

Morbid curiosity? Discussion of the disposal of amputated limbs on online question and answer sites

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Abstract

Amputation is a growing health issue with implications for the corporeal form and sense of bodily identity. Disposal of the removed limb (the amputate) has historically been suggested to impact on patient adaptation to amputation, although understandings of limb disposal are scarce within existing research. The growth of online question and answer sites has created opportunities for social actors to post and respond to a vast array of topic areas, including those that are seen as morbid or taboo. This paper then explores the discussion of amputate disposal within threads from two popular question and answer sites. Using thematic analysis, the paper examines how perceived ownership of limbs, understanding of the amputate as ‘waste’ and recourse to grotesque humour are key means by which limb disposal is discussed within these sites. Posters then create a new knowledge around the disposal of limbs, albeit one framed by uncertainty.

Keywords

Amputation, disposal, question and answer sites, health online, internet-mediated communication

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Background

Amputation is the removal of a limb from the body, often undertaken due to trauma to the limb or as a result of disease or illness, with amputation being in some situations a means to prevent mortality. Lower limb amputations are the most common (90% of amputations relate to lower limbs) and the prevalence rate for lower limb amputation in the United Kingdom (UK) is reported to be 26.3 per 100,000 people.¹ It is, however, suggested that rates of amputation may double by the year 2050,² in part due to an ageing population but also increasing rates of diabetes and vascular diseases, which are key contributors to the need for illness-related amputation.³ More men than women undergo amputation and most amputations occur in those aged over 60 years old.³

Amputation can lead to grief or trauma,⁴ akin to the loss experienced through the bereavement of a spouse,⁵ which impacts various aspects of patients’ lives including their body image and sense of self.^{6,7} Much of the existing literature around amputation focuses on the

adjustment and adaptation to amputation, including the experience of phantom limb syndrome⁸ and the role of prosthetic technologies in the lives of amputees.^{9,10} Phantom limb syndrome can cause patients significant pain and psychological distress and resultant can be seen to be indicated in difficulties with adjustment to amputation.¹¹ Other bodily losses, such as vision loss,¹² are seen to have negative impacts on the quality of life of patients and their mental health. Similarly, those who have experienced a mastectomy identify loss that covers a range of life experiences, from both body image to their own peace of mind about the robustness of their health.¹³ Amputation is

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therefore one of a number of health ‘losses’ we can identify, although understanding the unique question of disposal within this loss still remains uncertain.

Although the evidence is small, early studies suggest the way in which the patient’s amputated limb (the amputate) is disposed of has been correlated to positive adjustment to amputation.^{4,14,15} With time, most patients adapt to amputation successfully but the years following the amputation can be a time of significant challenge.¹¹ The existing literature around amputation details limited engagement with disposal as an act or experience within amputation,¹⁶ although there have been calls by patients and healthcare professionals for greater consideration of disposal within the care pathway of those undergoing amputation.^{17–19} For the most part then we see a ‘bracketing out’ of disposal in relation to research around amputation,²⁰ raising considerations of whether broader conversations and curiosities around disposal exists within the public sphere.

The act of amputation is itself seen as a ‘violent intervention’²¹ to the body given the radical alteration it engenders to the corporeal form. Although the growth of surgery has normalised the anatomical body and surgery itself is seen as a means to treat illness or disease and stall more permanent bodily disruption (such as death), amputation has long been seen as one of the ‘more invasive and gruesome operations’.²² Given the extent of bodily transgression that amputation can then be seen to entail, it is perhaps unsurprising that curiosity around amputation exists, specifically around the amputate (the removed limb).²³ The amputate is often still viewed as the ‘property’ of the person from whom it has been amputated. Questions around what then happens to amputates may centre on this notion of the limb being ‘residue of that which is no longer “me” but still definitively “mine”’.⁸

Consumption of the ‘grotesque body’²⁴ is also not a new phenomenon – social actors have long shown fascination in asking, understanding and viewing aspects perceived as ‘morbid’. Similarly, understanding the ‘monstrous’ is seen to reveal to us both the liminal and structural nature of corporality and identity²⁰ and thus is a source of both ‘fascination and horror’.²⁰ Existing research suggests those who seek morbid material on the internet show great passion for the material they encounter and that it does not necessarily impact negatively on their outlook on their own lives,²⁵ suggesting ‘morbid curiosity’ may not be inherently problematic to those individuals. This paper then explores one facet of such ‘morbid curiosity’, social actors’ curiosities around the disposal of limbs after amputation and seeks to understand how this topic is addressed within online public question and answer (Q&A) spaces.

