

Title: Occupational therapists' experience of community seating provision for clients following a stroke

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Abstract

Background: Guidelines in the United Kingdom recommend that seating should be provided prior to hospital discharge after a stroke. Occupational therapists often advise on seating to maximise function and minimise risks associated with posture and sitting. Little is known however as to their experience of the seating provision process.

Aim: This study aimed to acquire a greater understanding of occupational therapists' lived experience of seating provision for clients following a stroke.

Method: The study drew upon hermeneutic phenomenology and eight occupational therapists were interviewed.

Findings: Four themes were identified including: a collaborative project, a race against time, unremarkable versus 'a battle on our hands', and out of our hands. Participants' experience varied greatly but appears to inform that seating is not always provided in time for hospital discharge. Participants seemed frustrated and conflicted when they faced barriers to seating provision and were not always able to meet clients' needs or practice client-centred care as they wished.

Conclusion: This study demonstrates a need to develop processes to allow prompt access to seating solutions during the stroke rehabilitation pathway. Occupational therapists may want to consider ways in which barriers can be reduced and further research to develop more effective pathways is recommended.

Key words: Occupational therapy, seating, stroke

Background

More than 100,000 people annually have a stroke and there are over 1.2 million stroke survivors in the United Kingdom (UK) (Stroke Association, 2017). The National Stroke Strategy (2007) radically changed the delivery of stroke care in the UK by promoting stroke specialist rehabilitation in hospital and the community. As a consequence, stroke rehabilitation generally follows a structured, multi-disciplinary pathway commencing on admission to a hyper-acute stroke unit, typically followed by a stay on an acute stroke unit. Some may then require further in-patient and/or community rehabilitation. Appropriate seating may be necessary in order to contribute towards effective rehabilitation and the National Health Service (NHS) is responsible to provide services based on clinical need and not the ability to pay (Department of Health [DH], 2000).

The term *seating*, in this study, refers to all types of chair including wheelchairs. A wheelchair is understood to be a 'device providing wheeled mobility and seating support for someone who has difficulty in walking or moving around' (World Health Organisation [WHO], 2008:11). Other seating may include upright armchairs, riser/recliner armchairs and tilt-in-space chairs (Collins, 2008). The term *specialist seating* is used to describe seating that offers particular functions such as postural support and pressure relief and can be in the form of a wheelchair or static chair (Pinney et al, 2010). Evidence suggests that seating to support posture can improve oxygen saturations (Rowat et al, 2001), prevent secondary complications (Intercollegiate Stroke Working Party [ISWP], 2012) and maximise function (Barker et al, 2006; Petterson et al, 2006).

Most people regain their ability to walk in the first few weeks or months after a stroke, however many leave hospital with restricted or no mobility (Bernhardt et al, 2015). Sitting balance is

the ability to maintain a seated posture with the capacity to reach within and beyond arm's length, an ability that is required for most functional tasks. Reduced sitting balance however is common in chronic stroke cases and individuals unable to mobilise or maintain their sitting balance may require a wheelchair or specialist seating system to manage their posture and potentially enable them to carry out functional activity (Perlmutter et al, 2010).

There are guidelines that recognise that seating provision and positioning advice are key components of an occupational therapist's role (Scottish Intercollegiate Guidelines Network, 2010). To carry out this role occupational therapists in the UK should have access to resources to facilitate the seating provision process (ISWP, 2012; British Society of Rehabilitation Medicine [BSRM], 2004), and stroke rehabilitation guidelines recommend that seating is provided in time for a patient's discharge from hospital (National Institute for Health and Care Excellence, 2013). NICE state in particular 'Prior to discharge from hospital all appropriate equipment (including specialist seating and a wheelchair if needed) is in place' (NICE:14).

Practitioners in the UK can access wheelchairs from the NHS wheelchair service, but this is usually restricted to those with long term needs (Collins, 2001) and even when individuals meet the required criteria, delays in provision are common, with in the region of 70% of people waiting more than three months (NHS Improving Quality, 2014). For those requiring specialist seating it appears there is inconsistency in provision across the UK, with funding pathways only existing for specific groups (BSRM, 2013). No literature has been identified that explores stroke occupational therapists' experience of seating provision in the UK and it is this phenomenon that is the focus of this study. Almost one in eight deaths in the world are because of stroke (WHO, 2017), consequently this study may be of interest to practitioners in the UK and elsewhere. Thus, the aim of the study was to acquire a greater understanding of occupational therapists lived experience of community seating provision for people who have had a stroke. The research was guided throughout by the following research question:

What is the lived experience of occupational therapists involved in community seating provision in stroke rehabilitation?

