

Stroke survivors' perceptions of occupational engagement in hospital-based stroke rehabilitation: A qualitative exploration

Abstract

Purpose: Studies highlighting the time spent in self-isolating and inactive activities during stroke rehabilitation have led to the introduction of group programs and environmental enrichment to improve activity levels. A less explored perspective is to understand how the introduced changes align with the occupational needs of the stroke survivors. Therefore, the aim of this study was to explore stroke survivors' experiences of engagement in occupations during stroke rehabilitation. *Methods:* A descriptive phenomenological approach with semi-structured interviews explored stroke survivors' experiences. *Results:* Eight participants (5 male, 3 female, mean age 72 years) described their experiences with two themes emerging: (1) "I'm here for that reason": which highlighted therapy as an occupation which participants wanted to perform; (2) "Celebration of quiet moments": exploring the value of rest and recreation. *Conclusions:* This study provides a preliminary understanding of how stroke survivors experience occupational engagement during rehabilitation. There was an apparent shift in priorities with therapy considered the most important occupation and a strong need expressed for rest and relaxation to be factored into peoples' days. It appears the increasing activity levels may not always align with peoples' occupations and that due consideration of this malalignment may further enhance engagement and outcomes.

Keywords: Activities of Daily Living, Occupational Therapy, Motivation, Cerebrovascular Accident,

Introduction

Stroke remains one of the most significant causes of morbidity and mortality in Australia and there is a growing need for rehabilitation services to reverse the trend of negative impacts on quality of life for the stroke survivor and their carers [1-3]. As a result, sub-acute rehabilitation services need to extend attention beyond the discrete impairments and functional dependence that prevent a person from returning home [4], to include the occupations that a person wants, needs, and is obligated to perform both during and after stroke rehabilitation [5]. This focus is considered important for the maintenance of self-concept, wellbeing and continuity in life post stroke [5].

Previous studies exploring stroke rehabilitation highlighted that stroke survivors were inactive and unengaged outside of formal therapy [5-7]. That is, although the participants may have been engaged in sedentary occupations, this inactivity and social disconnection were considered to negatively affect participants' perceptions of self-efficacy, well-being and recovery success [5,6]. The results prompted studies to explore ways to increase activity outside of therapy and changes to the rehabilitation environment (including environmental enrichment) were implemented as a means to influence engagement in activity outside of therapy [8,9]. The methods were congruent with historical environmental enrichment studies, whereby researchers explored how to increase the social, cognitive, and physical stimulation of animals in a laboratory setting [10,11]. An enriched environment (EE) is defined as an environmental setup that facilitates enhanced sensory, cognitive and motor stimulation through the provision of generic activities (e.g. craft, internet, Wii) of the participant's choice [3,6].

Engagement in EE has been shown to successfully improve activity levels in participants whilst also supporting cognitive, social and psychosocial remediation [2,3]. Ada et al. [3] reported that EE disrupts a common cycle of inactivity and isolation during non-therapy hours. Bartley et al. [4] supported this finding, highlighting that additional benefits of

EE including increased opportunities for social interaction amongst individuals. Although both studies highlight clear benefits of EE, the activities available in these communal environments were chosen at the discretion of the researchers. As researchers and rehabilitation services seek to provide more opportunities for stroke survivors to engage in activity, it is equally important to explore and understand how stroke survivors wish to meaningfully fill their time with occupation. Activity and occupation are defined in this paper according to the descriptions of Golledge [12]. Activity is used to refer to a general category of activity, one which has unknown relevance and meaning to the person. Occupation is used to refer activities that are meaningful and purposeful for that individual. Therefore, the aim of this study was to build on knowledge of how people spend their time in stroke rehabilitation by exploring the lived experience through an occupational lens. The specific research was: what are the experiences of stroke survivors regarding their current opportunity for engagement in occupations during inpatient stroke rehabilitation?

Methods

Study Design

A descriptive phenomenological design was selected for this qualitative study as means to gain a deeper understanding of, and provide insight into, the experiences of individuals in stroke rehabilitation. Descriptive phenomenology allows an unbiased account of human experience, meaning, and consciousness to be captured [13]. Trustworthiness elements such as a clear rationale for the methodology, bracketing, and data saturation were incorporated into the study to ensure rigor of the findings [13, 14]. Ethical clearance to conduct this study was received from the human research and ethics committees of the participating hospital and universities. The study was completed on the acute stroke and rehabilitation unit of a major metropolitan hospital and all participants provided informed written and verbal consent prior to data collection.