The internet has been a major revolution in how information and knowledge is shared and exchanged. It has created new dynamics, particularly around health and healthcare information, allowing the general population to have greater access to information than they could previously.²⁶ The use of the internet for information related to health is not just the preserve of those experiencing illness, rather it is seen as an ‘everyday helper’ for information seekers²⁷ and the advent of spaces in which people can not only find information, but also ask and answer questions, has also enabled the internet to facilitate such wider ‘knowledge sharing’²⁸ among lay persons. Q&A sites have themselves been seen as different in what they offer when compared to other social networking sites around health-related topics,²⁹ they therefore provide an interesting platform to examine in relation to topics that could be seen as stigmatised or hidden from the social gaze. This paper then contributes to both our substantive understandings of how disposal of amputated limbs is imagined by lay persons who may not themselves have lived experience or insight of amputation, as well as to our knowledge of how online Q&A sites can provide a ‘safe’ space in which topics pertaining to the body, which may be perceived as morbid or grotesque, can be discussed without the constraints and censure that face-to-face communication may entail. Furthermore, considerations of the role such sites may play in highlighting the uncertainties and ambiguities that patients themselves may have in relation to amputation and limb disposal will be examined and the potential value of how general public understandings could be used to improved healthcare practices will be explored.

Methodology

This paper then examines questions and answers around the disposal of amputates on online Q&A message board sites. Such sites remain popular spaces on the internet, Reddit being one of the most frequently used sites and having over 112 million unique visitors since its inception in 2005³⁰ and Quora being a recent but growing platform that has outstripped the growth of more established Q&A spaces such as Yahoo Answers.³¹ Such sites are user driven communities that create ‘growing knowledge repositories’.³¹ A key feature of sites such as Reddit and Quora is that users can vote on answers, allowing a ranking of ‘knowledge’ to occur so the community can create a metric of what is ‘quality information’ (ibid). Some of these Q&A platforms have sub-boards or areas allowing specific topics to be examined,³⁰ on Reddit these are ‘Subreddits’ and there is a specific space for the discussion of morbid topics (r/morbidquestions); on other sites such as

Quora, the threads are grouped around particular topics (such as healthcare). Although these sites remain popular and therefore capture a 'snapshot' of public interest and discussion on topics, it is important to note such sites do not represent the 'public sphere' in part or entirety. This paper does not seek to make claim that such sites are in any way representative of the 'imaginings' of the general public around the disposal of limbs after amputation, but rather offer a 'way in' to exploring a topic that is generally hidden from public view and discussed in some online spaces.

The literature around amputation shows there is a dearth of work examining disposal in the context of amputation,¹⁶ which led to the enquiry around whether this lack of research is also manifest in a lack of wider social interest. The research was focused around the core research question of 'How is disposal in the context of amputation discussed in public fora?' The Q&A sites and threads examined in this paper were found using Google searches. This approach was adopted as it is akin to the steps that the general public may approach it when searching for information on this topic. Given Google remains the most popular search engine available, its ubiquity offers a high possibility that this is how the general public may approach seeking information on this unusual topic. The search 'disposal of amputated limbs' brought up a number of threads on the Q&A sites Reddit and Quora, which remain two of the most popular sites of this nature and are therefore highly visible to searches on this topic within Google. The top five most popular from both sites were then examined for the analysis. This resulted in 25 posts from the five threads on Quora and 304 posts from the five threads on Reddit, giving a total of 329 posts within the dataset. The sample size is comparable to other internet mediated qualitative research of this type,³² which prioritises depth of insight over volume of posts.

Digital methods, such as analysing forum posts, are increasingly being used in social science research, allowing for the mediation of human interaction through computers to be understood more robustly and particularly in terms of how computer-facilitated communication creates new freedoms and opportunities for different types of communications. Using online digital methods is seen to be valuable for sensitive research topics, or those that would be stigmatised in wider social life.³³⁻³⁵ Topics pertaining to health, illness or the body are also of increasing popularity in online communication for the general public.^{36,37} As has been described elsewhere, forums particularly offer valuable tools by which lay persons can seek help, advice or information on health-related topics.³⁹ The unusual nature of the topic and the lack of wider social outlets in which it could be discussed makes

computer-mediated communication on the topic more pertinent. Particularly as netnography – the observation of social phenomena through online settings – is seen as an unobtrusive approach that allows a 'window into naturally occurring behaviours',³⁴ allowing for both flexibility in approach and accessibility to understand how social interaction occurs online. Using online data of this type does limit the dataset available in that it is constructed by the parameters of what interaction has occurred on fora in this instance, and there is no opportunity for further probing of responses or communications by the researcher. It is, however, a highly useful method and, for this study, provides a valuable fit between research topic, question and method.

