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The Experiences of Couples Affected by Stroke and Nurses Managing Patient Rehabilitation: A Descriptive Study in Singapore

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ABSTRACT

Background: Stroke in a family affects both patients and their spousal caregivers. Despite advances in the medical management of stroke, less is known about the social and cultural factors that impact couples regarding stroke recovery.

Purpose: The purpose of this study was to explore the experiences of stroke from the perspectives of couples affected by stroke and the nurses managing patient rehabilitation.

Methods: An interpretive descriptive study was conducted. Purposive sampling was used to enroll 17 participants, comprising eight nurses, five spousal caregivers, and four stroke survivors. Individual, in-depth interviews were performed at a rehabilitation hospital in Singapore in June 2018.

Results: The primary theme was the diverse meanings of stroke recovery attributed to limited conversations about the care decisions made by couples and rehabilitation nurses. The second theme was the challenges in nursing responsibilities that hindered the recovery of patients with stroke.

Conclusions/Implications for Practice: The meaning of recovery differs between patients and their informal and formal care providers. This issue should be explored in patient–provider conversations, as these conversations highlight the values and preferences that affect the stroke recovery trajectory. Enhancing shared decision making by patients, spousal caregivers, and healthcare providers during the stroke trajectory may promote the alignment of values that are critical to the stroke recovery experience. Further research into whether and how to incorporate shared decision making in rehabilitation hospital settings as an interventional component is warranted to better support stroke survivors before discharge.

KEY WORDS:

stroke, couples, rehabilitation, nurses, recovery, experiences.

Introduction

Stroke is an acute condition in which the blood supply to the brain is disrupted because of either a burst blood vessel (hemorrhagic stroke) or blockage by a clot (ischemic stroke). Both scenarios reduce the supply of oxygen and nutrients to the brain (World Health Organization, 2019). Stroke is a chronic disability affecting 15 million people globally (National Institute of Neurological Disorders and Stroke, 2018). Of these, five million patients with stroke die, whereas another five million experience permanent disabilities, such as hemiplegia, incoordination, loss of sensation, swallowing difficulties, bladder and bowel incontinence, aphasia, cognitive deficits, and diminished mobility and self-care skills (Palmer & Palmer, 2011). In Asian countries such as Taiwan, Korea, Japan, and urbanized parts of China, the burden of stroke is serious, with reports of higher mortality rates compared with North America and Europe. This may be attributed in part to a more rapidly aging population in this region than other parts of the world (Kim, 2014).

In Singapore, stroke is the fourth leading cause of death, contributing to 10%–12% of all deaths. The burden of stroke in Singapore is expected to rise, causing challenges to the healthcare system (SingHealth Group, 2019). In 2016, Singapore's public hospital system admitted 7,413 patients with stroke (National Registry of Diseases Office, Health Promotion Board, 2018).

Stroke is a more significant health problem in Asia than in Europe or the Americas (Feigin et al., 2014). In Asia, stroke occurrence is highly related to vascular risk factors like hypertension, diabetes, and hypercholesterolemia (Kim et al., 2016) as well as tobacco consumption (Venketasubramanian et al., 2017). According to the 2016 Singapore Stroke Registry Annual Report, the number of stroke episodes in the Singaporean Chinese, Malay, and Indian populations has increased since 2007 (National Registry of Diseases Office, Health Promotion Board, 2018). Although the medical conceptualization of stroke is well established, little is known about the social and cultural factors that affect couples' recovery after a stroke. Knowing the social factors of stroke

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recovery helps healthcare professionals understand how stroke couples perceive and respond to stroke illness (Goffman, 2009). On the other hand, cultural factors affecting stroke recovery target the recovery-related cultural beliefs of couples (Conrad & Barker, 2010).

"Stroke recovery" refers to the gradual improvement of physical and cognitive functions after an episode of stroke (Palmer & Palmer, 2011, p. 15). Stroke recovery varies from one individual to another, with some fully recovering and others suffering long-term disabilities such as paralysis (Centers for Disease Control and Prevention, 2018).

