovery, resilience and endurance (Weitz, 2011). Scars also provide ‘topics’ of the body’s history, with stories about them revealing how bearers view the past in their present (Burnett & Holmes, 2001); accidental scars frame the body in historical and heritage terms as something to value and be custodian of, with a moral duty to do so – in this context, that one must be vigilant to protect one’s body from adversity (Burnett & Holmes, 2001). These embodied stories then convey physical, social and moral body histories, locating a person in time and space and in their personal relationships although not necessarily focusing on illness (Frank, 1995). More broadly, these social stories ground us in everyday life, often providing us with coherence and meaning (Plummer, 2013).

However, memories of the processes and meaningful interpretations of past events are selective; we cannot command every detail of events leading to scarring (Burnett & Holmes, 2001) and in childhood transplantation, as for now-adult liver transplantation recipients, bearers may not be aware of the biomedical reasons for interventions that led to their scars. Each scar story then is a representation; narrators turning first to culturally available frames to construct new narratives about their identity yet also challenging or broadening these frames, for example by telling fantastical stories (Weitz, 2011). Put another way, ‘scars are sites of the struggle between making sense of what is real or mythic in one’s past and indeed one’s present’ (Burnett & Holmes, 2001:21).

The scar itself can also communicate a story, as a signal or code that connects with the audience’s own understanding of the world. Hall’s (1980) work on encoding/decoding is useful here: that in order for any symbol to be fully and properly interpreted the audience must first be able to recognise it and understand what it symbolises. The reception, interpretation, and use/response of the scar’s image will depend on what the viewer is familiar with, and the cultural references and associations that they make. Turner (1999) usefully distinguishes
here between different types of viewers of bodies: thick/hot memberships, largely now historic in Western societies, share obligatory body markings whose meanings and understandings are commonly understood; thin/cool social relationships reflect the growing individualism in contemporary society where reading of individualised body marks neither requires nor encourages engagement with their bearers.

Taking Glancy’s (2004) theological interrogation of St Paul’s boast of how his scarred torso resulted “from Gentile stones and from Jewish whips” (2 Cor 11:24-25) illustrates how scars are positioned and understood by audiences. First, how the scar’s bodily location might itself convey a story of the reason for the scar; second, how the shape of the scar might offer further cues for interpreting what caused it; third, how culturally available frames might underpin audience interpretations of the scar bearer’s moral worth or social position; and fourth, how the bearer might tell stories about their scars to influence a different interpretation, overriding the cultural cues given by the scars’ shape or bodily location and the culturally normative frames. Together these factors act to situate, explain and contest the cause and meaning of scars to their audiences. In the context of Paul, Glancy observes:

The legibility of an individual body is contingent on social bodies, particularly on the socially inscribed body that is the object of the gaze and the socialized eyes of the one who gazes’ (p100)

... Ancient audiences distinguished between the mark of a sword slashing a courageous breast and the mark of a sword slashing a cowardly back. They distinguished even more sharply between the martial tracing left by a sword and the servile tracing left by a whip or a rod. (p107)

As Glancy points out, audiences of the time would find it difficult to read Paul’s scarred body as either bearing ‘badges of valor’ or ‘marks of dishonor’. Glancy’s insights help our thinking about the recognition, interpretation, and stories told about scars from innovative yet rare surgical procedures with which contemporary audiences – and indeed the scars’ bearer – may not be familiar.
From this brief overview we can see how scarring left by transplantation operations exists at a number of social, cultural and individual levels, all interplaying but not offering a satisfactory explanatory focus if treated in isolation. These multiple and polysemous dimensions are illustrated in the accounts of those bearing the marks of the surgical scar discussed below.