The use of such online material within research follows the now established principles for internet-mediated research and was guided by the ethics principles for such research.³⁸ The posts used were freely available within the public realm and did not require a log in to the sites to be accessed. No contact with the posters was made by the researcher and poster names have been removed from any quotations within the paper to divorce post and poster within this paper. Although a broad research question informed the initial research topic, an inductive constructionist approach to the themes was taken following the approach detailed by Braun and Clarke.⁴⁰ The use of a constructionist orientation enabled examination of content (what is said) and presentation (how it is said) and connected the broader themes to relevant theories and concepts. Thematic analysis is now widely used within health-related research as it can be usefully used within the context of applied research and, due to its reflective nature, it offers flexibility across the topic, audience and research questions posed.⁴¹ It is suggested that,

'TA (Thematic Analysis) is a flexible method that allows the researcher to focus on the data in numerous different ways. With TA you can legitimately focus on analyzing meaning across the entire data set, or you can examine one particular aspect of a phenomenon in depth. You can report the obvious or semantic meanings in the data, or you can interrogate the latent meanings, the assumptions and ideas that lie behind what is explicitly stated (see Braun and Clarke, 2006). The many forms TA can take means that it suits a wide variety of research questions and research topics'.⁴²

Practically speaking, it entails a 'bottom-up' approach; what is present within the data guides the themes that are generated by the research in their analysis. For this research, the six steps outlined by Braun and

Clarke^{40,42} were utilised. These steps entail: (a) familiarisation (reading through the threads and posts in this instance); (b) generating initial codes (identifying key words, ideas, concepts in the posts, including both semantic and latent aspects in this instance); (c) searching for themes (meaning making across the codes and the data as a whole, looking for broader connections between these codes); (d) reviewing themes (assessing the selected themes, checking they are indeed themes and not simply codes and whether they reflect the data as a whole); (e) defining and naming themes (creating succinct labels for the themes so that they neatly encapsulate the broader idea of the theme; this was an iterative process in this analysis); and (f) writing up (linking themes through their ordering and creating a convincing story). The three themes generated from this analysis process are discussed below.

Findings

Three main themes were generated from the analysis and examine how disposal of limbs after amputation was being discussed on the sites and threads examined by the general public. The themes overlap in terms of the lay knowledge being generated by the posters on these threads, but all offer a different insight into how disposal of limbs is perceived and imagined within contemporary healthcare. The three themes are: the amputate as (still) personal property; narrating the amputate as waste; and invoking the grotesque.

The amputate as (still) personal property

For a number of posters in the threads explored, ownership and disposal were viewed as being intimately connected, the amputate was routinely narrated as being ‘yours’, something owed by the person who has undergone amputation;

‘Why couldn’t the hospital charge some small, nominal fee to ensure there was no biohazard while also allowing you to keep a part of the body you were born in?’

The right to be able to choose the final destiny of your own body parts was therefore invoked frequently by posters both in their answers to the original thread questions around disposal but also in response to other posters’ responses. The removal of limbs for some posters did not, in their view, change the nature of whose limb it was, even after it became a ‘part’ rather than being within the embodied whole.

‘A professor of mine has his leg amputated and they incinerated it...He wanted to keep it and have it

encased in a mould, because, as he said, “it was *his* leg!” But they wouldn’t let him.’ (Italics poster’s own.)

The unfairness perceived around lack of patient choice or adherence to patient wishes was therefore visible, as the above quote shows through the stress on *his*, limbs are seen as belonging to the person from whom they have originated and disposal that negates this ownership was called into question on online threads.

The language used to describe disposal, particularly when used in personal reflections, also reinforced the notion that the amputate still belongs to the person from whom it was removed:

‘Quite a lot of patients want to keep their amputated limbs. I once saw a man’s leg being sealed in a two-layer plastic bag before being placed in a leg-shaped wooden box for him to take home with him.’

The use of ‘their’ in the example above and ‘his leg’ in the quotation below demonstrates how possession of the limbs was attributed to the person from whose body the limb had originated by posters. Through the sharing of anecdotes, online posters can reinforce experiences where the ‘owner’ of the now removed limb has been able to enact their choice and wishes around the disposal of the limb and the outcome of this:

‘My dad had his leg amputated recently and while we didn’t ask about cremation, he did ask if he could keep part of it. The doctors advised against it – but never actually said no.’

‘I used to work at a funeral home and we’d kept a leg in the freezer for 10+ years because someone had it amputated and wanted to be buried with it.’