Participants

Eligibility criteria for involvement in the study were the following: over the age of eighteen, receiving active hospital-based stroke rehabilitation for first or subsequent stroke, and adequate communication and cognitive abilities (as identified by the treating team) that allowed for the provision of in-depth information regarding their experiences of occupational engagement during stroke rehabilitation in an interview. Individuals were considered ineligible if they were medically unwell.

Procedure

A pragmatic approach was taken for the recruitment stage of this study with the research team contacting the treating team once a month over a four-month period. All eligible participants were approached by a member of the treating team to seek consent for their details to be provided to the research team. Researchers then met with all interested participants to obtain informed written consent. The interviews were completed at a mutually convenient time for both participants and members of the research team (LG and MM). Verbal consent was also sought prior to the commencement of the interview. Following each interview, participants were reminded about the possibility of a second interview to clarify information or ask questions surrounding newly identified topic areas.

Data Collection

Baseline demographic details of each participant were collected from medical records at recruitment into the study. The demographic details gathered included: age, gender, number of days since stroke to interview, number of days since entering stroke rehabilitation to interview, and admission Functional Independence Measure (FIM) score (motor, cognitive

and total score) [15]. The Oxfordshire (Bamford) Classification of Stroke was used to classify type of stroke [16].

Semi-structured interviews lasting between 20-45 minutes were conducted in the hospital ward and audio-recorded. A semi-structured interview guide allowed key aspects of the study aim to be explored and for the participants to raise additional points. Each interview commenced by exploring the participant's stroke experience as a way to establish a basis for addressing topic areas that occurred prior to and following the stroke event. Examples of subsequent questions included "Tell me about a typical day for you before the stroke" or "Tell me about your stroke?" as a means to understand the participant's roles and occupations, and how stroke onset may have impacted on their ability to engage in these whilst in hospital. Topic areas central to the analysis of this study related to establishing a typical day for a participant on the rehabilitation ward, their ability to engage in occupations, and their reflections on what could be developed in the rehabilitation ward to increase opportunities for occupational engagement. Participants were encouraged to talk openly and share their experiences, thoughts and opinions in a level of detail they felt most comfortable. Member checking occurred at the end of each interview with the interviewer summarising what was discussed.

Data Analysis

Interviews were transcribed verbatim with confidential and identifying information removed. All members of the research team contributed to the data analysis for this study. Analyses were completed in dyads (LG and SP; MM and PS) using Colaizzi's strategy of descriptive phenomenological data analysis [13]. This form of data analysis allowed for the research team to identify new phenomena surrounding opportunities for occupational engagement in stroke rehabilitation through the perspectives of individuals' everyday experiences [13]. Prior to

conducting data analysis, researchers declared any personal biases, assumptions and presuppositions [13] regarding the topic to ensure themes extracted from the data were a true representation of the participant's own thoughts, beliefs and experiences. Prior to analysis, the research team identified that they held an assumption that individuals wanted more opportunity in and out of therapy for engagement in occupations. This assumption was bracketed and set aside, with review after each interview to ensure that this was not influencing the results.

Colaizzi's approach to data analysis allowed researchers to elicit a comprehensive description about the phenomenon [13] regarding opportunities for occupational engagement in stroke rehabilitation. This was achieved through the process of: 1) reading transcripts multiple times to formulate general understanding 2) extracting significant statements relating the phenomenon under investigation 3) formulating meanings from significant statements 4) organising significant statements into theme clusters 5) formulating significant themes from theme clusters 6) emergent themes defined into an exhaustive description of the phenomenon [13]. A total of four themes initially emerged from the data set, two for each dyad. Two members of the research team (LG and MM) discussed the emergent themes to ensure that identified themes clearly reflected the study findings. The discussion led to the four emergent themes being merged into the two final themes.