**Findings**

*The physical scar*

Transplantation scars have a dynamic and often unique physical trajectory: the surgical incision leads to scar formation, yet this rarely occurs in a uniform way. Most organ transplant recipients also bear additional scars from surgical tubes and drains, and many have scars from previous or subsequent operations. For those who had surgery before they were conscious of it (generally before 5 years old), the scar could be conceptualised as “just a part of me” (Bessie, teenager, 2 transplants aged 0-9 years), subsumed into the body and compared to other more ‘natural’ body marks across the lifecourse such as birthmarks or stretchmarks. However, this is not to suggest that all those scarred in infancy felt the same way about their scars as they grew older.

For those old enough or well enough to understand that they required surgery, the liver transplantation scar began life as an imagined concept, with clinicians using a doll with a zipper to illustrate to children what their incision would look like. For this first childhood liver transplantation cohort the procedure was so new that there were very few recipients with existing scars to show those who were waiting for transplantation. Some, now-adults, had been asked by doctors to talk to people waiting for transplantation and as part of that discussion might show their scar as a form of experiential knowledge. However, recipients observed differences between the appearance of the imagined and actual scar:
Everybody gets [shown] the doll with the scar and the tubes go here, and tubes go there, [indicates] and I’m [looking at my body post-surgery] thinking ‘that’s not right’. (Lucy, 30s, 1 transplant aged 10-14)

I don’t know if it was the surgeon or someone else, telling me that I’d have a scar, like a Mercedes badge sign, straight down with the two forks. Didn’t work out like that... it’s maybe more of an L shape I think, ’cause it comes across to almost this side [indicates a Lexus shape] (Joshua, 30s, 1 transplant aged 10-14)

Depending on the point reached in their lifecourse, the scar became more or less salient, more or less ‘part of me’, more or less ‘liked’ in the context of body image, but it was seldom a fixed entity. Attitudes and relationships towards the scar changed, as its physical appearance changed, and as its bearer grew older, often with reflection back to their younger self’s hyper-critical attitudes to their body’s appearance, with the physical scar seen as a measure of their social desirability. Other scars were also of a significant size; for example a Kasai scar, formed after the surgery to remove blocked bile ducts, conducted in order to slow the progression of liver damage, runs across the top of the abdomen. During further surgeries or pregnancy, the appearance and physical sensitivities of these scars changed, as were attitudes towards them, even when they had ‘faded’:

My initial one [a Kasai scar] was very faded, ’cause I’d had that ten years by then. The second [a transplant scar] was very red, very, very bright red, and I couldn’t get the sun on it. I’d say it was quite sort of raw. But that generally faded. I didn’t mind it so much then. Later, I didn’t like it [laughs]. (Natalie, 20s, 1 transplant aged 5-9)
The symbolic meaning of the scar

In talking about what their scar signified or meant to them, bearers’ accounts conveyed much more complex ideas than when thinking about its physical appearance, with quite contradictory meanings recounted within and between participants. ‘Mercedes’ and ‘Lexus’ were terms used only in the context of relaying clinical consultation conversations. Recipients with complex underlying conditions requiring more than one surgical procedure tended to describe their scars or abdomen in quite violent terms, drawing on ideas of conflict and battles fought, yet with a certain degree of ambivalence and acceptance – ‘it is what it is’:

It’s like a battleship. (Fiona, 30s, 1 transplant aged 5-9)

It’s a scar. It’s a war story, if you like. A war wound. (Nick, 20s, 2 transplants aged 0-4)

With every biopsy I have and whatever stuff gets added to it, yeah, my stomach looks like a war zone, but you know there’s nothing – it is what it is. (Lucy, 30s 1 transplant aged 10-14)

Of note, the scar’s significance to its bearer was commonly expressed using synecdoche – figuratively using the scar, the only visible part of the entire procedure, to refer to the whole transplantation process and especially its outcome:

My scar doesn't bother me because that saved my life. (Orla, 30s, 2 transplants aged 10-14 and 30-34)