Method

A qualitative methodology was chosen in order to acquire a greater understanding of occupational therapists' lived experience of seating provision for clients returning to the community following a stroke. The authors are experienced occupational therapy practitioners and discussed their personal views and assumptions during the design stage and recognised the importance of ensuring a reflexive approach throughout. This led to an idealist and interpretivist ontological and epistemological position resulting in a joint decision to opt for a hermeneutic phenomenological approach. As outlined by Thomson et al (2011), this methodology provides a framework to acquire a greater understanding of the phenomenon of interest via the interpretation of the everyday experiences of participants.

Prior to applying for ethical approval, six occupational therapists working in stroke rehabilitation and attendees of a stroke support group were consulted to ensure the study was relevant and to help design recruitment literature. Ethical approval was subsequently obtained from the <BLINDED> and formal recruitment began. An email inviting potential participants to express interest was sent to members of an occupational therapy stroke specialist interest group and was also advertised in an occupational therapy monthly publication. Purposive sampling was used as outlined by Streubert and Carpenter (2011) to recruit eight occupational therapists with a range of practice experience, according to Finlay (2011) participant numbers in this region are in-keeping with phenomenological studies. Participants were required to be working in a stroke rehabilitation service and treating a caseload of clients less than six months post-stroke. They also needed at least one year's experience working in a stroke rehabilitation

setting. All participants were provided with detailed information about the study and had the opportunity to ask questions before signing a consent form. Further detail regarding the participants is provided below in Table 1. Pseudonyms have been used to protect the identity of participants.

[Table 1 near here]

Following a pilot interview with the aforementioned occupational therapists to develop an interview guide, each participant was interviewed once by the first author. For convenience potential participants were offered an individual interview via a face-to-face meeting, phone or through Skype if they preferred. Semi-structured interviews with opening, transitioning, probing and closing questions were used to achieve depth and detail enabling participants' subjective and multiple views to be explored (Brinkman and Kvale, 2015). Interviews lasted between 30-80 minutes and were audio-recorded and transcribed verbatim.

Data analysis was carried out influenced by hermeneutics and the writings of Van Manen (1997; 2006) and Finlay (2011) with a focus on researcher reflexivity. In particular, the first author kept a reflexive diary and interview transcripts were read and re-read with due regard to her prior experience and presuppositions which were discussed with the second author until consensus was agreed. Thus, a narrative summary was produced for each interview and thematic analysis was then completed and linguistic and lifeworld reflections noted. Van Manen (2006:715) states that phenomenological enquiry is practised as writing and that 'it is in the act of reading and writing that insights emerge'. In this way interpretations were developed by following investigative lines of inquiry and through the process of writing and re-writing and discussion between the authors.

Findings

Four themes relating to the lived experience of seating provision emerged, these were: a collaborative project, a race against time, unremarkable versus ‘a battle on our hands’, and out of our hands. These findings are provided below with a selection of representative participant quotes.

A collaborative project

All participants talked about working with others during the seating provision process. Sometimes this involved consulting with one colleague to agree seating recommendations but could involve collaborating with a number of different parties. Participants working in in-patient settings all described sharing seating responsibilities with their community colleagues due to restrictions on their own ability to work with clients in the community. One participant stated:

She wanted to take her chair from home... into the nursing home ...but, I'd never actually assessed her in it... So I handed that over to the community team (Terry)

The ability to transfer any unresolved seating issues provided a mechanism to enable the practitioner to focus on ward responsibilities and ensure that clients' needs were met when discharged. This practitioner was also able to consider clients' personal preferences and share responsibility thereby contributing towards what she considered to be flexible and client-centred practice.

Participants talked about sharing seating provision responsibilities with a range of other professionals including community nurses and clients' families. An opportunity to collaborate

seemed to enable participants to share their wider duties and responsibilities and to make efficient use of resources while ensuring that their duty of care was met in particular.

