

# PROSTHETIC REHABILITATION IN PRACTICE

## Abstract

The aim of this research was to explore the experiential knowledge of patient-facing staff working in a prosthetic rehabilitation centre in the United Kingdom. Eleven members of staff with varied roles and levels of experience took part in semi-structured interviews. Transcripts were analyzed using thematic analysis. Six themes were identified: 1) *defining successful rehabilitation*, 2) *the complex reality of patient-centred care*, 3) *organizational and interpersonal challenges*, 4) *who provides psychological support?* 5) *prosthetic as a panacea*, and 6) *crash landing*. These findings highlight the impact of rotational roles in an environment reliant on experiential knowledge, the challenge of applying patient-centred care models, and the negative effect of unrealistic beliefs about prosthetics on patients and staff. This study contributes to a limited pool of literature articulating the experiential knowledge of staff in the context of rehabilitation after major lower limb loss, facilitating the translation of practice-based evidence into evidence-based practice.

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In the United Kingdom, there are 35 National Health Service (NHS) Prosthetic and Amputee Rehabilitation Centres that provide a service to those with limb deficiency from all causes (Research and Disability Clinical Reference Group, n.d.). Approximately 65 per cent of patients who experience major lower limb amputation (MLLA) will be referred to a rehabilitation centre for consideration for a prosthesis (Robinson, Sansam, Hirst, & Neumann, 2010). The patient will begin prosthetic rehabilitation once the limb has been manufactured, learning how to don and doff the limb, adjust the fit using prosthetic socks, and practicing walking. Where patients are able to attend every day, rehabilitation usually lasts for five to six weeks (St George's University Hospitals, 2018). Despite this extensive contact between staff and patients during the early months after MLLA, and the increasing profile of limb loss in healthcare services, little attention has been paid to the experiential knowledge (i.e., knowledge gained through direct encounter with a person, subject, or thing; Burnard, 2005) of staff working in MLLA rehabilitation services. One exception, van Twillert, Geertzen, Hemminga, Postema, and Lettinga (2012), explored the complexity of establishing evidence-based practice in a prosthetic rehabilitation team. The authors reported that rehabilitation staff encounter a variety of problems when they want to implement the results of scientific research into practice, including lack of evidence, contradictory results, different classification systems, and diverging stakeholder interests, all against a background of continuous technological changes.

At the time of writing, there is a lack of data as to what constitutes best practice in MLLA rehabilitation (Cumming, Barr, & Howe, 2006). As a result, staff working in this context rely heavily on their experiential knowledge to guide and inform practice. However, van Twillert et al. (2012) noted that this experiential knowledge is rarely made explicit in prosthetic rehabilitation. More research is needed that explores and articulates the experiential knowledge held by rehabilitation staff to make this information suitable for sharing (e.g., with other healthcare professionals and service providers) and, thus, for training and service

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improvement (van Twillert et al., 2012). Making knowledge accessible in this way also permits discussion of what constitutes relevant knowledge (as opposed to tradition or dogma) in this field of practice. This study seeks to address this omission by exploring the rehabilitation process from the perspective of those who work directly with patients throughout this journey.

The aim of this study is to explore the experiential knowledge of patient-facing staff working in a variety of disciplines in a prosthetic rehabilitation centre in the United Kingdom. Three broad questions will be explored: first, how do members of staff at an NHS MLLA rehabilitation centre experience their roles? Second, what challenges do these individuals encounter in their roles? Finally, what is their understanding of the primary challenges faced by patients during the first year after MLLA? Through this final question, we aim to offer a novel perspective of the recovery journey that complements extant reports from the patient perspective (e.g., Gallagher & MacLachlan, 2001; Liu, Williams, Liu, & Chien, 2010; Norlyk, Martinsen, & Kjaer-Petersen, 2013). It is hoped that by making explicit the experiential knowledge of rehabilitation staff, this study will enable us to take a step towards the transformation of practice-based evidence into evidence-based practice and, consequently, service improvement.

### **Method**

#### **Context of the Research**

This research took place at a UK-based NHS amputee rehabilitation centre. The rehabilitation centre is located in a community hospital but operates as a relatively self-contained unit comprising a medical clinic, rehabilitation gym, prosthetic workshop, and consultation rooms. Patients attending the centre have undergone MLLA due to a variety of causes including vascular conditions, trauma, infection, disease, or congenital defects. Patients usually attend full-time for several weeks post-surgery, either on an inpatient or outpatient basis, to learn to use a prosthetic limb. After discharge from the initial rehabilitation phase,

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patients will continue to attend the centre periodically throughout their lifetimes for ongoing health checks and prosthetic reviews.

It is also important to note that not every patient is suitable for prosthetic rehabilitation. Walking with a prosthesis requires a considerable increase in energy expenditure over and above 'normal' walking (approximately 30 per cent for transtibial and 70 per cent for transfemoral amputation; Stewart & Trimmings, 2008). The average age of users of NHS rehabilitation services post-amputation is 65, and many are suffering from secondary conditions such as cardiovascular or cerebrovascular disease, diabetes, cancer, or other injuries (Limbless Statistics, 2013). Therefore, many patients do not have the requisite strength and fitness to safely operate a prosthesis and accommodate the additional energy demands (e.g., Robinson et al., 2010).

### **Sampling and Participants**

Ethical approval was sought from and granted by the first author's University Research Ethics Committee, the NHS Research Ethics Committees, and the Health Research Authority. A maximum-variation, criterion-based purposive sampling strategy (Sparkes & Smith, 2014) was used in an attempt to represent the views of the multi-disciplinary team. To be eligible to participate, all participants were required to be aged 18 years or over, not suffering from cognitive impairment, and currently employed in a patient-facing role in the rehabilitation team at the centre. Characteristics accounted for in the maximum variation sample were role type and number of years spent working with MLLA patients. In the context of this research, those in junior positions had less than three years' experience and were in rotational positions, remaining in role for only six to nine months. Those in senior roles had more than five years' experience and were in static positions. A total of 11 members of staff were recruited and gave informed consent to participate. All participants were female, as there were no male staff working in the sampled groups at the time of study. As a result, this study lacks a male

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perspective, which would be an interesting avenue for future research. The sample included one clinical psychologist, one senior nurse specialist, one prosthetist, one team leader, two occupational therapists and five physiotherapists. Two physiotherapists held rotational positions, while the remaining nine participants were permanent members of staff. Length of time spent working with individuals with limb loss varied from six months to 30 years, and level of seniority varied from band five (first role as a graduate) to band eight (team lead).