Here, in making sense for themselves of what had happened, the scar became an acknowledgement of what recipients and their donors had experienced through liver transplantation, and a material reminder of how close the recipients themselves had been to death. The scar was understood as a physical mark of respect to the donor
who had given them the ‘gift of life’ (Siminoff & Chillag, 1999), and following Shildrick (2008), it is possible that modification through revision might risk transformation of both the recipient’s personality and identity. During their interviews, some recipients reflected on the possibility of cosmetic revision, extending ideas of their body as a biomedical project to ones familiar to researchers of body modification and cosmetic surgery (Crossley 2005; Elliott 2008; Pitts 2003). Developmentally and/or legally unable to give their consent for transplantation in their early childhood, now-adults could seek and consent to their scars’ revision, yet three influences appeared consistently to challenge this. First was the scars’ figurative link to the donor, as shown above; seeking surgical revision to improve its appearance was understood as showing disrespect to the donor and their family:

I didn’t need cosmetic surgery. It’s not something I want to hide. It’s something that cost a lot of blood, sweat and tears for quite a few people, so I don’t want to cover it up and just forget about it. I suppose it’s a reminder in a way. (George, 30s, 1 transplant aged 0-4)

If I was ashamed of it, you know my mum gave me [part of] her liver. It’s kind of ungrateful. And with my second [transplant], I don’t know much about the family obviously, but I know that a little boy died in a car crash - I believe. I may be wrong. But I know that someone somewhere has had a heart-breaking experience and I’ve benefitted from that in a huge way. And I think to be kind of too distraught about [the scars] would be to kind of disrespect that in a way, I guess. (Bessie, teenager, 2 transplants aged 0-9)

Second was the notion, influenced by regular stories in mainstream media, of cosmetic procedures such as ‘tummy tucks’ and liposuction (and by extension revision of scars) being vanity surgery for an undeserving group of patients and thus an unreasonable request for limited NHS resources (Gimlin, 2010). Inconsistent and unclear clinical decision guidelines regarding what cosmetic surgery could be provided through the NHS (Cook et al, 2003) may also have added to recipients’ reluctance to seek revision as a ‘deserving’ case. Very occasionally however,
clinicians themselves raised revising the scars' unsightly appearance. When offered to Fiona, she embraced their revision:

When I was in Year 11 at school – I was 15 – they said to me, “Would you like, do you want your scar neated up? ’Cause let’s be honest, it is a bit of a mess. And then we could also do a bit of liposuction to tighten it up”. I said, “Oh my God! Liposuction. Yeah, go for it! Do it! [Laughing] ’Cause it’s the only time I can get it under the NHS, just do it”. So I – I had it tidied up. (Fiona, 30s, 1 transplant aged 5-9)

Third, and related to the above two influences, was recipients’ sense of needing to display an ongoing gratitude for their transplantation. As survivors they continued to require regular medical oversight through their adult lives, and expressed mindfulness of the risk of staff thinking they were ungrateful. Non-clinical audiences might also imply that recipients should continue to feel grateful for their life-saving interventions many years after they took place (this is discussed further below), adding to this felt perspective. Indeed, only one recipient in the sample claimed she had regularly requested revision of her scars with various paediatric and adult clinicians, and this had eventually been carried out seventeen years after her transplant. She clearly portrayed the gratitude she reluctantly felt she was expected to show clinical staff:

It was a long negotiation. When I used to speak to the children’s team about it, they made me feel very much like, “Well it’s a scar, if you didn’t have that you wouldn’t be here”. And that used to upset me. (Tina, 20s 1 transplant aged 5-9)

Significantly, despite being offered and accepting surgical revision aged 15, later in her interview Fiona referred to her scars’ current appearance as “still a mess” that “would probably scare them off the beach”. She appeared clear she would not seek further revision, yet would accept it if offered:
Interviewer: It's [revision] not something you're actively seeking?

Fiona: No, no, no, not at all. No.

Interviewer: Just wait and see if somebody suggests it?