Posts that talked about the ownership of limbs and used personal stories were often emotive in their content and style:

‘A friend of mine had her leg amputated due to cancer. She never asked about what would happen to the limb and made it through hospitalization and recovery without mentioning it. Quite some time later, she received a box in the mail from the hospital. Inside it was a sealed can, not unlike a coffee can. Mystified, she opened it and found the cremated remains of her leg. She was then faced with the dilemma of what one does with a limb that’s predeceased them. Eventually she held a funeral for it in her garden. Because what else do you do with the charred chunks of your own severed leg?’

Phrases such as ‘charred chunks’ and ‘severed leg’ give a much more violent and un-sanitised picture of

amputation and disposal of amputates, evoking ideas of the grotesque or abject, the image of ‘charred chunks’ of a leg contained within a can seeming more akin to a scene from a horror film than to our understandings of a patient’s experience post-amputation.

Other posters, however, adopted more unemotive approaches in their posts and some attempted to explain the change of ‘ownership’ through the consent processes attached to undergoing surgery itself, demonstrating how threads such as these can provide more factual offerings for those seeking answers to the questions originally posed:

‘Before surgery, the patient signs a waiver giving up ownership of their “surgical leavings” after which the limbs may be donated to a medical school, kept by the hospital if it is a teaching hospital or disposed of as one of the four types of medical waste.’

Medicine itself was then seen to interfere for some with the right to choose what happens to one’s body but factual information (such as regarding how consent changes in the example below) was often interspersed with more personal opinion on the posts examined:

‘Legally it’s yours, but when you sign a consent for surgery, there’s also a statement that you allow them to dispose of any parts of fluids ... They get pretty uptight about things like that, even if it is YOUR body.’ (Capitalisation poster’s own.)

Disposal was then, for some, viewed through the lens of ownership. Tales of the experiences of others who have undergone amputation were sometimes invoked to provide evidence demonstrating how patients’ wishes were or were not enacted within those situations. The understanding of the amputate through the notion of it being ‘residue of that which is no longer “me” but still definitively “mine”⁸ may therefore be apt to understanding this ‘ownership’ approach to discussing disposal after amputation. Such perceptions of ownership may highlight a disconnect between clinical practices of treating human tissue as ‘waste’ and how patients may imagine their limb still as ‘theirs’. This disconnect becomes more pertinent in light of recent scandals around the disposal of ‘solid’ clinical waste (including limbs) in the UK and raises questions around how patient centred or sensitive ‘waste’ disposal is to the feelings and emotions that are perhaps entangled with the amputated part. The disconnect around how limbs could be disposed of was also highlighted in differences around possible practices for disposal within posts, including limbs in boxes (a form of limb coffin), ritual garden burials and the desire for preservation of said limbs (including as a

means of future reunion). Our norms and values for what options exist for the disposal of limbs are constrained by context (such as the lack of ability to seek a limb cremation in the UK due to the lack of a death certificate for the body ‘part’) as well as the lack of precedent among patients around how disposal is handled, but anecdotally a variety of approaches have been taken by patients on the personal disposal of their limbs (AUTHORS), mirroring the variety of possible approaches discussed on the sites examined here.

Narrating the amputate as waste

Another key way that questions around disposal on online Q&A sites were addressed was through more factually orientated posts. Such posts did not draw on the more emotive or philosophical questions of who limbs belong to after amputation or to the personal reflections and anecdotes seen in the theme above and instead sought to provide a more evidence-based approach to addressing the threads’ original questions and often used the lens of the amputate being classified as ‘waste’ after surgery. This approach that sees body parts as ‘waste’ is itself an interesting and somewhat unique phenomenon. Other forms of human tissue, such as gametes and organs, or human fluids, such as blood, or breast milk, are often seen as ‘prized’ in terms of their ability to be donated or gifted to others,⁴³ having a ‘biovalue’, to adopt Waldby’s term.⁴⁴ Indeed, narratives of bio-intimacy⁴⁵ within donation are now being seen by some as part of biological citizenship and hierarchies of donation could be a useful means to frame such considerations.⁴⁶ Within such hierarchies, limbs, which are not seen as ‘reusable’, are perhaps understandably consigned to notions of ‘waste’, but this is itself not necessary unproblematic, as will be discussed within this theme.

Often posts that sought to position the amputate as waste would often seek recourse to legislation to support their answers and would often detail specifics of the area to which they were referring (e.g. United States (US) or UK):

‘According to the Act on the disposal of anatomical waste and human tissue...’