Couples affected by stroke report that stroke is a significant life-changing event for patients that affects the marital relationship (Coombs, 2007). In particular, spouses often express "feeling lost" upon their partner's discharge home from the hospital. Spouses often engage in a trial-and-error process to support their partner with little guidance or support provided by healthcare professionals (Satink et al., 2018). In another qualitative study, family caregivers expressed their feeling overwhelmed by the enormity of the tasks before them when patients with stroke were discharged home (Lutz et al., 2011). This was reported by caregivers who felt responsible for providing care 24 hours a day. The Stroke Foundation of Australia (2019) reiterated that both patients with stroke and their caregivers, often spouses, grieve after a stroke. This may be attributed to the poststroke losses of normal life routines, independence, and mobility.

Nurses, as the primary healthcare providers working in close proximity to patients and their families (Petera & Liaschenko, 2004), are vulnerable to moral ambiguity regarding their responsibility to support these couples (i.e., stroke dyads) reach their goals and fulfill their expectations of recovery from stroke. Together with other healthcare professionals, rehabilitation nurses work together with patients with stroke and their spousal caregivers at the front lines of managing stroke recovery. Thus, the authors of this study assert that the experiences of patients with stroke, spousal caregivers, and rehabilitation nurses should be illuminated before developing supportive interventions for stroke recovery. Singapore was the focus in this article.

Community hospitals in Singapore are designed to provide rehabilitative services for patients and family members after acute care, to facilitate patient recovery to an optimal level of functional abilities, and to resume activities of daily living before returning home (Ministry of Health, Singapore, 2017). Stroke-related healthcare in Singapore is predominantly focused on providing care to individual patients with stroke. Support for patients with stroke and their spousal caregivers, as couples in recovery from stroke, is lacking. In choosing this target group, the authors hope that the findings enable rehabilitation healthcare professionals to systematically plan and develop suitable interventions for stroke couples in the Singaporean context.

Aim and Objectives

The overall aims of this study were to enhance the theoretical understanding of the meaning of stroke recovery to stroke

couples and to nurses involved in their predischarge hospital care. The specific objectives of this study were to (a) gain an in-depth understanding of how couples cope with stroke recovery; (b) explore the social and cultural factors affecting couples' recovery after a stroke; (c) identify how nurses perceive what supports and hinders couples' recovery in the community; and (d) explore the meaning of stroke recovery for patients with stroke, spousal caregivers, and rehabilitation nurses.

Methods

Study Design

Interpretive description was selected to address the understanding of clinical practice in terms of health, illness, and experiences within a healthcare context (Hunt, 2009; Sandelowski, 1986; Thorne et al., 1997). This approach has been used successfully to uncover knowledge regarding what drives nursing practice (Forbes et al., 2012; Stevenson et al., 2015) and is anticipated to guide the future development of a support intervention for couples after a stroke in a Singaporean context.

Sampling Strategies and Setting

Purposive sampling was adopted by the research team to recruit participants based on their rich, firsthand knowledge of the subject matter (Polit & Beck, 2010). With reference to Thorne (2008, p. 94), "An interpretive description can be conducted on samples of any size, in that the vast majority of studies have sample sizes between five to 30 participants." Participants were recruited from one urban stroke rehabilitation hospital in Singapore.

Inclusion and Exclusion Criteria

Couples who fulfilled the following inclusion criteria were invited to participate in the study: (a) at least 21 years old and able to provide written consent, (b) patient experienced either an ischemic or hemorrhagic stroke episode, (c) spouses who self-identify as both a spouse and the primary family caregiver to the patient with stroke, and (d) able to communicate comfortably in English. Nurses were recruited who met the following inclusion criteria: (a) at least 21 years old and (b) have working experience in the stroke rehabilitation ward of the target hospital.

Exclusion criteria included patients with stroke with cognitive impairment, as assessed using the Abbreviated Mental Test score (total score for the Abbreviated Mental Test is 10). In this regard, patients with stroke who scored less than 7 were excluded because of cognitive impairment. In addition, patients with stroke with severe dysarthria as determined by a speech therapist assessment report were excluded to prevent the risk of becoming emotionally distressed during interviews (Savage, 2006).