Participants spoke about working with others to share knowledge and skills as demonstrated by the following statement regarding the benefits of working closely with the local wheelchair service to access expert knowledge of different back rests:

They were very helpful and had... different Jay backs... With increased sensory input around his back... he was able to sit ... in a more standard chair (Terry)

It was not clear however if the same outcome would have been achieved without collaboration. There appeared to be a perception that the ability to access specialist skills and knowledge produced better outcomes. Despite recognising the benefits of joint working, participants described an element of caution in their professional relationship with others. For example, two participants valued working with company representatives to trial different types of seating, but both were mindful of the potential for the representatives to gain financially from the situation.

As well as barriers, participants described enablers to seating provision. One participant, working in an acute setting, shared an office with a community therapist who she could transfer work to as a client was discharged home. This participant described how this shared space allowed for informal discussion relating to the progress of clients and provided an opportunity for both to reflect on their seating provision practise. Simply being near to colleagues seems to be an enabler, promoting opportunities to share responsibilities, skills and knowledge.

A race against time

All participants described seating provision as a time pressured activity. One participant, employed in an in-patient rehabilitation unit, described the pressure she experienced to secure seating for a safe hospital discharge:

It can be really quite time pressured... to get a chair...prior to them leaving hospital
(Terry)

A number of participants working in in-patient settings quoted their ward's average length of admission targets, indicating that the time pressure may originate from "pressure ...to try to get the beds moving" (Nicky). Participants also described pressure to get something arranged as quickly as possible in order to maximise function. Some participants spoke about the importance to secure seating to prevent complications associated with poor posture. One participant described the number of clients referred to her service with potentially avoidable secondary complications:

I see so many patients that have come back into our service completely... contracted
and I just know that if they had an appropriate chair I wouldn't...be botoxing them, I
wouldn't... be advising tendonectomies (Jo)

Such comments give the impression of a vulnerable body post stroke, suggesting that without adequate seating some may be at risk.

Unremarkable versus 'a battle on our hands'

The experience for the participants of providing seating seemed to vary considerably. Although it was at times described as 'straightforward' (Alex; Sam) or 'easy' (Terry), all participants also referred to their task, at times, as a struggle. Interview discussion often focussed on

therapists' concerns and the difficulties they experienced to deliver what clients need and the term 'battle on our hands' (Lee) was used to describe this. Participants often described a protracted wait for seating and numerous barriers which were sometimes viewed as 'insurmountable' (Toni). Some participants explored the reasons for this and the following comment illustrates the perception that seating provision is dependent on the client's level of need:

If you can sit in a standard... wheelchair then you're laughing but if you can't then it... takes forever and we have to fight quite hard (Toni)

Participants used words like 'stumbling block' (Terry) and "barriers" (Nicky) to describe obstacles encountered during the struggle to secure appropriate seating for their clients. They all spoke at length about the different barriers they encountered. For example, one participant described difficulty experienced to secure a wheelchair for a client because of the restrictive criteria of the wheelchair service and social services:

So we've got a lady... that can only tolerate two hours sitting in a wheelchair. She's going to go home...but...she's bed bound because we can't get the care package to work around a two hour window and wheelchair services won't even come and assess her because of that (Lee)

This participant seemed to perceive her local wheelchair service's four-hour sitting tolerance criterion as inflexible and unfair, suspecting it was "plucked out of the air". Another participant employed on a ward that served three different commissioning bodies described how wheelchair services' criteria varies between each area:

It's really frustrating for us as therapists because you can see somebody's needs but one out of three times you can't get it...because of the postcode lottery (Terry)

In this example, seating provision depended upon where the client lived. Comments describing situations where participants were not able to access seating for clients due to restrictive service criteria was common. One participant described funding processes as ‘grey’, ‘murky’ and ‘blurred’ (Toni) implying ambiguity. Another participant described a process of ‘to-ing and fro-ing’ (Jo) to negotiate funding responsibilities for seating provision. One participant perceived her role as a ‘middle man’ (Jo) who would be surplus to requirements if responsibilities or processes were clearer. For this participant, ambiguity in service provision appeared to be an inefficient use of clinical time and resources.

Out of our hands

At times participants described seating provision as out of their control – or out of their hands. One participant talked about trying to obtain seating from social services but concluded ‘We have no control over patients getting them’ (Lee).