### **Data Collection**

Traditionally, medical research has been dominated by positivist methods such as randomised clinical trials (e.g., Watts, 2011) and objective performance indicators such as waiting times (Pope, van Royan, & Baker, 2002). However, as noted by Hagger and Chatzisarantis (2011), "... adherence to a single theoretical or methodological approach is not only dogmatic and, frequently, born of prejudice and lack of understanding, but also detrimental to understanding and developing unique and new perspectives on behavioural phenomena" (p. 275). Recommendations have been made to embrace qualitative research and alternative paradigms in which knowledge is viewed as multiple, situated, and socially and historically bounded (e.g., interpretivism). Such paradigms enable us to explore "the cultural contexts of health – that is, the practices and behaviour that groups of people share and which are defined by customs, language, and geography" (Greenhalgh, 2016, p. ii). The unique contribution made by qualitative research in this respect is being increasingly recognised within domains such as healthcare quality (e.g., Pope et al., 2002), evidence-based medicine (e.g., Green & Britten, 1998) barriers to change implementation (e.g., Grol, 1997) and the transition from hospital to home (e.g., Hodson et al., 2016). This research was underpinned by interpretivism; that is, ontological relativism (i.e., reality is multiple, created, and mind-dependent) and epistemological constructivism (i.e., knowledge is constructed and subjective) (Wadey & Day, 2018).

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At the onset of data collection, the first author had spent five months embedded in the research setting engaging in observation, interaction with staff and patients, and work as a contracted volunteer for up to two days per week within the hospital (for reflections on this period, see Sanders, Wadey, Day, & Winter, 2019). Each member of staff took part in a semi-structured interview lasting between 28 and 87 minutes (average = 67 minutes). Semi-structured interviews were used to enable and encourage participants to speak of their experiences in their own way and through their own lens. This approach allows researcher and participant to engage in a mutual dialogue, where the initial topics envisaged by the researcher may be adjusted and restructured during the course of the interview in light of participant responses (Smith & Osborn, 2008). All interviews took place in a meeting room at the rehabilitation centre at a time of the participant's choosing, and were audio recorded with permission. The potential topics envisaged for this interview were developed directly from the research questions of this study, and included: the individual's career path to date, experiences working at the rehabilitation centre and with MLLA patients, any challenges she had faced and how she had dealt with them, and what she believed to be the primary challenges facing individuals undergoing rehabilitation after MLLA. Participants were also given the opportunity to discuss any experiences or topics that they considered relevant. After each interview, the first author made a note of any initial thoughts or reflections in a reflexive journal, allowing any unexpected or interesting concepts to be explored in more detail with subsequent participants (Williams, Ma, & Martin Ginis, 2017).

### **Data Analysis**

To provide the fullest possible understanding of the participants' perceptions, inductive thematic analysis was used to systematically identify, organise, and achieve insight into patterns of meaning across the data set (Braun & Clarke, 2012). Through focusing on meaning *across* a data set, thematic analysis allows the researcher to make sense of collective meanings

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and experiences. To start, the first author transcribed each interview verbatim. Rather than a simply mechanical act, the transcription process was an interpretative one enabling her to build familiarization with the data and begin to create meanings (e.g., Lapadat & Lindsay, 1999). This process was complemented by reading and re-reading the transcripts and making notes on initial ideas about data content. The second stage of analysis involved generating codes to identify and provide a label for potentially relevant features of the data. These codes were a mix of descriptive and interpretative labels that acted as shorthand during latter stages of analysis. The next stage involved sorting the different codes into potential themes. The first author collated relevant coded data extracts under the identified themes, then reviewed the themes in relation to the coded data, the entire data set, and the overall story they told about the participants' experiences. Finally, a report was produced that provides a concise, logical, coherent, non-repetitive, and interesting account of the story the data told, both across and within themes (Braun, Clarke, & Weate, 2016).

### **Research Quality and Rigor**

Five practical strategies were used to evidence the credibility, rigor, generalisability, and significance of this research. The first strategy was author self-reflexivity, achieved through the first author's use of a written journal to understand how she affected the data collection and analysis process. The first author also presented her interpretations of the data to the co-authors, who acted as 'critical friends' by exploring, debating, and reflecting upon possible alternative interpretations of the data (Sparkes & Smith, 2014). To increase reflexivity and enhance transparency, the research activities and decision-making processes were documented in an audit trail (Cresswell & Miller, 2000), which was reviewed and interrogated by the co-authors. In the pursuit of credibility, thick description (i.e., detailed participant quotations) is provided in the results section to account for the specificity and circumstantiality of the data, which may otherwise appear divorced from its context (Tracy, 2010). Thick

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description also provides the reader with evidence to reflect upon and to make connections with their own lives or the lives of others and may also enhance naturalistic generalisability and transferability (Smith, 2017). Finally, the identified themes and proposed practical implications were presented to a group comprising five participants interviewed during the initial data collection, and three new members of staff, to gain a sense of generalisability (Wadey & Day, 2018). Staff were invited to reflect on which themes (if any) resonated with them, whether they recognised their own experiences in the data, and any other ideas they might have to address the issues raised. Through this process of active reflection, staff reported that the findings overlapped with their own experiences, and a space was created for the less dominant voices and perspectives to be heard. For example, the presentation of findings that challenged the views of the senior members of the group enabled junior staff to voice their opinions and experiences, even where these diverged from those of their supervisors. This gave a fuller picture of the dynamics between different groups of staff in the centre and elaborated upon the practical implications presented.