Data Collection

Data collection using individual interviews with patients with stroke, spousal caregivers, and rehabilitation nurses took place from June 1, 2018, to June 30, 2018. The duration of each interview ranged from 20 to 60 minutes. A semistructured interview guide with open-ended questions was used to conduct the interviews (Table 1). The interview guide for this study was systematically developed using a framework for the development of a qualitative semistructured interview guide. The steps in this framework were as follows: (a) identify the need for semistructured interviews; (b) retrieve and synthesize knowledge and gaps related to the research topic; (c) develop a preliminary, semistructured interview guide; (d) conduct a pilot test of the guide; and (e) complete the semistructured interview guide (Kallio et al., 2016).

Data Analysis

Data analysis began with independent coding of the transcripts by three members in the research team. On the basis of Thorne's (2008) interpretive description, the transcribed data were "chunked" into meaning units or codes. Patterns were then organized by relationships and associations. Attention was focused on identifying participants' emotions that signaled important concerns. After coding and consensus of the first three transcripts for an initial coding structure, the remainder of the transcripts were coded and modified, building on this structure every three to five transcripts. Theorization occurred by inductively building a coherent whole using an iterative reasoning process that focused on how patterns operated and how the preliminary findings were shaped. Reconceptualization occurred when the themes provided a coherent structure of constructs, informing patterns of ideas on care management for stroke couples and the meaning of stroke recovery in the rehabilitation hospital (Thorne, 2008). The codes and coding structure were managed by the first

author using NVivo 11 software (QSR International, Melbourne, Australia).

Rigor and Reflexivity

Rigor or trustworthiness was determined using the criteria proposed by Tobin and Begley (2004), which were credibility, dependability, reflexivity, and transferability. Credibility was determined by scrutinizing the findings for coherence in conveying participants' experiences. A particular challenge for the first author as a researcher was reflexivity, to keep her assumptions in abeyance, as she was a nurse with 6 years of experience in caring for patients with stroke and their families. As such, she was conscious of the dynamics of the interviewer-interviewee relationship and reflected on how her role shaped the creation of different knowledge in a reflexive diary. Credibility was also established using peer debriefing with the second and third research team members, who had expertise in qualitative methodology (Spillett, 2003) and had over 18 years of combined experience in gualitative research. To improve dependability, two of the researchers engaged in the process of coding and recoding for data analysis. Any discrepancies were verified with the third team member to achieve consensus. Finally, transferability was ensured by considering the applicability of findings (Marshall & Rossman, 1999) to the context of rehabilitation hospitals in Singapore. Although this study may not have attained data saturation, the participants provided rich descriptive data, and the research design employed a unique context that ensured the significance and relevance of the findings (Jeanfreau & Jack, 2010).

Ethical Considerations

Ethical approval was obtained from the Human Subjects Ethics Applications Review System of the Hong Kong Polytechnic University (Reference Number HSEARS20180205008) and the National Healthcare Group Domain Specific Review Board in Singapore (Reference Number 2018/00117). In light

Table 1

Semistructured Interview Guide for Research Participants

Semistructured interview guide for couples with stroke

- I would like to hear more about your experiences on how you manage yourself after the stroke situation.
- (a) Perhaps, would you like to tell your story of how you (the patient) and partner first experienced the stroke event?(b) Then, what experience stood out for you as challenging?
- (c) What experience stands out for you as important in the recovery when they were going to be discharged home?
- (d) What might you tell someone else wanting advice as to how to cope?

Prompts to get at social or cultural forces that shaped their experiences: Can you tell me more about how you decided to...? Can you tell me more about what made you want to...?

Semistructured interview guide for nurses

- I would like to hear more about your experiences on how you provide care for stroke patients and their spouses in the ward. (a) What is a typical day for you caring for patients with stroke and their spouses?
 - (b) What makes your work with them challenging?
 - (c) What facilitates your work with them?
 - (d) What advice would you give a new nurse who is working with patients with stroke and their spouses in the community?

of the ethical importance of maintaining participant anonymity and confidentiality in human research (Clarke, 1991) and of the relative ease of recognizing participant identities because of the in-depth interactions and rapport between interviewers and interviewees in qualitative inquiries (Fouka & Mantzorou, 2011), in this study, participants' names were replaced with pseudonyms for transcription and analysis to ensure anonymity and confidentiality. Furthermore, these pseudonyms will be used in any future dissemination of research findings.