Some provided more depth and detail within their answers, addressing more specific aspects of disposal:

‘The Human Tissues Act states that “material taken from the living should normally be disposed of by incineration in accordance with current guidelines”. However, a crematorium cannot legally cremate any human tissue or organs from a living person. Patients are with their rights to sign for their leg and take it

away with them; they may bury it themselves or burn it on a bonfire ... The hospital's waste management service, which would normally incinerate human remains in bulk, can incinerate a limb and retain the ashes and return them to the patient.'

These posts were more likely to perceive the amputate as 'medical waste' than to narrate them as the property of the patient from whom they had been amputated:

'... removed body parts are considered medical waste and disposed of via predetermined (specific) methods that are detail in the medical centre operating procedures.'

Within these more factual accounts, the patients' choice regarding their limb was often seen as secondary to medical decision making, and was narrated through the lens of religious or cultural choices:

'The majority of the time one of three things happens to the limb:

1. The limb is sent to biohazard crematoria and destroyed.
2. The limb is donated to a medical college for use in dissection and anatomy classes.
3. On rare occasions when it is requested by the patient for religious or personal reasons, the limb will be provided to them.'

Religion was then seen in more factual presentations as being the only legitimate reason as to why patients would be able to have agency over the disposal of the amputate, and again the narrative of medical waste and resultantly the need for waste to be disposed of 'properly' can be seen:

'Some religions require that if a body part is removed that you have a ceremony and bury it. Otherwise I know of no reason they would just let you have it. They have to consider sanitation.'

Patient wishes were therefore not seen within these more 'factual' accounts as central to disposal, which is in direct contradiction to the view presented by other posters and described in the first theme, whereby the amputated part was seen as 'belonging' to those from whom it originated. Such contradictions are perhaps not surprising among lay accounts such as those examined here. The disposal of human tissue, such as in relation to foetal remains, has for example long been the subject of scrutiny around ownership, their 'proper disposal', and whether they should indeed even be classified as 'medical waste'. The idea that 'The disposition of bodies and body parts remains under the cultural

authority of biomedicine and the state'⁴⁷ is therefore evident within this theme but, in comparison to theme one, this serves to further show how the 'terrain is contested'⁴⁸ in relation to body parts and their disposal.

Despite a number of posts dealing in more 'factual' or informational accounts (as opposed to more personal reflections that coalesced around ownership and personal agency over amputated limbs as seen in the first theme), this was tempered by uncertainty in many answers around the disposal of limbs by posters;

'As far as I know they go with the clinical waste for incineration.'

'Depends on the patient and the culture, I guess. A few weeks ago, a patient on my floor had a BKA [below knee amputation] and the family requested the leg be sent to the funeral home for burial. Might've been an isolated incident, though.'

The use of caveats such as 'As far as I know', 'I guess' and 'Might've been an isolated incident' demonstrates uncertainty around the topic of disposal. Similarly:

'I've heard that you have a legal right to keep anything that comes from your body as long as it's sanitary. To this effect, hospitals will put body parts in vacuum bags or sealed jars.'

The suggestion of 'I've heard' demonstrating the hearsay that potentially exists around disposal, the lack of clarity, creating almost mythological atmospheres around the consideration of how amputates are disposed of. This may reflect the contested nature of the disposal of body parts that we see in relation to wider discourses around the body and specifically around what 'medical waste' can be defined as.^{47,48} This may in turn help to understand why people turn to online Q&A sites to find information for topics for which no obvious answer is seen to exist and where posing the question may be viewed as 'morbid' or in some way socially unpalatable. Online sites therefore provide value opportunities to discuss such topics, but the lay knowledge base on which they draw and around which these internet-mediated communications occur are not always able to provide 'facts'. Uncertainty may then be a feature in broader social understandings of how limbs are disposed of after amputations, reflecting broader social and political contestations around notions of the body within medicine, but online sites such as those examined do, however, allow for social actors' 'wonderings' to be shared in a way that is safe from social censure.

Invoking the grotesque

The third main way in which disposal in the context of amputation was discussed was through the narrative or humour, particularly ‘dark humour’ that engages with the morbid or macabre nature of the consideration of amputees and amputation as an act. One poster noted that the ‘factual’ answer to disposal was ‘Just as creepy as I suspected it would be!’ showing that persons are engaging with consideration about disposal and that notions of the ‘abject’⁴⁹ are visible in so doing. Others demonstrated their imagining about disposal further in light of answers to questions about disposal on the threads examined:

‘I’ve just drawn a mental picture of some poor guy dumping a bin of amputated limbs into the incinerator. Then, he comes home one day and takes off his coat and a finger falls out of his pocket.’

