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Uncertainties in Occupational Participation Among Acute Stroke Survivors: A Qualitative Descriptive Study

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Uncertainties in Occupational Participation Among Acute Stroke Survivors: A Qualitative Descriptive Study

Stroke causes diminished occupational participation from the acute phase, considerably impacting quality of life. We aimed to explore the experiences of diminished occupational participation among acute stroke survivors. We conducted a qualitative thematic analysis on interviews with 12 participants within 3 weeks post-onset. Results identified four themes: (1) being at the mercy of uncertain physical recovery, (2) resistance to role loss, (3) disconnection from daily life, and (4) awareness of supporters. This study offers new insights for developing a rehabilitation approach that integrates an occupational perspective from the acute phase. It is important to addresses not only physical recovery, but also prioritize the restoration of meaningful occupational engagement, personal identity reconstruction, and continuity in daily life disrupted by stroke by closely monitoring their fluctuating emotions and promoting awareness of supporters may be effective strategies for client-centred occupational therapy in the acute phase.

Keywords: Acute care, Acute stroke, Stroke survivor, Qualitative research, Occupational Therapy, Occupational participation

Introduction

Stroke is a leading cause of death and disability among adults worldwide (Feigin et al., 2016). For stroke survivors, recovery of occupational participation (Taylor & Kielhofner, 2017) is crucial for the quality of life, psychological health, and reconstruction of social roles. Occupational therapy, based on the idea that 'all human beings are occupational beings' (Kielhofner, 2009), is important in understanding the effects of reduced occupational participation after a stroke and supporting recovery (Hildebrand et al., 2023). In fact, occupational participation goes beyond performing activities. It is a meaningful concept for individuals, influencing personal values, roles, and connections with others (Loh & Jonsson, 2016; Connel et al., 2019; Bonsaksen et al., 2015; Klepo et al., 2022; Preez et al., 2018). The *Model of Human Occupation* (MOHO) describes occupational participation as 'participation in work, play, and activities of daily living (ADLs) that structure a person's life' (Kielhofner, 2009).

In many cases, a stroke results in a significant loss, making it challenging for survivors to participate in occupations they value. This impact is reflected in challenges related to resuming daily and social activities (Tse et al., 2022) and returning to occupational roles (Matos et al., 2024). This decline in occupational participation can lead to a loss of identity, a diminished sense of self-worth, and social isolation (Martin-Saez & James, 2021).

Although previous studies have enhanced our understanding of stroke survivors' decline in occupational participation, many of them focused on the chronic phase or later stages of rehabilitation (de Diego-Adeliño et al., 2010; Takashima et al., 2016; Towfighi et al., 2017; Williams & Murray, 2013). Conversely, knowledge about the decline in occupational participation during the acute phase of stroke remains limited. Williams and Murray (2013) highlight the impact of reduced occupational participation beginning in the acute phase on psychological well-being and social connections. However, research that comprehensively explores the specific impacts of the acute phase remains scarce.

Occupational participation is a dynamic and adaptive process during post-stroke recovery, which is influenced by individual and environmental factors and temporal dimensions (Tse et al., 2022). In the acute phase, diminished occupational participation first becomes evident, and understanding its experiences can significantly influence subsequent social participation and role recovery (Visvanathan et al., 2019; Parikh et al., 1990; Mitsunaga et al., 2021). Therefore, we explored how stroke survivors in the acute phase experience diminished occupational participation in order to provide new insights for occupational therapists to develop a comprehensive rehabilitation framework that incorporates an occupational perspective from the early stages.

Methods

Design

We applied a qualitative descriptive design using interviews to understand participants' experiences with stroke in relation to their occupational participation. The study was approved by the Ethics Review Committee of Health Sciences University of Hokkaido, Japan (approval number: 21R148141). Written informed consent was obtained from all participants.

Instrumentation

We used several tools to assess the participants' functional status.

*Functional Independence Measure (FIM) (*Deutsch et al., 1996*)*. The FIM assesses an individual's level of independence in performing ADLs, including self-care, mobility, and communication (Deutsch et al., 1996). Scores range from 18 to 126, with higher scores indicating greater independence. Its validity and reliability have been demonstrated in previous studies (Deutsch et al., 1996; Ottenbacher et al., 1996).