Fiona: Yeah. If someone says, “Oh do you want me to give it - I could give that a good go”. I'd say, “Yeah, go on. Yeah”. But I wouldn't [ask] “Oh please can you do it?”

What these experiences convey is the scar’s cultural importance as well as its moral significance. This relates to themes that appear in the study of both body modification and cosmetic surgery where the underlying presence of the body in contemporary society is equally a project to be worked on. As Gimlin (2006) points out cosmetic surgery can offer participants who worry about their ‘all too present’ body an opportunity to place it in the background so that it doesn’t intrude into the everyday. However, as we have seen for the bearers of these scars, even this ‘tidying up’ brought out some of the complex issues involved in organ transplantation and the ‘gift’ that has been given to allow them to live until the present.

The personal and social career of the scar

Adults transplanted as very young children recalled revealing their scars in primary school as material ‘proof’ or ‘truth’ to confirm to other children that they had indeed received a liver transplant. In the context of their young age and the newness and complexity of the intervention, the scar spoke for children who were not sophisticated storytellers and signalled the surgical procedure to an audience that could similarly not fully comprehend what had taken place. For these very young children, the scar did not seem to be understood as a marker of difference but rather as confirmation that the surgical act of transplantation had taken place as Grace (20s, 1 transplant aged 5-9) recalled:
I was still in primary school, and most of my teachers knew what was wrong. They didn’t ask any questions, they just said, “You all right?” “Yeah, I’m fine”. But if [a student] said, “I’ve heard you’ve had a transplant, is that true?” I’d show them my scar. It’s like [indicates lifting her top] “there you go”.

British schoolchildren in the 1980s and 1990s had limited opportunity to conceal their scars when getting changed in communal spaces for physical education (PE). Here, schoolfriends’ remarks following their own appraisal of the scar, devoid of context about its cause, could influence recipients’ own feelings about it, regardless of when their surgery happened:

I remember being a bit nervous about my scar, and I remember taking my top off [for a PE lesson] and my friend went, “Oh! Your scar’s not that bad at all, is it?” And I just was like, Oh my God! And I wanted to hug her…I think if her reaction had been different that could’ve completely changed the way I think about [my scars] now. But that one reaction - I’ve just never had a problem with my scar. (Cassie, 20s, 2 transplants aged 5-14)

There was one girl, when I was changing in PE, was like, “Uggh! Look at your scar!” And it affected me more then, I’d say, from sort of fourteen onwards. I hated it. (Natalie, 20s, 1 transplant aged 5-9)

To limit scars’ display to wider audiences some bearers reported their parents reminding them to keep them hidden, and by extension, to be secretive about their surgery (Frank, 2004), even if they themselves were content with their appearance. However, later in their lifecourse, scar stories would need to play a central role in the context of romantic relationships, a future that at the time of surgery their parents could not always imagine:
“I think my parents probably didn’t think we’d get married, they probably didn’t think we’d have kids, because people might be grossed out by our scars.” (Cassie, 20s, 2 transplants aged 5-14)

In telling the story of the scar, bearers needed to set out for romantic partners not only the scar’s non-normative appearance but also the ontological conditions of the transplantation world, both its history and the uncertain nature of what might come. To not undertake this storytelling was to deny a life with intimate relationships, although as Liam observed, the story might need to be told to any number of potential partners before meeting one who could ‘handle’ what might be perceived as a ‘monstrous body’ (Shildrick, 1996):

I thought to myself, well, what am I going to do? Never, never sleep with anyone? Well, it’s always going to be there, so eventually [there’ll be] someone along the line, who could handle it. (Liam, 20s, 1 transplant aged 0-4)

In this context, it appeared imperative for recipients that their liver transplantation story was told before the scar was revealed. Vital to all recipients in these commonly recounted strategies was feeling able to trust someone, based on an expectation of how the other would behave in the future relationship, yet involving significant risk and uncertainty (Gilson, 2003); as Natalie (20s, 1 transplant aged 5-9) succinctly explained:

‘It takes a lot for me to trust people to tell them about the scars, or let them see the scars, or know [about the transplant]. If I don’t trust somebody, I don’t tell them at all.’