Reflexivity was used to facilitate rigour, meaning that every decision made throughout the study was critically reflected upon as a strategy to ensure that they were not influenced by the personal views, beliefs, judgements and values of the researcher. Additionally, each interview ended with a summary of the main messages conveyed as a form of member checking. Analysis was ongoing and after six interviews it was determined that no new information was being obtained. A decision was made to continue for an additional two interviews and no new information emerged from the two additional interviews. Each

interview was attended by two members of the research team to ensure bracketing of assumptions and to take field notes. The analysis of the interviews by the two dyads and subsequent alignment of the four emergent themes adds rigor and validity to the findings.

Results

Participant characteristics

A total of eight participants were recruited from the stroke rehabilitation ward of a major metropolitan hospital over a period of four months. A longer length of stay for one participant allowed a second interview to be conducted as a means of gathering further insight into their perspectives on the research aims and objectives. This interview did not yield any additional information. The remaining seven participants completed one interview. Three eligible participants were not recruited for the study as two were discharged to home before the interview could be completed and one was not available for interview at the agreed time.

Participant ages ranged between 45 and 87 years of age with an average age of 72 years (Mdn = 72, SD = 12.64). There were five male and three female participants. The average number of days since the onset of the stroke to the interview was 25.5 days (Mdn = 21.5, SD = 12.13) with an average number of days since entering the rehabilitation unit to the interview of 17 days (Mdn = 15, SD = 11.02). The average admission FIM total score was 66.35 (Mdn = 63, SD = 20.00) with participants presenting with physical limitations including hemiparesis and facial paralysis. Seven participants presented with an ischemic stroke, with only one participant presenting with a haemorrhagic stroke. Five participants were left hemisphere affected and three were right hemisphere affected. One participant experienced a total anterior circulation stroke, one participant a lacunar stroke, two a posterior circulation stroke, and four a partial anterior circulation stroke.

Interview Findings

Two themes emerged from the interviews in relation to participants' experiences of occupations during hospital-based stroke rehabilitation. The first theme, "*I'm here for that reason*": *therapy as an occupation*, related to therapy being described by participants as the most important occupation for them at that time, it was an occupation they not only needed and were obligated to perform, but an occupation they wanted to engage in. The second theme, "*celebration of the quiet moment*": *the value of rest and recreation*, reflected that although time was spent in self-isolating and sedentary activities there was significant meaning attributed to these, as rest and relaxation included a strong emphasis on being able to get out of the ward environment. Each theme will now be explored in more detail. Each participant has been allocated a pseudonyms and details are provided regarding their age and FIM score with the first quote.

"I'm here for that reason": Therapy as an occupation

Participants described lives prior to their stroke that were full of caring, productive, social, and leisure occupations. At the time of the stroke, participants were working, caring for children or spouses, filling their days with journeys out of the home, or working within the home. As described by one participant who was constantly repairing or fixing things at home there was "*never a dull moment*" (George, 71 years; FIM 63). All participants clearly identified that therapy had become the most important occupation at the time of the interviews and that the therapy program provided by the hospital was highly beneficial to their recovery journey. As reflected by Colleen (70 years; FIM 72) "*I'm doing [therapy] and that's what I'm in this space for...but that's me, as a person. I'm here for that reason, and that reason only.*" Without therapy services on the weekend, participants found themselves without

structure or meaning and engaging less socially. *“It’s shocking...Yes, it’s so lonely. I just watch television or read all day.”* (Hazel, 78 years, FIM 63). Therapy not only provided structure, meaning, and activity, it influenced the way in which participants thought about occupational engagement. Without it, they were left at risk of occupational imbalance. *“Well, I found this weekend a little boring...I really didn’t know what to do when there was no one here on a weekend.”* (Noel, 82 years; FIM 80).

Participants described two main motivations for therapy. These included a strong desire to return to their pre-stroke abilities and occupations, and the opportunity to participate in occupations that aligned with being at home, during therapy. For some, therapy was not immediately seen as meaningful. However, as they began to engage in therapy, they began to understand the benefits of it to their overall health and wellbeing, and their transition home. For most participants, physical limitations resulting from the stroke meant that they were unable to participate in the pre-stroke occupations of meaning to them. As Mark (67 years; FIM 62) described:

“Oh there’s lots of things I’d like to be doing, but there’s lots of things that I can’t do...It’s just things I physically can’t do. I can’t walk around, go to places, do things, get in the car, go drive places.” (Mark).