*Stroke Impairment Assessment Set (SIAS) (*Chino et al., 1994*)*. The SIAS is a stroke-specific assessment tool that evaluates motor function, sensory function, and coordination in stroke survivors. Scores range from 0 to 76, with higher scores indicating better function. Its validity and reliability have been confirmed in prior studies (Chino et al., 1994; Tsuji et al., 2000).

*Mini-Mental State Examination (MMSE) (*Folstein et al., 1975*).* The MMSE is a widely used cognitive screening tool designed to evaluate global cognitive function across multiple domains, including orientation, registration, attention and calculation, recall, language, and visuospatial skills. Scores range from 0 to 30, with higher scores indicating better cognitive function. A score of 24 or above is generally considered within the normal range. The MMSE has demonstrated good validity and reliability across diverse clinical populations (Tombaugh & McIntyre, 1992; Mitchell, 2009).

Participants

Purposive sampling was performed. Patients who experienced a first-ever stroke and were subsequently admitted to a regional core hospital were eligible for inclusion. The inclusion criteria consisted of: 1) the first and only stroke in the acute phase defined by Japan as within 21 days (3 weeks) after stroke onset (Shirobon.net, 2022) Exclusion criteria were: (1) cognitive impairment, defined as a MMSE score <27; (2) aphasia, as observed clinically; and (3) a history of stroke.

Based on these criteria, 13 participants were enrolled in the study. However, one of them refused to partake in the interview. The sample consisted of 12 participants as described in Table 1. Each participant was assigned a unique ID (i.e., P1, P2,) and interviewed by the first author, a licensed occupational therapist, with 8 years of experience in the acute care ward.

Interview Development

The interview guide was developed through a multi-step process to ensure its relevance and clarity (Kallio et al., 2016). First, we reviewed existing qualitative studies involving stroke survivors to identify established knowledge and gaps warranting

further investigation. This review also highlighted key conceptual and methodological considerations, such as aligning with the concept of occupational participation and avoiding redundancy.

Based on these insights, we drafted clear, comprehensible questions aimed at exploring participants' experiences of occupational participation. The draft guide was pilot tested with five participants, whose feedback confirmed that the questions were appropriate and easy to understand; thus, no revisions were necessary. The final interview guide was confirmed through discussion among the research team and was used in the study (Table 2).

Data collection

Data collection was performed between April and September 2021 using a semi-structured interview. The interviews were recorded using a voice recorder and transcribed verbatim. Each interview lasted between 30 and 45 min. As this study was conducted during the acute phase, the duration of each interview was decreased to reduce the burden on the participants. Participants who actively engaged in describing their experiences and reflecting on their occupational participation were selected for additional interviews. Among them, those whose schedules allowed for further participation were interviewed up to three times.

In the subsequent interviews, participants were first invited to reflect on the content of their initial interviews. Follow-up questions were then asked to explore specific aspects in greater depth. These included timely prompts aimed at eliciting more detailed information about previously mentioned occupations. This included how frequently the occupations had been performed before the stroke, the physical or cognitive demands they entailed, and participants' current feelings toward those occupations. Additionally, participants were asked whether their thoughts on occupational participation had changed since the previous interview and, if so, in what ways.

During the interviews, body language, facial expressions, and tone of voice were recorded in field notes to gain a deeper understanding of the participants' feelings. These field notes were used to supplement the interview data, provide contextual understanding of the participants' narratives, and capture their engagement in rehabilitation and ADLs. This allowed for a more nuanced interpretation of their experiences in the study. The interviews were conducted in a private consultation room designated for confidential discussions, ensuring a quiet and distraction-free

environment. Only the interviewer and the participant were present during the interview, providing a secure and comfortable space to protect the participants' privacy. To ensure that the interviews did not interfere with the participants' treatment, all interviews were conducted outside of their scheduled therapy sessions. With participants' permission, the interviewer also observed their rehabilitation and ward life while working as an occupational therapist while hospitalized.

All data used in this study were kept confidential in a vault, accessible only to the interviewer.