Fiona and Kevin, both of whom had their transplants over twenty years ago as young children, highlighted the extreme adverse reaction they needed to prepare themselves for as now-olds:
Particularly when I was with my [now] husband, you do think, “Oh. Hang on a minute. I've got to take my top off here. And I've got to explain before they absolutely have the shock of their life and fall off the sofa or something”. So you do have to actually say [first]. (Fiona, 30s, 1 transplant aged 5-9)

Because I don’t just go, “Oh, by the way, I've had a transplant, here’s the scar! Let’s see where we are now, shall we?” It’s more of, well, tell it, because you can read about anything, but when you see something, it gives you a different idea, and that’s kind of a worry for me, because it can put people off extremely and it makes them think twice about stuff. (Kevin, 20s, 1 transplant aged 0-4)

*Non-intimate audiences*

Potentially disclosing scars to less intimate audiences also takes place across a wide range of situations and contexts; some anticipated while others unforeseen, with wide-ranging reasons for concealing or revealing them, from feeling neutral about who saw the scars to being very careful to keep them hidden. However, recipients did appear to think carefully about whether and why they might reveal or conceal their scar, and what the potential outcomes could be, in each context. Although both men and women generally reported following a ‘tell then show’ strategy for those with whom they hoped to build an intimate connection, strategies with other audiences were contextually and personally contingent; involving either hiding them completely or dressing with their scars exposed and explaining them only when questioned, in what could be generally seen as an inverse strategy of ‘show then tell’. Interviewees had become aware that most audiences would not recognise or be able to interpret the scar as indicative of liver transplantation, because of the relative newness and rarity of the procedure and the additional scars many recipients bore; as Rebecca, (30s, 1 transplant aged 5-9) observed: “When I’ve been on holiday I’ve had people stop me and ask me [laughs] if I've had my appendix out”.


Alcohol abuse is never an indication for childhood liver transplantation, yet brief explanations of the procedure offered to strangers in social contexts where alcohol was being consumed led some audiences to question the recipient’s behaviour with regard to their drinking, with comments such as “if I was a friend of a liver transplantee, I think I would be a good friend if I told them not to drink” (Maisie, 20s, 1 transplant aged 0-4) regularly encountered. This moral approach situated recipients as both blameworthy in their requiring transplantation and in how they subsequently lived their lives, as George (30s, 1 transplant aged 0-4) illustrated:

‘Cause that does wind me up a little bit. That people look at me and they think, “Well, what are you doing in a pub? What are you doing, doing this [drinking alcohol]? Shouldn’t you be in cotton wool?”

Anticipation of a moral approach to alcohol use could itself prevent disclosure of being a transplant recipient, either through showing the scar or telling a story about it:

If I’m drinking and I think that they [strangers] will have an issue with it - if they know that I’ve had transplants – then I’ll maybe keep [the transplants] to myself, ‘cause I don’t want to get hassled when I’m trying to have fun. (Bessie, teenager, 2 transplants aged 0-9)

Although young child audiences lacked the sophistication of being able to properly decode the scar’s meaning, and when away from the pub the now-adult recipients were removed from an imagined connection with alcohol misuse, for these recipients the scar had become a clearer marker of their difference, through which they occasionally understood themselves to be the ‘scary’ or monstrous person. In that context, an audience of younger people was perceived to need careful protection from observing their physical difference:

Sometimes, in public swimming, you think – ‘cause some people, you get little kids now that’ll look at you, and go, ‘Cor she’s a bit spesh [special] isn’t she?’ – More like you didn’t want to bloody
scare them, to be honest. And you take your top off and you try and get your next top on, or wrap your towel round if you’re going swimming, or whatever. So sometimes yeah, it’s more like you don’t want to scare the poor kids [laughing]. (Fiona, 30s, 1 transplant aged 5-9)