Thus, rather than answering questions around disposal, some posters were narrating hypothetical scenarios, which were often playful, but often had an underpinning notion of ‘dark’ humour. This seemed particularly welcome on threads where the morbid was celebrated (such as particular ‘sub-Reddit boards’); ‘I love morbid questions so much’ said one poster on a thread about disposal.

Some posters’ answers utilised only humour to address disposal. For example, the following question, ‘What do doctors do with amputated limbs?’ generated answers including:

‘They play a very unpleasant form of Jenga.’

‘They build Frankensteins.’

Even when posters were attempting to address the topic of disposal in a factual way, other posters contributed more humorous replies that created narratives around disposal that drew on the grotesque and dark humour:

Poster 1: ‘The actual answer (for the UK/Ireland and US at least) is that when something is removed or amputated in a hospital, it becomes the property of the hospital. They *could* give you it back, but they probably won’t because it would most likely mean explaining to a higher up where it went.’

Poster 2: ‘Dr. Username, could you step into my office for a moment?’

‘What’s this about boss?’

‘Dr Username, I see here on the schedule that you amputated three arms and a left kneecap today, is that correct?’

‘Yes, of course.’

‘But Dr. Username, there are only two arms in the medical waste bin, care to explain...?’

‘I don’t know nothing about that.’

Poster 3: ‘They said it was for their dog. He’s just a pup,’ ‘I’m very disappointed in you Dr. Username.’

Poster 4: ‘Aww, I didn’t mean nothing by it. And nobody else was going to use it for anything.’

Common across this exchange and the posts above was the centrality of medical professionals within the act of disposal and the grotesque was often invoked in relation to the imagined actions of doctors, including around imagined ‘foul’ play by medics. Given a recent news story of Indian doctors using a man’s amputated leg as a pillow under his head,^a this humorous discourse around doctors’ practices in the face of amputation can perhaps now be read in a more unsettling way that creates questions around dignity and patient vulnerability. In noting that ‘it would feel so weird to throw away a leg’, there is a clear demarcation of amputation as everyday practice for medical professionals but an extraordinary imagining for many people (including posters on the threads examined) and of the differential (unequal) power relations between doctors and patients in this context. Amputees by virtue of being within this liminal space given they are no longer part of the living body, but their existence as an object separate appears also to be surrounded by mystery. Medical professionals will be party to what happens in relation to disposal but their insight and experiences are not necessarily transposed to public consciousness, in that the liminality around the amputee persists.

Given the nature of the topic, puns were frequently used as part of the humour within the posts:

Poster: ‘I see trusts come to the hospitals here in [US city] and pick up the red bags of biological waste.’

Responder 1: ‘Oh they’re just giving them a hand.’

Responder 2: ‘Outsourcing biohazard waste removal gives them a leg up on the competition.’

Some engaged with recourses to dark humour as a means to consider their own choices if they faced amputation:

‘Maybe I’m a little messed up in the head, but I’d find a taxidermist. Once it’s nice and preserved the uses are

endless ... I'd have way too much fun making stupid jokes and freaking people out.'

'If I ever (hopefully not) have to lose a limb, I'd want to keep it in formaldehyde. It would be sweet to mount the jar behind a light on my bar wall.'

In doing so, considerations of the grotesque and abject were invoked, utilising notions of shocking others in the humour related to the amputate as an almost playful object. Such posts were from those who had not identified themselves as amputees on the thread, and thus were based on imagined scenarios; however, whether such 'humour' would be enacted if those persons did face decisions around amputation and subsequent disposal of the amputate is unknown.

Although dark humour is undoubtedly a feature of face-to-face interaction, indeed dark or 'gallows' humour has been found to prevalent within healthcare interactions,⁵⁰ online spaces such as these seem to allow greater opportunity for such humour, particularly as humour itself is suggested to be a 'founding member' of the internet.⁵¹ The anonymous nature of the interactions means such humour is perhaps more 'easy' for posters to engage in and a recourse to humour is often seen as more likely when there is a sense of unease about something. 'Some suggest that the more serious the situation, the greater likelihood that dark humour would appear'.⁵⁰ Given that the disposal of limbs after amputation is not a topic readily discussed in social life and amputation is itself a serious, body-altering procedure, the use of dark humour on sites such as those examined is perhaps unsurprising. Whether such humour would be used 'offline' if this topic was discussed remains unknown, anecdotally the discussion of our research often evokes dark humour within interactions with others, and the role and use of humour in relation to this topic is something that could be usefully examined in future research. Caution must, however, be shown in assuming all such humour is benign. As Shakespeare⁵² eloquently notes, 'making fun' of those with physical disabilities is a comic stereotype in the Western world, and even if we accept that 'Making a joke is the fundamental strategy, in our society, for compensating for tension or anxiety',⁵² we must be vigilant that not all humour is funny for everyone.