Data analysis

Data analysis was conducted in three phases, following the thematic analysis framework proposed by Braun and Clarke (2006). In Phase 1, the first author repeatedly read the interview transcripts to become familiar with the data and identify potential themes. Meaningful phrases and actions related to occupational participation were carefully analysed. In Phase 2, the first author extracted phrases related to occupational participation and developed initial codes. Particular attention was paid to preserving the diversity of codes while organising them into comprehensive elements and higher-level subthemes. Throughout this process, the second and third authors (occupational therapists with expertise in qualitative research) reviewed the analytical content. Any discrepancies in interpretation were thoroughly discussed to reach consensus. In Phase 3, the first author examined participants' narratives in detail and extracted key phrases to clarify the structure and composition of each theme. Regular meetings with the second and third authors were held during this phase as well, to ensure the validity and consistency of theme development.

The analysis was not a linear process but involved iterative revisions and reflections (Braun & Clarke, 2006). The codes and themes were developed using a data-driven approach grounded in the content of participants' interview narratives.

Trustworthiness and rigour

To ensure credibility, member checking was conducted during the second and subsequent interviews, allowing participants to review and validate the researchers' interpretations. Dependability was enhanced through an iterative data analysis process conducted by the first author and reviewed by the other authors. To improve transferability, thick descriptions were incorporated by providing detailed demographic information and comprehensive excerpts from participants' narratives, enabling readers to assess the applicability of the findings to other contexts. To enhance confirmability,

field notes were systematically recorded to document researchers' reflections and analytical decisions, minimising interpretative bias (Berger, 2015). The standards for reporting qualitative research checklist (O'Brien et al., 2014) were used to ensure the quality and transparency of this study.

Results

The experiences of diminished occupational participation among stroke survivors during the acute phase were extracted as four themes: 'being at the mercy of uncertain physical recovery', 'resistance to the loss of daily roles', 'disconnection from daily life', and 'awareness of supporters'.

'Being at the mercy of uncertain physical recovery'

The participants were confused by the sudden onset of their physical disability and felt that their ability to return to significant occupations was dependent upon the unpredictable course of their physical recovery.

In the first interview, conducted on day 3 after illness onset, P1 stated, 'I am thinking about quitting my job'. He was a police officer with approximately 40 years of experience. However, during the second interview (day 9), he said 'I can see the possibility of returning to work.… I need to be prepared to revise my job description accordingly', showing signs of physical recovery. In the third interview (day 21), he reversed his stance: 'If I cannot work, I have no choice but to leave it to chance'. This statement indicated that he had begun to abandon the hope of resuming his work.

P7, an avid stream fisherman, expressed a strong desire to resume fishing in the first interview (day 3), stating, 'If possible, I would like to start again. I don't expect my body to fully recover, but I want to get as close to my previous state as possible'. However, by the second interview (day 9), his outlook had shifted: 'I feel like I have mostly given up'. In the third interview (day 18), he said 'I think stream fishing may be too difficult, but if I move further downstream, I might be able to do something safely. My recovery has been progressing faster than I initially expected'. This shift illustrates his process of reevaluating occupational participation within the constraints of his physical recovery.

In the first interview (day 4), P8, who had severe left hemiplegia, described herself as pathetic because she could no longer engage in farm work and hoped that her condition would improve. In the second interview (day 21) with no improvement observed in her physical condition, she tearfully admitted, 'I want to be at least able to

go to the bathroom by myself.… I have given up farming. I need help when going to the bathroom. I am sorry'.

All participants anticipated some degree of physical recovery; however, their actual recovery trajectories varied and were difficult to predict. Regardless of the extent of recovery, their emotional well-being and aspirations for occupational participation were closely tied to their physical conditions.

'Resistance to the loss of daily roles'

The decrease in occupational participation resulted in a strong sense of resistance to the loss of one's roles and relationships with others. For example, P5, who was primarily responsible for homemaking in her household, was desperate to return to her pre-illness role:

> 'My husband cannot cook, so I must cook.… The tub is dirty after my husband cleans it, and he cannot fold the laundry well. I am sorry for him, but I am not happy when the housework is not done the way I want it'.

Similarly, P9 expressed concern about her husband's well-being in her absence, stating, 'If I am not there, my husband will struggle'. She emphasised her sense of duty to resume household tasks for his sake. P4, who was responsible for providing meals for her daughter, asserted, 'I have to continue preparing meals'. Her statement reflected her determination to maintain her parenting role. P12, who regularly attended harp lessons, expressed anxiety about the impact of her absence on her peers, stating, 'If I miss my lessons, it will inconvenience everyone'. Her concern highlighted the social expectations tied to her participation.