Conversely, in hyper-masculine contexts (Stoudt, 2006), exposed scars could be interpreted as signs of tough masculinity, echoing notions of their being ‘war wounds’ or ‘battlegrounds’. For example, intense fighting at school had led to one young man’s shirt becoming undone and his scars being exposed. Instead of seeing a ‘monstrous’ body, the scars were taken as a mark of invincibility, as Kevin, (20s, 1 transplant aged 0-4) observed: “I had a boy come up to me one day and just ask me ‘Oh, dude, how do I get one of them?’” In a subtly different way, scars could be deliberately revealed to convey a false impression of bravado in order to challenge both a younger audience’s prevailing belief of what violence meant along with its bodily swagger; here a now-adult recipient teacher described using his scar to convey the potentially awful outcome of unchecked aggression:

I work in quite a tough school, and I only work with students who are at risk of being excluded, or who are about to be excluded. I work with inclusion and with students with social and emotional and behavioural issues. So, they’re these kids who walk around pretending they’re everything and they haven’t got a worry in the world and then I’ve shown them my scar and ‘Oh! Sir!’ And they can’t look at it. It’s just classic. (James, 30s, 1 transplant aged 5-9.)

For strangers, who had little ‘identifying’ context, stories of survival were commonly conveyed in quite imaginative ways. Echoing Glancy’s work on soldiers’ chest scars being ‘badges of honour’ and their own notions of violence in referring to their scar, for example as shown above, these stories hid the vulnerabilities that lay behind transplantation. Although female scar bearers did not convey any stories that told of their heroism, they immediately recognised and were not surprised to hear this type of explanation told by their fellow male transplant recipients. For men, the story and ‘re-story’ (Plummer, 2013) of their scar developed to reflect their growing older
and their changing social circumstances. For example, George, (30s, 1 transplant aged 0-4), whose family worked on a farm, illustrated:

I’ve got loads of stories. Used to tell kids when I was at school I fell into a combine harvester. I’ve got a really convincing one where I got stabbed in a club, I was defending my girlfriend’s honour. I got all the elaborate talk up behind it and everything, get a few people on with that.

In conveying these stories of heroic battles to inquisitive strangers, often in response to a stranger asking questions about their scars, the most common way that adult men reported explaining their scar was in the context of a non-human other, most commonly a shark in an exotic location (only benign sharks visit the UK). This plausible story of a different rare event not only gave a possibly credible explanation and provided entertainment but also conveyed the bearer’s heroism. For example, Nick recounted:

Whenever I’m on a night out [strangers ask] ‘how did you get that [scar]?’ ‘Oh, because I went to Florida a couple of years ago, and I was out on Miami Beach, and I was swimming and I got attacked by a shark’. ‘Oh really?’ ‘Yes, it was really bad’. (Nick, 20s, 2 transplants aged 0-4)

These ‘heroic’ stories projected scars as markers that were unlikely to be interpreted properly by their audiences. Perhaps fatigued at the time, aware of a ‘cool/thin’ audience, or not wanting to be drawn into a longer conversation with the self-investment that telling the transplant story would require, the ‘shark’ narrative served to shut down further audience questioning. However, alongside these more fanciful stories, there exists a recognition among recipients that there are people who are genuinely interested in understanding the scar’s origins, in which case the transplant would be explained when the time and space was considered right to do so. These stories then never stop being told as scar-bearers grow older, with clear lines emerging between the educational, the heroic, and the ‘shock comedy’ – and the different scar signals received by different audiences:
I mean I still get it on a daily basis back at the gym. But I actually play on it sometimes, it’s a nice way to – it’s a polite way of doing it. Oh, there’s hundreds of stories flying round that I’ve been bit by a shark, or I’ve saved this person from drowning. It’s a comedy side of it. No, if somebody is interested, and genuinely interested, then I will explain it to them. But if it’s somebody that’s just come into a bar, and just being nosy, then I’ll give them the comedy side of it. It makes me laugh and then I can walk away and they walk away going, ‘has he really been bit by a shark?’ Or something like that. So, it’s the stupid side of it, and it’s the way I deal with it. (Oscar, 30s, transplant aged 5-9)