These physical limitations became a motivator for participants to attend therapy, as they saw therapy as the only means of supporting a return to their pre-stroke lifestyles. For some, important events occurring in the near future also provided additional motivation to attend therapy.

“the sooner I’m out, the better.... end of September. Yep, that’s my goal. It was the... 15 September, but I said I had to be realistic because – see, all our [travel group] is going away ... on the 16th. So I wanted to be out by the 15th.” (Agnes, 87 years; FIM

36)

Participants spoke of the symbiotic relationship between therapy and recovery and the time sensitive nature of the interaction. Mark identified that *“You’ve got to have therapy. Really, you’ve only got a certain amount of time for all of this to get working again”*. This relationship further highlighted the importance and meaning behind therapy as not only an occupation they needed to do, but also wanted to do.

For one participant, the therapy provided as part of the rehabilitation program offered opportunities for engagement in occupations she typically performed at home. Hazel described a day in rehabilitation that included occupations usually performed at home *“Ah it’s so good. There’s always someone coming taking me to cooking, or taking me out to the garden or OT.... I planted some seeds today and I planted some seeds last week....and I’ve been cooking three times.”* Opportunities to participate in occupations aligned with her pre-stroke roles proved a significant motivating factor to attend therapy, making therapy both a rewarding and enjoyable experience. When Hazel was further asked what else she would like to do in hospital in addition to therapy, Hazel replied *“More cooking, more gardening and more coffee club.”*

Participants had wide ranging views on what could be offered to enhance engagement in occupations outside of therapy. Many understood the challenge in achieving this due to a combination of factors surrounding the person, the environment, and the occupation of choice. For example, Mark stated that although there may be many activities that stroke survivors may want to engage in outside of therapy, physical limitations may not make it possible *“You’ve got to be well enough to be able to be mobile, to get out there and do something. Some of the people there are not mobile at all. They’re just stuck in bed.”* George stated that although he would like to be able to do repairs or use tools whilst in hospital,

organisational policies and protocols may inhibit his ability to engage in this activity as you “just [have to] be careful of, the safety factor, that’s all.”

“Celebration of quiet moments”: the value of rest and recreation

This theme describes the need for rest outside of therapy hours that was expressed consistently by participants’ and the links to physical and mental recovery from the therapy. The need to rest was described by participants as a phenomenon associated with experiencing a stroke. Participants seldom reported the need to rest during a typical day prior to the stroke. However, it had become an important part of their daily routine in hospital. When asked to describe a typical day on the rehabilitation ward, participants indicated that early starts were common to allow for a continuous cycle of multiple therapies, leaving many of them “flat out ‘till lunch”. Due to the intensive rehabilitation schedule, opportunities for rest were few and far between, leaving many participants both exhausted and tired:

“[I have] one therapist after the other. I have [name], the speech therapist, nine, and then [name], the physio, at ten. [occupational therapy] at eleven and lunch – she goes till 12. Lunch is at half past. Then I start again at one with more physio, then [occupational therapy] again and sometimes [speech therapy] in the afternoon....so, by four o’clock in the afternoon, I’m tired.” (Colleen)

Participants also described that therapy was not the only contributor to feelings of exhaustion and tiredness but that recovering and adapting to physical limitations as a result of the stroke were physically, emotionally, and mentally demanding: “I tell them that the stroke – you get very tired. I yawn and carry on. I’ve never yawned so much in my life as I do since I’ve been here.” (Colleen)

Reflecting on activities they enjoyed doing after or between therapy sessions, most participants identified that this time, however long or short it may be, was very important for rest.