In contrast, P2 showed resistance to a complete role reversal: 'Until now, I was the one taking care of them; but now, I will be the one being taken care of'. This shift led him to worry about his relationships with his significant others: 'I think my relationship with them will fall apart in the future'.

'*Disconnected from daily life*'

Diminished occupational participation caused participants to feel disconnected, resulting in a profound sense of loss and despair. For instance, P2, who started working as a sushi chef after graduating from junior high school, stated, 'Work was an essential part of my life. I do not know what to do now that I have suddenly become like this'. He further conveyed his despair by stating, 'I cannot see the future; it is pitch black'.

Similarly, P7, a newspaper delivery worker, stated, 'It feels as if I have lost my dreams', indicating that his sense of loss extended beyond financial concerns to a

broader feeling of disconnection from his envisioned future. P11 also, who could no longer walk his dog or carry out routine tasks, struggled with the uncertainty of returning to daily life. In tears, he said, ‘This is the end of my life'.

A farmer, P8, described a dream where ‘The radishes grew to my height, and I talked to them’. However, as her paralysis persisted and she stopped having these dreams, she lamented, ‘I cannot even dream about it anymore; so, I can only say that this situation is pathetic’. For these participants, the productive occupations that were deeply embedded in their daily lives provided financial support and a sense of purpose, making them an indispensable part of their lives.

‘Awareness of supporters’

Despite the significant losses and despair caused by diminished occupational participation, the participants realised the importance of accepting support and encouragement from others. This gratitude fuelled their hope to re-engage in their occupations, marking an essential step in their rehabilitation process.

P6, an active religious worker involved in community clean-up, initially questioned her life’s purpose following her stroke: ‘Why at a time like this?’ Despite receiving a prognosis that indicated the possibility of permanent damage, she displayed extraordinary determination to rebuild her life for the community’s betterment. She stated, ‘I still have to work for the community’, and ‘I can do my best because the community needs me’. The community’s importance served as a motivating factor in her drive to achieve complete recovery.

In contrast, P3, a 97-year-old man, experienced limitations in self-care abilities. Although he aspired to maintain his independence and avoid becoming a burden to his family, he expressed deep gratitude for the nursing support he received. ‘I try not to bother them as much as possible, but it does not work. I am grateful to the nurses who took care of me’, he noted. In the process of accepting a new reality, he began to feel more gratitude than frustration.

P10 also experienced anxiety about being unable to return to work. However, the support from his colleagues helped alleviate his concerns. He stated, ‘At first, I was overwhelmed with anxiety. Now, I feel a sense of relief knowing that there is someone who can take over my responsibilities at work’.

This theme highlighted the transformative power of recognising and appreciating the support of others through a shift in perspective. This realisation reduced feelings of hopelessness and fostered hope and resilience.

Discussion

In this study, we explored how participants in the acute phase of stroke experienced diminished occupational participation through an interview-based investigation. As a result, the experiences of diminished occupational participation among stroke survivors during the acute phase were extracted as the four themes. This study highlights that diminished occupational participation in the acute phase is particularly characterised by the experience of being at the mercy of uncertain physical recovery. Although recovery trajectories may differ beyond the acute phase, the findings suggest that uncertainty about physical recovery is a central and defining experience during this period, profoundly shaping occupational participation.

These findings highlight the importance of tailoring rehabilitation strategies to address the profound uncertainties affecting occupational participation in the acute phase of stroke.

Uncertainty in physical recovery

The decline in occupational participation during the acute phase was characterised as a daily experience in which survivors were at the mercy of physical changes. In this study, we conceptualised this experience as confronting the uncertainty of physical recovery. Traditionally, survivors' experiences in the chronic phase have been framed as a process of adaptation, with themes such as 'role reconstruction' and 'new learning opportunities' (Lo et al., 2021). In contrast, participants in this study described being in an unpredictable state where the extent and trajectory of physical recovery were unclear. Before they could begin adapting, they faced a more fundamental uncertainty: the perception that 'the future was entirely unclear'. This uncertainty stemmed less from day-to-day fluctuations in physical function than from anxiety surrounding the persistent ambiguity of the recovery process and its eventual outcome. Participants expressed this experience as one of confusion although rooted in the varied pace and patterns of recovery across individuals. Mishel (1990) defined uncertainty in illness as 'the inability to determine the meaning of illness-related events or accurately predict outcomes'. Consistent with this definition, participants in our study reported oscillating between despair and hope, struggling to reconcile their shifting physical condition with a desire to regain control over their lives. This experience of being at the mercy can also be interpreted, within the theoretical framework of the MOHO (Kielhofner, 2009), as the impact of uncertainty regarding one's performance capacity on the client's volition.