Discussion

Disposal of limb(s) in the context of amputation is therefore discussed in a variety of ways in online Q&A sites. The disposal of amputated limbs is an unusual topic, in part due to the difference in how the removed limb is viewed, being seen more often as 'waste' than reusable or as donatable and therefore

different from how other human tissue or human fluids may be considered or (re) used. The unique attributes of the amputate and its significance for amputees makes understanding considerations around disposal fruitful, and this analysis of lay accounts contributes towards this discourse. The means of discussing disposal on the sites analysed here often demonstrates an underlying curiosity around both practices of amputation and subsequent disposal by those who engaged with the threads examined. Such curiosity often draws upon notions of the abject or grotesque to create humour, but also offers broader insights into (mis) understandings around disposal. Three key aspects framed the discussion of disposal on the threads explored here. These were: the importance attributed to the ownership of the amputate in considering disposal; the offering of tentative 'facts' and attempts to discuss disposal more objectively through understandings of medical waste; and disposal itself as a source of grotesque or dark humour. Common across these discussions were uncertainty around disposal and the sense of morbid curiosity that this initially entailed and continued to engender.

Uncertainty was then a feature of both the questions and answers on the threads explored, demonstrating a lack of knowledge and awareness around disposal; even among those who sought to present 'facts' from policies or regulations, there was often a tone of uncertainty present within their posts through the language used or the way their posts were framed and constructed. This sense of uncertainty chimes with the wider lack of literature and research around disposal,¹⁶ the ongoing overlooking of the potential importance of 'proper disposal' for patient dignity⁵³ and the calls of medical professionals for greater information for patients and staff to help address such questions with clinical settings.^{17,18} As others have suggested, 'medical knowledge is characterised by "gaps", inconsistencies and uncertainties',⁵⁴ thus it is perhaps unsurprising the general public seek out and question the uncertainties that they themselves have, especially given that technology creates spaces in which such questions can now be readily posed and discussed.²⁶ Q&A sites can be seen to be circular paths of knowledge in this sense – people seek an answer to a question, others contribute, but if the answers feature uncertainty then the feedback loop of question/answer continues; this perhaps explains why it is possible to find threads on the same and different Q&A sites asking questions that are fundamentally similar in focus.

For some posters, the discussion of disposal returned back to questions around the ownership of limbs, drawing forth the notion of 'me/mine' that Crawford⁸ highlights in relation to the experience of amputation. In doing so, the discussion of disposal

online makes visible the liminal nature of the amputate; the amputate is no longer part of the embodied whole, yet for many it is still viewed as the 'property' of the person from whom it has been removed. The body is both liminal and structural in this context;²⁰ with the amputate as both object and subject.⁵⁵ Underlying considerations around bodies and the power and agency of patients within the context of amputation are then illuminated through the discussions of these posts, particularly when we contextualise 'humour' around hypothetical undignified practice by medical professionals in relation to examples of malpractice (see footnote 1). Such ethical and philosophical questions are often highly emotive and raise questions about the nature of bodies, definitions of 'medical waste' and the role of patient choice within surgical settings. Existing research suggests some patient concern around amputation focuses on the desire not to lose part of 'them' and that patient questioning around can be sometimes met with silence by healthcare professionals, such as in the case of Sobchack⁵⁶ who asked following amputation, 'where, indeed, was my leg?' (p. 55) and received no reply. Thus, although online threads may be engaging with potential wonderings, the issues they raise may in fact (inadvertently) be highlighting issues that may be pertinent to patient experience. Although such posts do not offer us any firm conclusions about the role of disposal in adjustment to amputation, and further research on this is clearly required, there is a clear statement by posters that limbs are seen as 'belonging' (in a property) perspective and thus a loss of control over the disposal of their limbs could potentially be problematic. This, as noted above, requires research to understand if such a link between disposal and adjustment is indeed present, but the role of 'ownership' could be an important framing or question for any such research.

Online spaces often provide new opportunities to ask questions for which there would not otherwise be space within contemporary society, in this sense '... social media like Reddit are fulfilling unique information and social needs'.²⁹ This certainly appears to be the case in relation to posing questions around the fate of limbs after amputation; amputation is not death, there is no funeral over which the limb can be mourned^b and therefore such questions appear to have no natural normative space in which to be discussed within society. Online settings, however, especially sites where the morbid or unusual are actively cherished as a topic of discussion, can provide such an opportunity for those who wish to discuss these topics. However, it is perhaps worth noting that 'morbid curiosity' is not itself always benign and indeed questions about the nature of curiosity into limb disposal from those who have not themselves

experienced amputation could, some would argue, fall into this 'problematic category' of such curiosity. For example, Baumgarten⁵⁷ argues that 'any form of meddlesome or voyeuristic curiosity, even apart from any harmful consequences that would come from acting on it, seems to debase those who experience it' (p. 10).