This awareness of the polysemous meanings of the scar and others’ reactions (imputed or not) to its physicality points to the significance of the body as a corporeal marker of personal narratives and negotiations. It also indicates the way that inventive narratives of scarring can play a positive as well as negative role in the lives of the interviewees.

Discussion

Acquiring transplantation scarring is not a discrete event; scars have a dynamic physical trajectory and bearers express changing relationships with them over the lifecourse. Bearers are careful to create their own representational meaning of their scars, although this appears to align closely to conventional norms of gratitude to organ donors. The story of the scar is told numerous times, first through the use of zipper dolls by clinicians who tell children their own stories of what the scar will look like as a surgical imaginary, and subsequently re-storied (Plummer, 2013) by bearers over the lifecourse to new audiences, from passers-by to more intimate others. Decisions are made without discernible pattern, either to not tell any story yet display or conceal the scar, or to ‘tell-then-show’ or ‘show-then-tell’, dependent on each social circumstance and audience. Stories that are told are most commonly of heroic survival; for intimate audiences, the scar is an integral part of the transplantation story,
being ‘proof’ or part-explanation of biomedicine’s ability to rescue. For those not intimate, the story of heroic survival against the odds is selectively packaged to give particular impressions (Burnett and Holmes 2001), such as those involving violent altercations with humans or sharks.

Being interviewed years after their first transplant, we cannot be sure about the ‘reliability’ of transplant recipients’ remembered events and the specific details surrounding the recounting of these stories. However, our focus here is not to hold these narratives up to an idea of a ‘correct’ version, but rather to understand how the narrative construction of self through telling stories about scars over the lifecourse is contingent on individual, social and cultural differences. Similarly, we had little data on how gaining an additional transplant scar had affected recipients’ attitudes towards them; some recipients had had a subsequent transplant just days or months following their first, or were in infancy at this time and were unable to make a distinction between ‘before’ and ‘after’. Indeed, participants who had had more than one transplant often referred to their scars in the singular.

In the absence of a predominant liver transplantation story, for this cohort at least, the scar continues to lack any identifying features to allow for a correct interpretation. As a relatively new and still relatively uncommon procedure the liver transplantation scar especially remains open to interpretation by others; there appears to be no ‘fixed’ scar pattern for an observer to interpret with ease. Glancy’s work enables us to be sensitive to multiple meanings of the scar. First, that the location of the scar on the body might tell a story of the reason for the scar; and second, how the shape of the scar itself might also offer cues for interpreting what caused it. Hall’s approach in cultural studies and his work on coding and receiving has a significance for this research given that he points out that, ‘before [a] message can have an ‘effect’ (however defined), [it needs to] satisfy a ‘need’ or be put to a ‘use’, it must first be appropriated as a meaningful discourse and be meaningfully decoded.’ (1980:165). We would argue that the scar as a sign is not easily decoded - the receiver needs to interpret the scar in terms of their own life narrative and assign meaning to the transplantation process both bodily and socially. This polysemous dimension
allows for many meanings and interpretations, especially where the message is not clear to the recipient. Medical innovation means almost limitless possibilities for reasons behind scars.