Backe et al. (1996) examined the experiences of stroke survivors during the first week after onset and emphasised their early recognition of role disruption and the importance of support. Their findings overlap with the last three themes identified in the present study. However, our findings place greater emphasis on survivors' active responses to role loss, the sense of anxiety and grief arising from detachment from everyday life and a meaningful future, and the process by which awareness of supporters serves as a foothold for recovery amid psychological instability. In this way, our study offers a more dynamic portrayal of the acute-phase experience than that described by Backe et al. By conducting up to three interviews during the acute phase of stroke, we believe this study enabled the sensitive capture of the dizzying temporal dimensions specific to this phase (Tse et al., 2022). Building on this, the present study highlights that these experiences are deeply rooted in the uncertainty characteristic of the acute phase, specifically the inability to foresee the course and outcome of physical recovery. This uncertainty profoundly shapes survivors' daily lives and provides the context for understanding their psychological struggles and adaptive efforts.

In the acute phase, individuals struggle to comprehend the rapid and uneven progression of their physical condition and its implications for daily life. This psychological state aligns with the early responses described in models of disability acceptance. Fink's (1967) early stage-based model defines acceptance of disability as a progression through shock, defensive retreat, acknowledgement, and adaptation. More recent approaches, such as those proposed by Livneh and Antonak (2005), view acceptance of disability as a dynamic, multidimensional, and non-linear process influenced by personal, social, and contextual factors. From this perspective, the experience of being at the mercy of uncertain physical changes can be understood not simply as emotional turmoil, but as part of an adaptive process involving efforts to make decisions amid uncertainty. Although this experience may partially align with the early emotional responses described in disability acceptance models, the acute phase is not solely about acceptance but also about ongoing adaptation and negotiation with one's evolving condition. Our study participants did not merely move toward acceptance. Rather, they actively engaged in strategies to regain a sense of agency and construct meaning in a constantly shifting reality. Thus, rather than viewing 'being at the mercy' as a precursor to acceptance, it may be more accurately understood as a reflection of the uncertainty and fluidity inherent in the acute phase.

Characterised by the participants' perception of being suddenly cut off from their daily lives and from the continuity of their pre-stroke selves, this theme emerged as a key theme in the acute phase. Although previous studies have reported similar experiences in the later stages of recovery, such as a sense of distance between the pre- and post-stroke self (Murray & Harrison, 2004) and marginalisation after discharge resulting from an inability to fulfil expected roles (Martinsen et al., 2013), our findings suggest that such experiences of disconnection occur more abruptly and extensively during the acute phase. Furthermore, Murray and Harrison (2004) and Martinsen et al. (2013) suggest that disruptions in self-perception and role fulfilment following stroke may lead to identity disturbances. In our study, being disconnected from daily life was interpreted as a disruption of occupational identity, as participants lost occupations that had core personal meaning.

It has also been reported that such an identity crisis can affect the client's role and relationships with family and friends (Horne et al., 2014). As expressed in the theme of 'resistance to the loss of daily roles', participants in our study described their strong will to maintain these roles and resist relinquishing them. These sentiments highlight not only their commitment to valued roles but also a psychological resistance to entrusting them to others. This resistance appeared to stem from anxiety about losing their identity and position within their families or communities. Although these experiences have been reported in previous studies (Christiansen, 1999; Rhoda, 2012; Horne et al., 2014), we consider resistance to the loss of roles to be a unique theme that reflects the characteristic psychological state of the acute phase, when physical conditions are uncertain.

Application to Practice

The stroke survivor's physical situation can leave them at the mercy of it psychologically, causing their thoughts and feelings about occupational participation to fluctuate daily. In the acute phase, it is essential for occupational therapists to address clients' current perspectives on occupational participation as well as their long-term goals.