Whether the type of curiosity evident of the sites examined here is 'debasement'⁵⁷ to those who have experienced amputation remains unclear, but it is possible to note the sharing of personal stories on the threads examined. However, although no particular 'offense' to any posts was identified, this is not representative of the population per se and whether the morbid curiosity around disposal more broadly is problematic for those who have experienced amputation is unknown. It would, however, be a worthy subject of enquiry as part of wider research agendas to understand the role of disposal within the amputation experience, given the dearth of insights that exist around this topic.

Anonymity may play a role in facilitating posters' engagement with the topic examined here, particularly in relation to the morbid curiosity and darker elements of humour that were seen within the threads explored within this research. Whether such humour would be present in face-to-face interactions remains unknown, but existing research around online spaces suggests posters are more likely to make comments that others may see as inflammatory when posting in an anonymous capacity online.^{58,59} Anonymity has, however, been seen to be a valuable feature of sites such as Reddit in relation to other topic areas, where open conversation may be viewed as challenging or stigmatised (such as in relation to mental health).²⁹ Whether the tone or content of posts would be modified if those who had undergone amputation were present on such sites remains unknown and further research would need to be conducted offline to explore how discussions around amputate disposal may differ between on- and offline settings. This paper can then only offer conclusions relating to the sites and threads examined here and, as noted earlier in the paper, no claims that these sites or posts are representative in any way of the general population per se can be made and how disposal is discussed in other online spaces, such as forums, blogs or on social media, would require further research. Despite these limitations, the examination of online discussions around disposal can provide a 'window' into public conversations around the management of limbs after amputation. For those working in healthcare settings, such conversations can be useful to explore as they may in some ways mirror the questions or concerns patients themselves may have, but that they may be worried were 'too morbid' to share.

Conclusions

This paper then details how lay persons, specifically those with no experience of amputation, imagine in online settings how the disposal of limbs is managed after amputation. Posters demonstrate the uncertainty around what does happen within clinical settings to the amputate, mirroring the liminality around amputates more generally.¹⁶ Some posters had a strong sense that limbs ‘belonged’ to the person from whom they had been amputated, highlighting a possible disconnect between how amputates may be viewed and imagined in lay considerations compared to how they may be viewed and ‘managed’ within clinical settings in care for amputee patients. This could have relevance to the relationship between disposal and adjustment to amputation but would require substantial further research. Dignity and choice are often seen as central values for healthcare, yet the perceptions of ‘ownership’ and choice in disposal discussed by posters may not reflect contemporary realities of practices.⁵² Such discussions, freely occurring due in part to the anonymity and freedom that Q&A sites engender, may then provide fruitful material to help healthcare professionals understand more about the uncertainties, views and perceptions that the public may hold around particular health topics.

The data presented here demonstrate how online Q&A sites can provide a ‘safe’ space in which topics that may be perceived as morbid or grotesque can be discussed without the constraints and censure that face-to-face communication may entail. This allows social curiosity to be enacted and the findings demonstrate that disposal is discussed online in a way that reveals a curiosity, one that often invokes the abject or grotesque and uses humour as a ‘way in’ to explore a topic that is otherwise veiled within society. Whether such morbid curiosity is ‘debasement’ to those who have experienced amputation would, however, require further consideration. The threads examined then demonstrate how new forms of knowledge and information exchange can be created within online settings, even for topics that could be described as morbid. Such discussions can, inadvertently, also mirror some of the wider issues that patients and healthcare professionals themselves have begun to identify in relation to considerations of disposal.^{17,18–20,60} Online spaces can then open up new opportunities for dialogue, possibly providing a barometer of social curiosity for bodily related topics that are often hidden from the public gaze.

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Notes

- (see: https://www.washingtonpost.com/news/worldviews/wp/2018/03/13/indian-doctors-amputated-a-mans-leg-then-it-was-used-as-a-pillow/?utm_term=.323e466ac0b3).
- However, we have begun to see the growth of processes (such as those at Leeds Teaching Hospitals Trust, UK, for the return of limbs to patients) and spaces (such as the community-funded limb burial site in Sheffield, UK) to enable the lost limb to be buried, and thus potentially mourned in the way we may see in the burial of a body.

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