### **Results**

#### **Defining Successful Rehabilitation**

This theme explores how staff define successful rehabilitation and how this definition differs between participants with different roles and experience. It also explores the ways in which more experienced staff encourage patients to adopt a multidimensional and individualised definition of successful rehabilitation. Staff believed that a key element of successful rehabilitation involved making positive changes in the lives of their patients, enabling them to move on from the trauma of MLLA. One senior member of staff explained, “it’s very much a moving forward stage, so something horrible has happened to them [the patients] but now, on the whole, they’re moving forwards.” Yet, while all the participants derived satisfaction from enabling patients to move forward, their perspectives on what



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constituted positive change evolved with experience. This was exemplified by junior physiotherapists, who focused on the importance of visible progress, often comparing their recent placements in other hospital services to the obvious progression they witnessed in MLLA rehabilitation (i.e., the transition from sitting in a wheelchair to standing and walking). One junior physiotherapist commented: “I like it here because the patient comes and there are clear, objective progressions, whereas in neurological rehabilitation you’re looking for, I don’t know, a flicker in their big toe or something.” However, senior staff and those in non-physiotherapy roles, such as occupational therapists and clinical psychologists, also recognised the risks of adopting and promoting a unidimensional definition of success focused solely on walking. Instead, they embraced a holistic approach to successful rehabilitation that emphasised ‘living well’ (i.e., the patient being able to do the things they want to do). This shift in focus from walking to living well occurred gradually via a combination of first-hand experience in their roles and supervision from more experienced staff. One senior member of staff reflected on her own development across her career:

I remember being them [junior physios] and thinking, ‘We can treat everybody, we can make a difference to everybody’, and it took me quite a long time to recognise that, or to feel comfortable that, not always getting a patient to use a prosthesis wasn’t necessarily a failure.

Senior staff also encouraged patients to engage with a multidimensional recovery process that included taking responsibility for their health and adopting positive behaviors. One senior practitioner described how she sought to equip patients with a broad understanding of successful rehabilitation and encourage these healthy behaviours:

Can they [the patients] see the reasoning as to why they’ve had the operation done to them in the first place? Am I ever going to get through to them that the fact that they smoked 50 cigarettes a day for the last 40 years is possibly the reason why they’ve had

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the amputation? Some patients, you're never going to be able to get them to see, and I guess that's partly because perhaps they don't want to see that they might have been the cause of their amputation, and I understand that, but I always found it frustrating. So, if somebody's wound's not healing but they're still going out and smoking their fags permanently and having a rubbish diet, well, I've not done my job either if I don't try and get them some help to try and tackle that. Admittedly, they have to want to be able to do that, but I have to try.

This participant accepted this process relied on patients' willingness to change, but more junior members of staff described feeling demotivated and frustrated when their attempts at encouraging behavior change seemed to have no effect on patients. These accounts suggest that effecting long-term behavior change is more challenging than supporting patients' functional progression. In some ways, it was more straightforward for staff to define successful rehabilitation purely in the context of walking than to adopt a more holistic perspective on what constitutes real success.

### **The Complex Reality of Patient-Centre Care**

This theme explores the delivery of patient-centred care in an MLLA rehabilitation context. In particular, this theme raises awareness of the difficulty of adopting this approach with patients who have no prior understanding of the rehabilitation process, and the pressure it places on junior staff with little experiential knowledge. The staff shared an understanding that delivering patient-centred care involved fostering proactive problem-solving and self-management in patients so they could direct their own recovery journeys. To this end, several members of staff spoke of using goal-setting to encourage patients to individualise their rehabilitation and shape their expectations of what they could realistically achieve. However, staff were also aware that it was difficult for patients to set individualised goals when they had

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no experience with the rehabilitation process. One senior practitioner described her approach to patient goal-setting as follows:

When you first see a patient and take their assessment, I always phrase it to them as, “This is your situation now. What are your problems, frustrations, issues or things that worry you or that you can’t do at this point in time?” They give a little list, and for some of them it may be, “I can’t walk.” For others, it may be, “I’m at home in my wheelchair and I can’t reach the cupboards,” that sort of thing. So, then I say, “Ok, so what would be your goals, what was it you want to achieve by being fitted with an artificial leg?” So, they may come up with the same things, “I just want to be able to walk around my house,” or, “Actually, yeah, I want to be down on the golf course in six weeks,” or, “I want to be able to climb Mount Everest in six weeks.” So, you start to read the patients and if someone says something where you’re thinking, uh-oh, that’s really off the scale of expectation, then I try to say, “Well, while you’re here at this initial rehab, it’s the first time you’re being fitted with an artificial leg, this is probably what you are going to achieve by the time you leave our department.

While more experienced members of staff could draw upon their experience to shape patients’ expectations during goal-setting conversations, juniors lacked confidence as they had insufficient clinical experience to anticipate realistic outcomes and likely recovery trajectories. This raises questions as to how effectively patient-centred care can be delivered when neither the patient nor the member of staff supporting them has a clear idea of what might constitute appropriate rehabilitation goals. Even senior staff tended to use non-committal language to communicate their expectations to patients, as described by one practitioner: “I quite often say to people, ‘I don’t know anyone that’s achieved that in your particular situation, but I’m ready for you to prove me wrong’”. However, while senior staff felt more comfortable and competent developing personalised rehabilitation plans that encouraged patients to take responsibility for

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their health and fostered positive behavior change, they often lacked the time to do so. Junior members of staff, who had more time to spend on such activities, were less able to identify what might be a realistic goal or how that could be broken down into appropriate steps.

Participants' definitions of patient-centred care also included patients being proactive in their rehabilitation, for example, selecting an exercise to complete rather than waiting to be told what to do while the staff attended to other patients. However, some also recognised that they did not always explicitly communicate these expectations to patients. One junior practitioner described how she saw her physiotherapist role as advisory, with the patient in control of the rehabilitation process, yet did not explain this to patients:

*Participant:* It's following our advice but being the locus of control, being your own case manager.

*Interviewer:* Do you think you make that clear to patients?

*Participant:* Well, I don't blatantly say it out loud, I suppose. But I think, I hope to be able to do it by asking them, "So, what are your goals for the next seven weeks?" and, "This is the process." But I suppose, this is completely unknown to them and they're just going through the process and, therefore, they are guided by us because they don't know any better.