By addressing the client's thoughts on occupational participation in the present moment, a foundation for understanding the client's volition even amid physical and psychological fluctuations can be built, thereby enabling client-centred occupational therapy support. Moreover, to prevent or address the loss of occupational identity in clients, it is important to reconstruct the meaning of their daily occupations and habits

through dialogues about what most valued. This can help clients reaffirm their own values and roles and provide them with an opportunity to reflect on the occupations that are important to them, even while they are at the mercy of unstable conditions in the acute phase.

It is also important to facilitate clients' early awareness of their supporters, as it can help with being at the mercy of a stroke during the acute phase. Stroke survivors experience social isolation as a result of low self-confidence and a tendency to withdraw from society (Kitzmüller et al., 2013). Lack of support causes a loss of social value, confusion, and worsening of stroke survivors' health (Salter et al., 2008). In the acute phase, supporters can help stroke survivors gain psychological stability and maintain their motivation for occupational participation. This study highlights the importance of a rehabilitation approach that integrates an occupational perspective from the acute phase. Such an approach should not only prioritise physical recovery but also promote early re-engagement in meaningful occupations, reconstruction of personal identity, and restoration of daily life continuity disrupted by stroke, thereby enabling truly client-centred support in acute rehabilitation.

Limitations

This study has certain limitations. The interviewer was a staff member at the hospital and was responsible for the occupational therapy of all the participants. This may have caused participants to consider the effect on their relationship with the interviewer and facilitated the participants' participatory observation in rehabilitation and ward life situations. However, it also facilitated the development of a trusting relationship and allowed for more in-depth interviews. Multiple interviews could not be secured for some study participants because of early discharge or transfer. Additionally, mild cognitive changes, post-stroke depression, or emotional fluctuations may have influenced their responses. However, to confirm the absence of severe cognitive impairment, we set a criterion for study participation. Furthermore, the interviews were designed to allow participants to freely express their thoughts and experiences while minimising cognitive and psychological burdens.

Conclusion

In summary, this study revealed that stroke survivors in the acute phase experience a multifaceted decline in occupational participation, characterised by four interrelated themes. These findings highlight the complexity of occupational experiences during the acute phase and support the development of rehabilitation

strategies that are sensitive to the unique uncertainties of this period. An approach that supports occupational identity while remaining attentive to the client's present emotional state is essential. This study offers new insights into providing truly client-centred support in acute rehabilitation.

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The authors report there are no competing interests to declare.

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Table 1. Participants' Demographic, Clinical Information, and day of interview(s).

Participant ID	Gender	Age	Side	SIAS	FIM	Important occupational participation	First interview	Second interview	Third interview
P1	Man	57	Left	67	83	Work: Police officer	Day 3	Day 9	Day 21
P2	Man	63	Left	59	81	Work: Sushi restaurant employee	Day 5	Day 21	
P3	Man	97	Left	69	80	ADLs: Self-care	Day 4		
P4	Woman	67	Left	73	93	ADLs: Homemaking	Day 7		
P5	Woman	81	Right	50	73	ADLs: Homemaking	Day 6	Day 10	
P6	Woman	70	Right	75	75	Work: Religious activities	Day 3		
P7	Man	59	Left	43	76	Leisure: Fishing Work: Newspaper delivery	Day 3	Day 9	Day 18
P8	Woman	87	Right	25	53	Work: Farm work	Day 4	Day 21	
P9	Woman	70	Left	71	85	ADLs: Homemaking	Day 4		
P10	Man	64	Right	56	51	Work: Traffic warden	Day 3	Day 10	
P11	Man	83	Right	53	76	ADLs: Walking the dog	Day 5		
P12	Woman	86	Left	68	92	Leisure: Harp playing	Day 8		

Abbreviations: SIAS, Stroke Impairment Assessment Set; FIM, Functional Independence Measure; ADLs, activities of daily living. FIM total score range: 18–126 (higher scores indicate greater independence). SIAS score range: 0–5 per item (higher scores indicate better function).

Table 2. Interview questions

1.	Could you tell me about your experience with activities that were important to you before the onset of illness?
2.	What are your thoughts about those activities since you had a stroke?
3.	Have your feelings about these activities changed over time after hospitalisation?
4.	Could you share any other thoughts about what we have discussed so far?