Although responsible for assessing need, another service, often had to approve funding in order for the recommended device to be provided. A few participants also described professionals in other services as powerless in as far the process and funding decisions made within their organisation. One participant reported that care home managers had little control over how their budgets were spent and others described how therapists involved in wheelchair provision were often required to seek management authorisation for their equipment requests. There was a sense that practitioners’ professional skills and recommendations were overly scrutinised and subject to the approval of others in senior positions.

All participants working in in-patient settings discussed how it was not within their role to continue therapeutic contact with clients in the community but instead would refer to the next therapy team in the stroke rehabilitation pathway if there were any unresolved seating issues.

Participants working in community therapy teams were situated at the end of the pathway and generally talked less about seating provision being out of their remit of responsibility. One referred to ‘the problem I inherit’ (Toni) suggesting that community therapists are perhaps responsible for any unresolved seating issues that therapists earlier in the pathway may not have been able to address.

Most participants described the need to compromise on seating options. One participant routinely ordered specialist seating for care home residents rather than wheelchairs, as that option was available. Another participant described positioning a client with bariatric needs in a wheelchair that was a ‘tight fit’ (Sam) while waiting for a specialist wheelchair to be provided. Short term compromises were common while waiting for individualised and more appropriate seating. One participant talked about ‘making do’ (Jo) with immediate resources, in order to respect a client’s wish to be discharged home. The following quote relates to this theme:

I think a lot of it...is about... making do... because patients really do want to go home... so they are not going to wait for specialist seating assessments (Terry)

This participant was in a position where she may have had to compromise her own standards to facilitate her client’s want. Participants seem to accept that something is better than nothing. However, some described feeling ‘disheartened’ (Toni) and ‘awkward’ (Nicky) living with the knowledge that seating may be substandard. Seating provision therefore appears sometimes to be based on availability and client choice rather than specific individual need.

Some participants described ‘gaps’ (Lee) or ‘black holes’ (Nicky) where a patient’s needs ‘fall between two pots’ (Lee) in funding pathways. In such cases, participants discussed the option of clients or their families self-funding seating requirements.

That conversation is done quite gently with the person because as a therapist it sits quite uncomfortably (Nicky)

It seems difficult for Nicky to have these conversations with her clients. There is a sense that it is unfair for individuals and their families to self-fund seating and that those without personal financial resources are at risk of missing out altogether. For some participants, in order to secure the required chair for their client necessitated actions which made them feel uncomfortable, but this sometimes appears to be the only viable option.

Whilst voicing their frustration at the barriers described above, participants also recognised that different seating providers or funders were under severe pressure and empathised with this reality in service provision. For example, one participant described her frustration when repeatedly asked to provide clinical reasoning for funding for a specialist chair.

It's almost like you've decided something and they're putting barriers up and questioning your clinical judgement... I know money is scarce and I know where they are coming from, [so] that's fine (Sam)

Although this participant seemed frustrated that she was having to justify her recommendations, she was also aware that such processes are probably necessary to ensure that limited funds used efficiently.

Discussion

Participants appear to value sharing responsibilities, skills and knowledge in order to manage workloads and achieve the best seating outcome for their clients. These findings are consistent with therapists' experiences in Isaacson's (2011) study, who worked with other healthcare professionals and product representatives to access expert skills and product knowledge to

clinically reason a problem. The findings also support Isaacson's (2011:18) study where participants described keeping an 'open yet cautious mind' when working with product representatives recognising their role as salespeople. This suggests the vigilant and professional role of occupational therapists in order to source the most appropriate product whilst also ensuring the welfare of their client.

Participants, it appears, often felt under substantial pressure to secure timely provision of appropriate seating to facilitate safe discharge from hospital, thereby maximising client function and preventing secondary complications. This experience of pressure on time can be considered in relation to Van Manen's (1997) description of the lifeworld as he describes the perception of time as being subjective rather than objective as might be associated with a clock for example. Participants in this study, whilst endeavouring to be client-centred, appeared to understand pressure as an integral component of their situation thereby giving the impression somewhat that their time can be perceived as being altered, counting down or running out resulting in a sense of urgency.