However, staff were also aware that empowering patients to direct their own activities carried risks, such as falling. Given that patients outnumbered staff at the centre, it was not possible for every patient to be supervised all the time during rehabilitation activities. When accidents did occur, even experienced members of staff questioned their clinical judgement. There are risks associated with walking on a prosthetic limb, and while some patients would be content to operate within the safe limits identified by staff, others would push boundaries and attempt more challenging activities than they were ready for. Thus, the successful delivery of patient-

centred care in this context relied upon patients having sufficient awareness of the risks inherent to prosthetic use and being able to balance that awareness with the desire to progress.

### **Organizational and Interpersonal Challenges**

This theme explores the challenges encountered by staff in the course of performing their roles. At an organizational level, reduced funding and staffing levels, together with the need to educate juniors and students, increased the pressure on the senior staff. The rotational nature of the junior positions also presented challenges for those in static roles, as each rotation brought with it new recruits of varying experience and skill, and the experiential knowledge accumulated by the previous incumbents was lost. Staff also spoke of the challenges engendered by the close relationships they developed with their patients, and the need to maintain a degree of professional and emotional distance.

Many of the challenges described by staff pertained to a lack of funding, which limited the size of the rehabilitation team and the hours they could work. This had altered the nature of some participants' roles, reducing the time available to work with patients and increasing the pressure to assess and refer on to other services. For example, senior staff recalled having previously taken patients out of the centre to tackle real-world tasks such as using escalators or public transport. Now, such opportunities were limited by lack of time, lower staffing levels, and more stringent health and safety rules. Limited funding also restricted the components that prosthetists could prescribe, which one senior member of staff described as the most difficult part of her job: "I think now, actually, the hardest part is money constraints, because we have to keep to a budget, yet we're being told we have to see more patients but spend less money, and that, to anybody logical, doesn't make any sense."

The staff in senior roles also found their remit increasing year-on-year as they were expected to deliver patient care alongside educating new recruits and completing project work (e.g., audits and developing eligibility criteria for new prosthetic technology). Some expressed

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concern that the increased pressure on their time was having a detrimental impact on the patient experience. One senior practitioner explained:

What we don't want to happen is that we're trying to think so much about our students, junior staff, and the groups of patients such as the MPK [microprocessor knee] patients at the moment that, for want of a better word, our bog-standard patients don't miss out from their experience of rehab and going through it. They're our bread and butter really. But even a single below-knee [amputation] is life-changing for somebody and they deserve just as much attention from the MDT and from us.

Another senior staff member worried that she was becoming less compassionate and more abrupt as she had less time to spend listening to her patients. She described the rotation of junior staff as a "rollercoaster or a hamster wheel, where they move on and you start again." Senior staff desired not only greater stability of junior staff, but also the option to choose who entered the team, having experienced significant variability in the quality of the new recruits. The junior staff also experienced challenges upon entering the team, describing some of the more senior members of staff as controlling and unwilling to accept change, which the juniors felt compromised their development as practitioners. One junior practitioner commented:

There are certain things that I suggest and it's a bit like, "Oh well, we've done that, and it doesn't work." I think they're very much like, we're happy to have ideas and suggestions but, ultimately, I think they'll have the final say. I can understand; I'm here for nine months whereas they're going to be continuing it. But it's different in other rotations where team leads or band sevens have been happier for you to try things and, if it doesn't work, that's part of the learning process for myself and the team as well. So, I suppose, in that sense, I don't feel like I've had much of a service development role, but maybe that's because they prefer to have that control over their service.

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At an interpersonal level, staff experienced challenges as a result of the close relationship they developed with their patients through the lengthy rehabilitation process. As one senior practitioner reflected: “Some of my patients I know from the first day I walked on the ward. . . . you feel like you’ve, sort of, grown up together.” Every member of staff described emotionally investing in their patients, which was exemplified through becoming part of the patients’ support networks. For example, some patients continued to contact members of staff directly even after leaving the hospital. The occupational therapists, in particular, described acting as advocates for their patients, particularly when liaising with disparate health and community services, as one senior practitioner explained:

I think if you let people know, ‘I’ve made that phone call, I’m chasing it’, they have confidence in you and that helps a little bit. Even if you can’t change it, I think if they know you’ve got their back and you are actually actively doing something and not just sitting back. It gives them little bit of confidence that someone is there fighting their corner.

However, while the staff valued this close relationship, they also recognised the potential negative impact of becoming emotionally involved with patients, not only upon their own well-being, but also on the patients’ recovery. For example, staff sometimes found their sense of responsibility for their patients permeated their lives outside the hospital. One senior staff member explained: “I can’t tell you the number of times in the middle of the night I’ve got up and, well, woken up and found myself sitting on the edge of the bed ready to jump up and jump out of bed to save someone from falling. . . . And it’s only because one doesn’t wear an awful lot in bed that you go, ‘Oh, I wouldn’t be dressed like this saving such and such’.” This sense of responsibility motivated staff to go above and beyond the immediate remit of their roles in order to support the patients. However, they recognised that, in some instances, providing this support had a negative effect on them (being taxing and placing additional

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pressures on their time) and upon the patients (causing them to become less proactive and independent, and delaying access to support). One senior practitioner commented:

I think there is a bit of learned helplessness, particularly if they've been in hospital for a long time. There is that expectation that you will sort it out. So, they will come back to me and go, 'Can you sort this out?' But it's like, you're at home, you have the number for the wheelchair repairs [service], you have to just make the phone call, and now I'm going to make the phone call on your behalf, but you could have just done it yourself.

Staff sought to address these challenges by maintaining an emotional distance from their patients. This enabled them to navigate potentially challenging scenarios such as delivering difficult messages or making decisions the patient may not agree with.

### **Who Provides Psychological Support?**

This theme explores participants' experiential knowledge of the psychological support patients required after MLLA, and how the limited clinical psychology resource available at the centre affected other members of staff. Participants in all roles felt partially responsible for providing in-the-moment psychological support to their patients, which was particularly challenging for junior physiotherapists, who lacked the experiential knowledge or formal training they believed they needed in order to perform this element of the role. This issue illustrates the uniqueness of the MLLA physiotherapist role, which demanded a more holistic skillset than junior staff had encountered in other roles.