It's difficult because you finish your lunch, you...got an hour break or half an hour or sometimes no break and on to the next bit of physical exercise. And you come back and you got two hours – you should be able to [do] a lot in that but you just want to rest. (Mark)

This period of time in the day allowed participants to prepare themselves for other activities they wanted, needed or were obligated to perform during the day. As Arthur (73 years, FIM 47) reflected: “*It's good to just get back and relax, and most of the time, I have a bit of a sleep first and then get to what I've got to do, like the exercises*”. The need for rest was influenced by the mental and physical demands of engaging in therapy, as noted below:

Resting – just full stop resting. It gives me a chance to rest back from all the physical exercise. I mean, 'cause I didn't realise how demanding it was. So, partly mental and partly physical as well. (Mark)

Participants also described that there is a strong misconception that hospital is a place of rest. As Gary (45 years, FIM 104) reflected “*People think at hospital you get to sleep all the time when the reality is, you hardly sleep in hospital...I haven't slept for more than three or four hours [at a time].*” Periods of extended sleep are difficult, due to nursing handovers and observations as well as “*that person's light goes on at two o'clock*” or “*[room mate] gets up and walks around my curtain.*”

Resting time also created an opportunity for recreation and for participants to interweave and engage in other occupations. For Agnes, when “*I've got time to myself*”, she enjoyed relaxing occupations such as crocheting and reading, reflecting her pre-stroke lifestyle. Quiet moments also provided opportunities for social interaction with other people

on the ward. For Agnes, the wardroom was seen as an avenue to meet people and forge new friendships: *“There's people here who are good and gentleman over there – he goes to the same meal times as I do. No. He's very good. He plays the golf too. That's a common thing we've got.”* Thus, for some participants, recreation time provided the means for which they were able to engage in occupations.

The opportunity to access the outdoors was a key recommendation of participants, as a means to provide further opportunities for occupational engagement during hospital-based stroke rehabilitation. Currently, participants identified that due to both organisational and physical limitations, accessing the outdoors independently was not possible with Arthur stating:

“I would like to be able to get outside and walk and so on and so forth but I'm not allowed...So it's really nice when my wife takes me for a bit of a walk and sit down and have coffee”.

For most participants, the outdoors presented an avenue to escape the confines of sterile hospital walls and connect with nature as a way of restoring the mind, body and soul. For two participants, the outdoors provided a space to get *“out of the air-conditioning”* and *“sit and enjoy”* as a way to *“refresh yourself”*. George also acknowledged that enjoying the outdoors was an important part of his pre-stroke lifestyle: *“at home got a big veranda out the front I can go and sit out there in the morning in the sunshine. It's a lovely, I'd love to do that...I can sit in the sun.”*

Discussion

The purpose of this study was to explore the experiences of stroke survivors concerning their needs and current engagement in occupations whilst in hospital-based stroke rehabilitation. The strongest theme to emerge from this study was the participant description that therapy

was an occupation that held significant meaning, value, and importance, and it was seen as the gateway to regaining purpose and meaning to life, and the sole determinant of a return to a pre-stroke lifestyle. This finding was similar to a study by Hammell [17] who highlighted that occupations such as therapy were meaningful due to their ability to instil life continuity and hope for the future. Furthermore, engagement in therapy allowed for participants to make progress towards goals that instilled feelings of hope and allowed them to envision a future of participation in occupations, rather than a sense of hopelessness at a future devoid of occupations [17].

For all participants, therapy was regarded as an occupation they not only needed and were obligated to perform, but something they wanted to engage in. Motivation is key to understanding a person's commitment to participate in activities associated with an occupation. The Model of Human Occupation (MOHO) is a commonly used occupational therapy model of practice and identifies that a person is motivated to engage in an activity when (a) they feel confident in their capabilities (b) it is valuable, meaningful and important and, (c) is enjoyable [18]. This motivation was enhanced when attendance at therapy provided the opportunity to participate in occupations reflective of their pre-stroke roles, particularly those which took place within their home environment. For example, Hazel was motivated to attend therapy as it provided her with the opportunity to cook and attend to the garden, two occupations at the core of her pre-stroke identity. This finding reflects that instrumental activities performed in a clinical setting, could generate meaning when the experience is integrated with the person's identity and life history [19].