As the whole sub-field of stigma research has demonstrated from the time of Goffman onwards, in the same way that a medical gaze (Foucault, 1975) exists so does a social gaze and this gaze is never passive. Following Turner (1999), and echoing Hall (1980), ‘reading body marks is, however, an uncertain from of textual practice because there are no necessary linkages between marks and roles’ (Turner, 1999:42) - here transplantation scars and their cause. Drawing on Turner’s typology of memberships of postmodern societies, we can usefully conceptualise different types of audience, which throw light on how story narratives might be chosen. Turner describes the role of bodily marks such as scars and tattoos as generating ‘hot’ loyalties in ‘thick’ societies (traditional tribalism, obligatory body marks, modernity). Here this type of audience that engages with the story of transplantation would commonly include close friends and family transplant clinicians and intimate others – or Goffman’s (1963) ‘wise’ and ‘own’, and those the bearer is seeking to educate, though, as we have shown in the context of cosmetic revision, this is not always unproblematic.

With regard to ‘cool’ loyalties in ‘thin’ societies however, Glancy (2004) enables us to trouble the notion further by showing us how culturally available frames might underpin interpretations of the scar bearer’s moral worth or social position; and how the scar’s bearer might tell stories about them to influence a different interpretation, overriding the cultural cues given by the scars’ shape or bodily location. This approach has been extensively studied in various forms of body modification in relation to the thin solidarities operating in cool societies (neo-tribalism, optional marking, modern urban society), focussing on the form of the stranger ‘who is geographically mobile and socially transient’ (Turner, 1999:44). This allows for the role of contingency and would allow for the enabling of a revisable self in the context of the story of the scar. For these ‘cool’ audiences, the scar becomes but a playful mark in the consumption of others bodies as surfaces of inscription. Such ‘cool’ observers relate to
the appeal of ‘shark attack’ story which is sufficient explanation without the need to relate an adult’s liver transplant scar to alcohol use or to childhood liver disease.

However, the scar cannot just be seen simply in these terms. As we have shown, it also acts as a signifier for others of the bearer’s moral responsibility. What gets confused in the context of liver transplantation scars is the underlying indication for the scar and how the recipient should live their life subsequently; for these cohorts especially the liver transplant is often related to alcohol use in adulthood rather than liver disease in childhood, where rare and complex underlying syndromes are most likely to be the underlying cause. The absence of a careful account of transplant, with or without scar display, then impacts on the moral worth of the recipient both in the present and in terms of the past as a recipient of an act of a donor’s generosity (Roberts, 2016). Only a more nuanced story counteracts this; not only that there is a liver transplant scar, but also how long ago transplantation might have occurred, and how adult life can be lived. Liver transplantation scars can appear therefore as a source of differentiation rather than of identification.

Conclusion

Despite sociology’s turn to the body in the 1980s and growing interest in body modification, understanding of the meaning and narrative of surgical scars has been absent, even as the reach of surgical intervention and potential recipients are increasing. In this article we have given a more nuanced understanding of how surgical scarring through organ transplantation shapes the corporeality of the body, the embodiment of the self, and the behaviour that is deemed morally appropriate.

We have also shown how corporeality and embodiment is not fixed across the lifecourse and how these recipients’ experiences are not discernible through identifiable patterns of scar stories. Despite a common experience of childhood liver transplantation, the only emerging traditions in the scar stories conveyed appear to be that of a ‘heroic survival’ narrative for men, and for both men and women a ‘tell-then-show’ transplantation story for intimate
others, rather than a tradition of ‘liver transplantation’ storytelling having yet emerged. Recipients with other organ transplantation scars such as heart and lung may offer other types of heroic narratives.

Awareness of the meanings associated with the scar as well as others’ reactions, imputed or not, to the physicality of the scar point to the significance of the body as a corporeal marker of personal narratives and negotiations. It also indicates the polysemic nature of the scarring and the way in which inventive narratives can play a positive as well as negative role in the lives of organ transplant recipients. The transplantation scar is a by-product of organ transplant surgery but plays a key role across recipients’ lifecourse. This area is ripe for sociological enquiry, drawing together medical sociology, biographical narratives, and normative expectations of the body.

References