Participants believed most patients would require psychological support at some point during their recovery. However, the senior staff had learned through experience that some patients were better equipped to cope with MLLA than others, depending on their personality, previous experiences, and coping resources. One senior practitioner reflected:

There are also some patients whose lives have been very easy, for want of a better word, and suddenly this comes along, and they don't have the mechanisms to cope with it.



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Sometimes you find people who've had a really tough time are actually better at coping because their life's always been in turmoil and this is just another spoke in the wheel. Staff also described how the rehabilitation process brought to light patients' past difficulties or traumas. One senior staff member commented: "Coming through rehab doesn't plaster over cracks in relationships or cover up things in the past; it normally opens them up." Another senior practitioner added: "Amputation is a loss and triggers other losses to come to the surface, and also other traumas. If anyone's had any previous traumas, often they are brought back or brought up by the amputation. So, you do get a certain number of patients who have long-term issues."

Despite patients' need for psychological support, the centre only had limited access to clinical psychology services. As a result of time limitations, the role of clinical psychologist at the centre had become primarily focused on assessing and referring rather than on treating. Consequently, the entire MDT played a role in supporting patients psychologically. Participants described how patients would open up to them while undertaking a rehabilitation task, such as practising using the kitchen or climbing stairs. One senior practitioner explained:

Quite often, if we do the classic 'make a tea', and they wonder why they're doing it, you explain that on a practical front, you know, 'You're bending, you're reaching, you're walking on different surfaces, you're chatting, the cognitive load, blah blah blah'. But actually, you sit down and chat to them over a cup of tea, and that just seems different from therapy, and that's the time I normally talk to them about how they might be feeling about it.

While senior members of staff felt comfortable providing this support due to their experience with patients and in life outside the centre, junior staff found this challenging, having received no formal psychology training. For example, one junior practitioner was reluctant to encourage patients to open up to her:

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*Interviewer:* If patients don't want to discuss their accident, do you try and push it?

*Participant:* I don't tend to, no. I don't think there's a need to do that. It's happened and they're ready to come to rehab, so just crack on with that. I'm just not very good at dealing with that sort of stuff.

*Interviewer:* What makes you say that? What would someone who is "good" at that do?

*Participant:* I don't know, sit down and talk about it? I don't know. I think, say, if one of the patients was having a bit of a crisis, I'd probably tend to go and speak to someone that I know is, or think is, better at dealing with that. I don't know. I'm not very sympathetic.

One senior practitioner expressed concern that the focus on functional progression in the gym might deny patients the opportunity to process what had happened to them, observing: "People [staff] do sometimes forget the psychological bit and they forget that people [patients] are grieving. So, people [staff] are still surprised when people [patients] burst into tears in the gym and I'm like, 'That's very normal! Don't panic!'" These discussions revealed a conundrum whereby senior staff, who were more comfortable providing patients with psychological support, lacked the requisite time whereas junior staff, with more time, felt unable to do so. Senior staff attempted to mitigate this issue by purposefully allocating to juniors those patients who presented with less complex physical and psychological issues. However, most patients would require a degree of psychological support at some point during their rehabilitation journey, so this strategy did not completely relieve junior staff of providing this service.

Participants also emphasised the lack of clinical psychological support available to patients throughout the NHS and in the community, where there is little provision for those who require ongoing support but are not psychotic. As a result, the staff were concerned that many individuals struggling post-MLLA became 'lost in the system' after leaving the centre, as one senior practitioner explained:

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*Participant:* There are patients who have been referred to me, come back at six weeks, and they're depressed, and I'm like, what am I going to do? They are stuck in a room, they can't actually get out of the house, they haven't got family, no one is visiting them. What am I going to do? Who wouldn't be depressed?

*Interviewer:* And what do you do?

*Participant:* I struggle. We try and get local services. I work with the occupational therapists to try and get voluntary services involved, you know, maybe befriending teams. But that's always difficult because you don't know what their local resources are. We try and refer them to the GP, but then they probably don't do anything anyway. They probably get left.

This participant's comments revealed a gap in the psychological support services available to those experiencing difficulties post-MLLA. This reinforces the perception that psychological support provided by the MDT at the centre might be the only such support patients receive after loss of a limb.

### **Prosthetic as a Panacea**

This theme explores staff's perceptions of the effect of the increasing profile of MLLA and prosthetics on patients' expectations of rehabilitation. It also addresses the impact of these unrealistic expectations on the rehabilitation process. Overall, the staff described the increasing visibility of individuals with MLLA in the media as a positive development that normalised limb loss and enabled their patients to feel more confident re-entering society. Yet, they also expressed concern that the media portrayal of prosthetic use was unrealistic and overly positive, perpetuating the view that a prosthetic could replace the body part that was lost. One senior practitioner reflected on the inaccurate messages she had seen in the media after the London 2012 Paralympics:

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They had someone [on TV], I think it was someone who wanted a microprocessor knee and didn't have one. Anyway, he was carrying the flame I think and had a fall, and then the commentators went, "If he'd had the knee he needs, that wouldn't have happened". And that's quite a difficult claim to make, actually. Completely not accurate and they didn't consult with any kind of prosthetic expert, of course. So, I do think the media has a responsibility for selling the idea to patients that you get this [prosthetic] and you won't fall over, which is not true.

Participants also noted that surgeons who carried out the amputations sometimes contributed to unrealistic expectations of life with a prosthesis. Specifically, surgeons often painted an overly optimistic picture of life with MLLA as they overestimated what prosthetics could offer. Consequently, many patients arrived at the centre with little or no knowledge of the difficulties of learning to walk with a prosthesis, or the physical strength, fitness, and cognitive skills it demands. These unrealistic expectations often extended to life after rehabilitation. For example, many patients were shocked when staff recommended that they have a wheelchair at home for the rest of their lives, as they would not be able to wear a prosthetic every day due to complications such as sores and swelling.