For all participants, occupations that promoted rest and recreation were considered highly meaningful whilst in hospital-based stroke rehabilitation. In stroke literature, occupations such as sleep, watching television, reading books and completing crafts, are considered to indicate a state of no activity, inactivity, reluctance to engage, non-therapeutic

and passive activities, and do not correlate with positive rehabilitation outcomes [5,6]. However, sleep and restful occupations such as reading can be considered essential for feelings of restoration and regeneration of cognitive and physical processes [20]. Hammell [17] suggests that they should be considered a 'restorative occupation' in that although they may not be goal-orientated or purposeful, they are profoundly meaningful and rewarding to an individual. The concept of 'restorative occupations' was described by the participants as the opportunity to recover from a tiresome and exhaustive daily routine, unwind from the stress and exertion of physical limitations and attempt to seek occupational balance.

Participant descriptions also pointed towards the need for rest due to fatigue, both cognitive and physical, and at times the descriptions raised questions about links between this time and neuroplasticity. Early animal and human studies suggest that sleep may influence neuroplasticity and outcomes after stroke [21]. In addition, the principle of interference [22] suggests that stimulation of a neural network outside of therapeutic training may disrupt the process of consolidation of neural changes. These are all factors that require additional exploration and consideration with future studies. Regardless, the results suggest that without opportunities for rest, people in stroke rehabilitation may not demonstrate the level of drive, determination and motivation to continuously and actively engage in therapy whilst in hospital-based stroke rehabilitation.

Finally, for some participants, rest allowed for engagement in recreational occupations consistent with their pre-stroke lifestyle such as watching television, listening to music, engaging in social connectedness, and accessing the outdoors. The opportunity to engage in occupations of their own choice during rehabilitation allows individuals to proactively determine how they spend their time outside of therapy. Rest that promotes leisure pursuits can contribute to a sense of meaning that is attributed to developing/sustaining occupational identity, exploring creativity and supporting a harmony and balance between occupations

individuals need, want and are obligated to perform [23]. Hammell [17] suggests that these occupations can also contribute positively to a person's perceptions of their own self-worth and dignity. Although these activities may not be considered to directly influence therapy outcomes, they do correlate significantly to the pursuit of returning to a pre-stroke lifestyle by contributing to a sense of purpose and meaning to daily-lived experiences, and to an overall sense of balance in a person's occupational performance [17]. Overall, these findings suggest that rest should be an integral component of the daily structure of hospital-based stroke rehabilitation as a means to support stroke survivors' recovery. Further research is required to establish if there are significant correlations between opportunities for rest and positive therapeutic outcomes.

Strengths and Limitations

A key strength of this study is the rich data that captures participants' experiences of opportunities for engaging in occupations during hospital-based stroke rehabilitation. Recruitment bias may have been a limiting factor of this study, as although all participants who met inclusion criteria were considered for the study, recruitment did not occur in line with consecutive admissions of individuals to the stroke rehabilitation ward. Equally, people who did not have adequate cognition and communication skills were not considered for this study. The FIM was collected as a means of reporting the current impact of the stroke of functioning however additional measures may have provided a wider representation of abilities. The results of this study were representative of the participants and the rehabilitation unit in which data collection occurred however further work is needed to determine if the experience is the same in a range of rehabilitation facilities. Furthermore, differences in hospital-based stroke rehabilitation programs may also impact the transferability of results to other services providing stroke rehabilitation programs.

Conclusion

Stroke survivors prioritised therapy as a major occupation during their time in hospital-based stroke rehabilitation. Two external motivators were seen to contribute to the drive, determination and willingness of stroke survivors to participate in therapy including a profound desire to return to their pre-stroke lifestyles and the opportunity to engage in occupations that reciprocated home. This study further highlights that rest and recreation were also prioritised occupations during hospital-based stroke rehabilitation. For stroke survivors, these occupations significantly contributed to perceptions of health and wellbeing as they allowed individuals to recuperate from the physical, emotional, and mental demands of active participation in therapy. This study has provided preliminary client-centred data and suggests that within the context of current stroke rehabilitation practices and research, there is a need to further investigate if and how to achieve balance between engagement in therapy and restorative occupations.

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Declaration of Interest

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Implications for Rehabilitation

- During hospital-based stroke rehabilitation, stroke survivors prioritised the occupations of therapy and, rest and recreation.
- People with stroke are motivated to participate when the activities within, and outside of, therapy align with their pre-stroke life and occupations.
- A daily stroke rehabilitation program should be balanced with opportunities for rest to support recovery time from therapy and possible consolidation of learning.

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