Barriers specifically related to wheelchair provision are well documented elsewhere in the literature and include time restraints, funding issues, equipment availability and environmental restrictions (Isaacson, 2011; Kenny and Gowran, 2014; Mortenson and Miller, 2008). Kenny and Gowran (2014) also acknowledged the lack of uniformity in relation to seating provision across and within different services and contexts; this links well with the results of this study which highlight inconsistency in terms of seating provision between service providers. Isaacson (2011) in particular made suggestions to overcome seating provision barriers, including the importance of collaboration between funders, which are similar to the enablers described by participants in the current study.

Mortenson et al (2013) also explored the notion of prescribers feeling compromised. In their study, participants felt conflicted when providing powered mobility for older people, struggling with their desire to be client-centred whilst working within the limitations of healthcare criteria and constrained funding systems. In the current study, the option to purchase seating privately was also a possibility that participants appear to often consider. Participants spoke about feeling conflicted when required to approach clients or family members about the option to buy a wheelchair or seating privately. This issue has not been explored elsewhere in the literature but is a likely phenomenon that deserves more attention, particularly as the NHS in the UK is expected to provide a universal service for all based on clinical need and not the ability to pay (DH, 2007). Participant experience in this study suggests that universal provision of appropriate seating is not consistently provided for all. In particular, many participants reported difficulty accessing services or equipment for care home residents due to restrictive service criteria. Indeed this does not appear to be unusual, according to the ISWP (2012) care home residents who have had a stroke rarely receive rehabilitation services and struggle to obtain a wheelchair from the NHS.

Some participants associated their experience of seating provision in relation to their position on the stroke pathway and their client's level of need and their likely discharge destination. In-keeping with hermeneutic phenomenology it could be argued that this range of experience might be best understood in relation to Heidegger's (1962) concept of *situatedness*; that is these experiences are likely to differ across services, at different times, and for practitioners and clients due to the unique set of circumstances for individuals at any given point in time.

The results of this study may be of interest to practitioners and service commissioners, some of which link closely and support the findings of previous studies. There are also findings in this study, which appear to be new and which throw some light specifically on the experience of occupational therapists involved in seating provision. These include participants'

appreciation of why seating provision barriers may exist and a sense of powerlessness for practitioners during the seating provision process which may encourage further research to improve services.

The knowledge and clinical skills of the practitioners involved in the treatment of people who have had a stroke comes across through all of the four themes. This can be seen in the selected quotes for example where there is recognition of the importance of thorough assessment and detailed knowledge as to how a stroke can affect individuals. Occupational therapists concerns about the appropriateness of interventions other than seating is evident also, as is the reflective nature of being a clinical practitioner whose decisions and recommendations may be scrutinised. In this regard further research relating to the resilience of practitioners working in services under high pressure with limited resources may be beneficial.

This study was carried out to find out more about the lived experience for occupational therapists involved in the provision of seating for clients who have had a stroke. Future research could explore the extent and daily reality of life for people who have had a stroke and who need seating but where provision is delayed or compromised. It would also be useful to gain greater insight into how seating provision is perceived and experienced by clients' families and carers. Future research is recommended especially to better understand how to improve joint working across services, which in turn might influence longer-term positive change in seating provision for people who have had a stroke.

Limitations

This study recruited occupational therapists only and it is important to note that seating provision often involves a range of other health professionals including physiotherapists across

the UK who may have similar or different experience of the phenomenon. The authors took care however to apply a reflexive approach and are confident that the findings are firmly anchored in the experience of the participants (Thomson et al, 2011).

Conclusion

To the best of the authors' knowledge this study is the first to explore occupational therapists' experience of seating provision for clients after a stroke in the UK. The results enrich understanding of this phenomenon and throw light on this area of practice which may be of interest to occupational therapists in the UK and elsewhere. Experience varied greatly although there are common themes. While at times straightforward, seating provision could also be complex and protracted. Barriers to provision left some participants feeling frustrated, uneasy or compromised as they were unable to access seating in a timely fashion, or to fully meet some clients' needs, or to practice client-centred care as well as they would like to. This demonstrates a need to develop processes and criteria to allow prompt access to seating solutions at any stage deemed appropriate during the stroke rehabilitation pathway. This study suggests that occupational therapists involved in seating provision for people who have had a stroke may want to consider ways in which barriers can be reduced and encourages further research to develop effective pathways that might result in more timely and client-centred seating solutions.

Declaration of interest: The authors report no conflicts of interest

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