The staff also believed that patients' families lacked understanding of the challenges of walking with a prosthesis and, as a result, some put their relatives under pressure to go through prosthetic rehabilitation. One senior practitioner explained:

A lot of patients have the perception, or their families, people around them have the perception, 'You've had the amputation, you're going to get a leg, and then you're going to be able to do all the things you want to do', because they don't understand how much effort it is just to put the thing on, to walk in, or the level of balance and control you need to be able to walk.

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In order to mitigate this pressure, participants described the importance of promoting a realistic picture during the process of deciding whether to undertake prosthetic rehabilitation. One senior practitioner explained:

That's the really important question for a patient to think about: what's going to be the added value to my life by having this piece of prosthetic componentry? And that's one I would really want them . . . think very honestly and hard about . . . what is this really going to add to your life? What bit of your life is this going to make better? So, why are you putting yourself through a very tiring, very hard work kind of experience, to no real gain? Apart from the fact that you've had a go, you've seen what it's like, you've tried it, and that's very positive. But then you need to cut your losses. Let's not carry on doing this and exhausting it and actually in the end making you feel like a failure.

Staff explained that patients were generally unaware of the cost of the equipment they were provided with, and of the financial pressure MLLA placed upon the NHS. Not every patient would benefit from high-end components, yet some still made requests after comparing their own prosthesis with those they saw other patients using. If patients were provided with components that did not live up to their (unrealistic) expectations, they tended to scapegoat both the prosthesis and prosthetist for problems that were often physical or psychological in nature (i.e., not a result of the prosthesis). One senior practitioner observed:

I think patients put a lot of expectation in their leg, so the prosthetist is in the firing line. It's always, 'The leg's not doing this. The leg's not doing that.' When actually it's them that's not doing the exercises. We often get blamed for life problems that are for other reasons or health problems, like, 'Ah well, I can't exercise because my leg doesn't fit properly'. 'Well, why doesn't your leg fit properly?' I think we're the scapegoat a lot of the time.

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Participants noticed that the tendency to blame the prosthesis increased as patients aged and became less physically able, or as their rehabilitation plateaued. One senior practitioner explained how the prosthesis could also function as a placebo for other problems, even those of a psychological nature:

In the prosthetic office, there is historically something called ‘The Magic Corner’ where, if someone’s really, like, you can’t sort them out, you’ll take the leg away for 15 to 20 minutes and then take it back and ask, ‘How’s that fitting now?’. ‘Oh, that’s perfect!’ And you’ve literally done nothing. It’s just, it’s psychological sometimes. It’s just, like, a placebo. They think it’s making them better and because it’s been gone and you seem to have done something...I’ve definitely seen it happen and it does work.

This discussion reinforces the emphasis patients place on the prosthesis as both the facilitator and barrier to successful rehabilitation, such that even psychological challenges are perceived to be caused or alleviated by a worse or better prosthetic fit.

### **Crash Landing**

This theme explores staff’s perceptions of the transition from the rehabilitation centre to home. This was agreed to be a critical and challenging period for patients, as they encounter the reality of day-to-day life with MLLA in an environment not designed for prosthetics and wheelchairs, and in a society in which they are a minority. In particular, staff described how the rehabilitation gym was not a good representation of day-to-day life, meaning that the reality of living with MLLA would not become apparent until patients were out in the ‘real world’. One senior practitioner observed:

When they go home it’s not the end of their rehab; it’s actually the beginning of learning how to live life as an amputee. It’s a bit like driving, you know? You learn, you have your driving lessons with your instructor and you think you’ve passed your test and

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you've learned and, actually, it's when you're out on the roads by yourself that you realise you haven't learned at all and this is where the learning begins.

Staff described how patients could be discharged into unsuitable housing (either because no suitable alternative was available, or the patient did not wish to move) or into a property awaiting adaptation. Some patients were forced to live in a microenvironment; eating, sleeping, washing, and toileting in one room. Staff explained how such issues are not prioritised by social services, meaning that patients in social housing may wait for a year or more before adaptations are made. The staff believed the home environment and patients' ability to function in it played a crucial part in the adjustment process, and worried for those who were discharged into inaccessible and isolated environments with no routine or peers to support the transition. One senior practitioner explained how some patients needed to experience living in what she deemed to be an unsuitable home before considering alternative options:

Quite often, getting them home with the houses they live in is a challenge, but they want to go home, so I will get them home...with compromise. That's the key words: with compromise. And sometimes they have to go back to that home to realise that that's the compromise they're making, and whether they want to actually live with that compromise or not.

The staff believed that even those patients living with family members felt isolated as nobody in their home environment understood what they were going through. By treating the patient differently before and after MLLA, some families made it more difficult for patients to come to terms with losing a limb. One senior practitioner commented: "I feel that we treat people quite normally, and [patients] could deal with it more, but at home it was much more difficult to be treated normally, because everyone's treating you...it's as if you're special, isn't it?" Even those patients who wanted to participate in activities with other individuals with MLLA

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often struggled to do so due to barriers such as lack of transport, lack of support, and loss of confidence, which contributed to reduced activity levels. One senior practitioner explained:

Over the years we've tried to encourage people to carry on going to the swimming group that we used to go to. You know, lovely disabled access, a group of amputees there, but everyone talks about it so much, the barriers that stop people doing it. They get home by themselves and then they think, "I just can't do it." Then they come back [for reviews] and they're not really effectively using their artificial leg either. They think, 'Oh, actually, no. I found it really hard so my leg's in the corner, in the cupboard'.

The occupational therapists, in particular, spoke of how beneficial it would be to be able to offer a graded discharge, whereby patients could move into an assisted living environment and learn to live independently with MLLA but with support available should they need it. However, it was challenging to source support for patients who needed it due to the lack of community services available.

Overall, staff felt that patients left the centre unprepared for the challenges that lay ahead. They also acknowledged the minimal impact they had on patients' lives outside the hospital, and that the review system did not necessarily identify those who were struggling. Although patients were invited to return to the centre for a review appointment at six weeks and six months post-discharge, the gap between appointments could feel lengthy to a patient who is struggling. The staff also felt that lack of time turned the reviews into a tick-box exercise rather than an opportunity for in-depth discussion. Although returning patients completed the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) and were referred on to a clinical psychologist if their scores indicated the presence of depressive symptoms, participants questioned how effectively they could identify those in need of assistance. One senior practitioner reflected:



We do have areas where we could highlight if a person is struggling, and we have things that we can offer them. Some patients don't want to take us up, some patients may well fall through the net because maybe they don't come for their six-week, six-month [reviews]. Maybe they're sitting out there floundering away.

However, in the absence of greater time, resources, or improved community services, the participants felt unable to do more to support patients after discharge from the centre.

### **Discussion**

With this study, we have made novel contributions to the MLLA rehabilitation literature in four ways. First, we have added to a very limited pool of literature exploring and articulating the experiential knowledge of staff in the context of MLLA rehabilitation. Second, we have provided a novel exploration of the experiences of junior staff in rotational roles, the difficulties they face in an environment that relies heavily on experiential knowledge, and the effect of this rotation on senior staff. Third, we have illustrated the challenges associated with the practical application of patient-centred care models in MLLA rehabilitation settings. Finally, we have described the negative effect of unrealistic beliefs about and expectations of prosthetics on both patients and members of staff.

Through this research, we have contributed to an understanding of how staff develop their practice philosophy in the context of MLLA rehabilitation. To illustrate, the staff described their roles as sources of pride and satisfaction through making a difference to each patient. However, the quality of this 'difference' and participants' definitions of what constituted successful rehabilitation varied between those with different roles and experience. For juniors, success was judged primarily on the basis of patients' functional achievements; at the point of discharge, was the patient able to walk with a prosthetic limb? Through experience, this focus on visible and objectively measurable functional progression developed into a more holistic and multidimensional approach to therapy that valued quality of life above functional

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capability. This aligns with the findings of Lloyd, Roberts, and Freeman (2014) who reported that the focus of physiotherapists working in a stroke rehabilitation setting shifted with experience from an initial mechanistic view to a greater focus on patient empowerment. In the context of this study, this shift seems indicative of a tension between the values engendered through physiotherapy training and the health service structure in the UK (i.e., measurable functional progression), and the values of staff with experiential knowledge of supporting recovery after MLLA (i.e., living well). We suggest that addressing this tension explicitly during the supervision process may support novice practitioners in developing a whole-person perspective that promotes patient agency in addition to functional progression.

Murray and Forshaw (2014) argued that, particularly in the West, health services are configured in ways that value and promote prosthetic use. When considered alongside the present findings and the characteristics of the MLLA population in the UK (primarily elderly and suffering from comorbidities), questions are raised with regards to the extent to which this philosophy is adaptive for the patient or cost-effective for the NHS. While there are undoubted physical and psychological benefits to enabling MLLA patients to be physically active (e.g., Wadey & Day, 2018), should prosthetics be at the heart of this strategy? The accounts of senior staff interviewed here revealed a tension between their experiential knowledge of how to help patients achieve psychological well-being, some of whom may be hindered rather than helped by a prosthesis, and the norms operating in health services (e.g., surgeons, physiotherapy training) and more broadly (e.g., in the media). Given that individual subjectivities of limb loss and prosthesis use are influenced by the cultural norms which surround the person (Murray & Forshaw, 2014), this mismatch goes some way towards explaining the high expectations of patients entering into prosthetic rehabilitation, and also of their families.

Consistent with the limited number of extant studies exploring the presentation of prosthetics in the media (e.g., Murray & Forshaw, 2014; Sansam et al., 2014), participants

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believed the media gave an overly positive portrayal of prosthetic use that reflected neither the challenges of rehabilitation nor the experiences of most patients. We have also revealed more about the effects of high expectations and a too-positive view of prosthetic rehabilitation. For example, the staff believed that patients' high expectations were associated with perceived failure when they were unable to live up to those expectations, tending to scapegoat the prosthetic limb and the prosthetist who fitted it. This suggests some patients view the prosthesis as a panacea for a range of issues, from poor health to a lack of self-care and low motivation, thus absolving themselves of responsibility for any perceived failure. This was captured succinctly by the vignette of the Magic Corner, whereby patients believe the prosthesis has been adjusted and, thus, their problem 'solved', even when no changes have been made. While this scapegoating of the prosthesis probably has a protective effect with regards to short-term affect, it seems likely to have a negative effect on the patient's relationship with their prosthetist and, potentially, that patient's long-term physical and psychological health.

Staff also believed that unrealistically positive cultural norms with regards to prosthetic rehabilitation encouraged families to pressurise patients into undertaking such a programme even when it was clinically inappropriate (e.g., too physically demanding or not conducive to meeting the patient's goals). Similarly, Stabell and Naden (2006) found relatives' expectations and demands were often unrealistic in terms of what rehabilitation and community care could offer. Where there was disagreement between what the service could offer and the beliefs of the patient and family, members of staff were faced with the difficult task of managing expectations and successfully engaging the patient in decisions about care. However, even staff with many years' experience questioned their judgement in the absence of data. It is hoped that, by articulating staff's experiential knowledge, this study will facilitate the translation of practice-based evidence into evidence-based practice, thereby addressing van Twillert et al.'s

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(2012) comment that clinical knowledge in MLLA needs further study to make it suitable for informing service improvement.

In addition to questioning their judgement and practice, our participants sometimes perceived a disparity between their own goals and priorities, and those of their patients. The staff wanted patients to take a central role in their care, yet this was not always explicitly communicated, particularly in the case of junior staff. Further, patients were expected to lead their own care only within certain (possibly implicit) parameters set by the staff. When viewed in the context of previous findings, it seems plausible that, without explicit communication, patients may feel subjugated in a way that undermines the clinicians' attempts to practice patient-centred care. For example, Harrison and Williams (2000) reported that, where physiotherapists felt the power imbalance between themselves and their patients was not significant, the patients found it overwhelming to the extent that their experiences did not reflect the collaborative patient-centred care model promoted by government policy. Financial and organizational factors, as reported here, can also cause dilemmas in patient-clinician interactions and a deprioritization of patient-centred goals (Levack, Dean, Siegert, & McPherson, 2011). This may cause patients to perceive a lack of agency and that the staff do not care about them, which may contribute to a loss of trust in the rehabilitation team (Manderson & Warren, 2010).

The relationship between staff and patient, and the latter's engagement with physical rehabilitation, may be further complicated by the individual's response to the loss of a limb. Participants held varied beliefs about the role of physical rehabilitation in psychological recovery after MLLA, with some focusing on exercise as a means of processing the experience, and others on giving patients time to grieve before encouraging functional progression. This echoes the work of other researchers (e.g., McCreddie et al., 2010; Setchell, Abrams, McAdam, & Gibson, 2019) who have emphasised the pressure patients

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perceive to maintain positive affect throughout rehabilitation, which may preclude the expression of grief. Staff in the current study also described the limited clinical psychology support services available to individuals with MLLA, both in the rehabilitation centre and after discharge. This was not because the clinicians believed it was not needed, but due to a lack of funding and long-term mental health services to which to refer patients. Indeed, the pressure on NHS mental health services due to financial constraints and staff shortages has been well documented elsewhere (e.g., Pym, 2018). The present findings indicate that, in the context of MLLA rehabilitation, a lack of clinical psychology support resulted in the MDT becoming jointly responsible for monitoring and supporting the mental health of many patients. This contrasts with the best practice described by Harvey et al. (2012) in their report on rehabilitation services delivered to military veterans at the Centers for Excellent in Amputee Care in the USA. In these centers, all patients with limb loss are seen by the Preventative Psychiatric Consultative Liaison Service, which “ensures early evaluation and intervention, but also helps to destigmatize any negative perception about seeking psychiatric help” (p. 50). Within the context of the present study, where resources are limited, ongoing clinical psychology support (as opposed to assessment and referral) was reserved only for those who demonstrated clear psychological pathology, and rarely extended beyond the point of discharge.

The consequent demand upon the MDT to offer patients psychological support was an aspect of the role that junior members of staff, in particular, found extremely challenging, having received no psychological training at university or in student work placements. It is possible that some patient behaviours which junior staff ascribed to poor engagement (e.g., low motivation or dependence on passive therapies) may in fact be indicative of psychosocial challenges (e.g., depression, anxiety) that were not recognised and, thus, were overlooked (Gardner et al., 2017). Senior members of staff, in contrast, reported feeling more comfortable

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offering patients a degree of psychological support, yet lacked the time to do so. This illustrates a conundrum almost certainly experienced in other healthcare settings: senior staff have the expertise but not the time to support patients with subclinical mental health challenges, whereas junior staff have more time but lack confidence and expertise. Given the heavy burden of MLLA on NHS funds (Moxey et al., 2010), it seems unlikely that the provision of specialist psychology support for rehabilitation programmes will increase. Therefore, it may be more beneficial to focus on up-skilling those members of staff who spend the most time with the patients: the physiotherapists.

This challenge of providing patients with psychological support also raises questions at policy level around the practicality of patient-centred care against a backdrop of reduced funding and staffing levels, and the impact that has upon patient-facing staff at all levels. Similarly, lack of time and resource were the primary barriers reported by nurses in Turner et al.'s (2017) study of the provision of psychological support in a cardiac rehabilitation setting. In order to address this challenge, the authors recommended that the nurses coordinate with psychological well-being practitioners to provide psychological support in cardiac programmes. A similar approach could be utilised in prosthetic rehabilitation programmes, where staff are similarly time-constrained and struggling to provide psychological support alongside their additional workload.

This study also offers a novel perspective of the transition from hospital to home, which has received little research attention in the context of MLLA (for one exception, see van Twillert, Stuive, Geertzen, Postema, & Lettinga, 2014). Staff in the current study conceptualised discharge from the centre not as the end of rehabilitation, but as the start of a longer process. This is in line with extant literature indicating that the reality of living with MLLA does not become apparent until patients are living independently in their own homes (e.g., Horgan & MacLachlan, 2004). Staff perceived this transition to be the greatest challenge

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faced by individuals with MLLA, characterised by a loss of peer and staff support, reduced accessibility, and poor community service support (e.g., van Twillert et al., 2014). This study also offers an additional dimension to previous findings, illustrating the lengths that patients will go to in order to return to their own homes rather than moving to somewhere new and more suited to their needs. This highlights the unique significance of an individual's home along dimensions other than functionality (e.g., social and personal meaning), closer attention to which may enhance the transition experience (Hodson, Aplin, & Gustafsson, 2016).

Finally, members of staff felt somewhat out of touch with patients' experiences after their departure from the centre, as they doubted patients' honesty and the effectiveness of information-gathering during post-discharge review appointments. Sansam et al. (2014) reported similar concerns, suggesting some individuals prefer to be a 'good' patient and 'pass' the assessment rather than openly addressing their struggles. At the other end of the spectrum, staff in the current study described how other patients expected them to continue to solve any issues encountered, even once the patient had returned home. The staff recognised that, by acting as an advocate for patients during the initial rehabilitation phase, they risked the patients becoming less proactive in solving problems for themselves. This learned helplessness (Seligman, 1975) echoes reports from van Twillert et al. (2014) that, while some individuals with MLLA actively seek solutions to problems such as prosthetic fitting, others may maladaptively accommodate the issue (e.g., becoming less functionally active upon encountering prosthetic fitting issue) if assistance is not immediately available. The present findings, therefore, add weight to van Twillert's conclusion that it would be helpful to teach patients a generic approach to problem-solving during the initial rehabilitation phase to enhance patients' confidence, prepare them for the post-rehabilitation phase, and minimise functional decline. This patient education could be supported with practical training for junior staff in basic counselling and communication skills to help them feel comfortable listening to

patients, shaping their goals and expectations of life post-MLLA, and promoting self-regulation strategies. This would help address concerns highlighted by staff not only in this research, but in work by van Twillert et al. (2014), around patients' ability to cope with the transition from hospital to home.

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