Nonmaleficence refers to the avoidance of causing unnecessary harm to participants of a study (Gillon, 1985, p. 130). Unnecessary harm to participants was avoided by identifying and mitigating potential risks to participants beforehand. If distress in a participant was encountered during the interview process, referrals for counseling services would be made with the consent of that participant. The risk of harm to participants in qualitative studies is generally considered to be low. No participant in this study required a referral for counseling services.

Results

Participant Demographics

Five patients with stroke, four spousal caregivers, and eight registered nurses were interviewed. The mean age of patients was 51.4 years (SD = 4.7), the mean age of spousal caregivers was 50.8 years (SD = 4.6), and the mean duration for the marital relationship of the spouses was 19.5 years. All four of the spousal caregivers were employed. Eight full-time registered nurses were interviewed individually. The mean duration of clinical working experience for the nurses was 4.9 years (range from 1 to 8; Table 2).

Perceptions of Stroke Recovery

Primary theme: Diverse meanings of stroke recovery

The primary theme identified was diverse meanings for patients, their spousal caregivers, and nurses, as these three groups held different perceptions of stroke recovery. As indicated in Figure 1, the different perspectives were rooted in differing values of stroke recovery. Moreover, these different perceptions hindered the effective coordination of care by nurses for both patients with stroke and their spousal caregivers. This was attributed to the limited conversations held between rehabilitation nurses, patients with stroke, and their spousal caregivers regarding how care decisions would be made. In particular, rehabilitation nurses perceived that spousal caregivers were skeptical and lacked trust about their nursing care because they did not perceive nurses as willing or competent to care for patients. In this regard, stroke recovery was not optimized for patients.

There are some family caregivers who refuse to take part in caregiver training. They feel that while the patient is in hospital, the nurses have to care for

Table 2

Subject Demographic Characteristics

ltem	n	%	Mean	SD
Patients with stroke $(n = 5)$				
Gender				
Female	1	20		
Male	4	80		
Age (years)			51.4	4.7
Ethnicity				
Chinese	0	0		
Malay	4	80		
Indian	1	20		
Incidence of strokes				
First time	4	80		
Second time	1	20		
Days after stroke			135.0	158.7
Barthel Index score			18.4	2.2
Spousal caregivers $(n = 4)$				
Gender				
Female	3	75		
Male	1	25		
Age (years)			50.8	4.6
Years of marriage			19.5	10.9
Ethnicity				
Chinese	0	0		
Malay	2	50		
Indian	2	50		
Employment status				
Working	4	100		
Not working	0	0		
Nurses ($n = 8$)				
Gender				
Female	5	62.5		
Male	3	37.5		
Age (years)	-		27.3	3.5
Ethnicity				
Chinese	2	25.0		
Malay	2	25.0		
Indian	1	12.5		
Filipino	3	37.5		
Years of experience in nursing	-		4.9	2.9

the patient's every need, and that they are paying for us, so they refuse to learn. We keep trying to teach them and tell them that we are trying to help them care for the patient at home. Sometimes they are still not receptive to learning. That is the challenge. (Registered Nurse 3)

When a wife, for example, is the main caregiver but she does not want to learn anything because she is paying...we need to explain, explain, and explain until she accepts the need to learn. That is the most challenging part. (Registered Nurse 2)

Despite providing health education, I think sometimes they (spousal caregivers) are going against us, I think this is mainly because trust in the nurses is

Figure 1

The Perceptions of Stroke Recovery

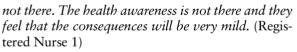
Primary theme: Diverse meanings of stroke recovery

- limited conversations about care decisions
- nurses perceive spousal caregivers as unwilling to participate in care and lacking trust in healthcare providers
- spousal caregivers want to resume work to contribute to their family financially
- stoke patients believe that they will fully recover while in rehabilitation hospitalization and resume their normal life after discharge
- Muslim couples believe that the stroke and recovery have been predicted and planned by God

Second theme: Challenges in nursing responsibilities that hinder the recovery of patients with stroke

- language barriers between rehabilitation nurses and stroke couples
- nurses perceive that nursing staffing shortages and heavy workload impact the recovery of patients
- nurses are uncertain about how to develop a strategic care plan to meet the needs of spousal caregivers who are working

Perceptions of stroke recovery



The spousal caregivers in this study primarily expressed financial-related concerns. They were uncertain about the degree to which patients would recover and considered resuming work to support the family, in conflict with their desire to care for the patient at home:

But even if it is taught to me, I would not be fully prepared to learn—aahhh—I mean with him because I am also working. I go, I leave my house at eight, I mean I leave my house at six a.m. and I come back in the evening at about eight p.m., and then I do not have much time to spend with him. (Spousal Caregiver 1)

I think it is very difficult, as I am the only one working and my children are all studying. It is so hard for me to manage alone. I need to pay all the bills. (Spousal Caregiver 3)

As a result of spouses working, patients with stroke relied on their peers, rather than on their spouse, for emotional support both in the clinical setting and after discharge:

So, you need somebody to talk to, you need somebody to give you moral support. During my hospitalization, I made friends with a group of patients there. Even after discharge, we get together and talk. I think that as human beings, if we have any problems, we need to communicate.... My wife is working and does not help me much. (Patient With Stroke 3)

In contrast, patients with stroke expressed optimism about the chances for a full recovery by the end of their stay in the rehabilitation hospital. Furthermore, patients stated that they expected to resume work and volunteer in initiatives to support the rehabilitation of other patients after their stroke:

I am confident that my legs and hands will support me, and I hope there will not be any issues with work. So, when I go back to work from nine a.m. to 10:30 p.m., I need to stand and wait for the IT personnel as a form of respect, lah, and I hope I can do that. (Patient With Stroke 4)

I want to volunteer to support other patients with stroke.... I will never forget the good things that people did for me. One day I will come back as a volunteer to help others. (Patient With Stroke 4)

Patients with stroke expressed a strong desire that their lives would return to normal after discharge, as they feared being a burden on their families: I do not like to put a burden on my children to take care of me, to support me financially, even to take time off work to take me to the hospital. For me, if you can be independent, you might as well do it yourself. So, no choice, my children still depend on me and need to come to me for support. (Patient With Stroke 3)

I do not have to give up and I cannot give up. Oh God, if I had given up, what would have happened to me by now? I must be strong for my wife and children. (Patient With Stroke 4)

Alternatively, Muslim patients with stroke believed that their stroke was a consequence of God's plans for them. They engaged in spiritual coping and self-rationalization to come to terms with why God had chosen them to have a stroke and to accept this in the context of their recovery:

The first thing that I asked myself, I will be honest with you, is why me? I asked God, why did you choose me? When God chooses you, you are the only selected one. God tests you for no formal reason. Whatever a patient with stroke has to go through, the hassles of life after a stroke, just take it as a gift from God. (Patient With Stroke 4)

This one God gives. Because God has decided everything, whether you can walk, or cannot walk, all is by God.... Everything you suffering from now, is God's way of punishing you. He makes you remember your past sins. Really you know, every sickness that happens is God punishing you. When God gives you a stroke, you must know how to take care of yourself. You know what it is being a Muslim. (Patient With Stroke 1)

Spousal caregivers of Muslim patients also believed strongly that God had reasons for what had happened to them. Similar to patients, the caregivers in this study perceived that a stroke was a way of "cleansing past sins" and, thus, they should accept their experiences and make sense of it in their lives:

Malay call this God knowing whatever is going to happen to us. It means that God has already predicted what will happen to us now and in the future. So, we have to accept it, lah. Sometimes in Islam the way is that, you know why you get a sickness? It is because God loves you. It is God's way of cleaning up all of your sins. (Spousal Caregiver 2)

<u>Second theme: Challenges in nursing</u> <u>responsibilities that hinder the recovery of patients</u> <u>with stroke</u>

The lack of care decisions in aligning diverse meanings of stroke recovery for patients with stroke, spousal caregivers, and nurses was intensified within three clinical contexts. First, language barriers were evident between rehabilitation nurses and stroke couples. Rehabilitation nurses were unable to adequately educate patients with stroke and their spousal caregivers before discharge, as they were not always able to speak and comprehend the others' language:

I think we have problems with a language barrier, since most older patients with stroke and caregivers use the old language. For this kind of situation, right, the main spoken language for us is English, because we are not from this country and we mostly speak English, so we are not used to speaking their languages, such as Hokkien and Mandarin. If they cannot understand, we need an interpreter, and we use another staff member to interpret for us. (Registered Nurse 2)

Yes! Very much, because some can speak Malay, some can speak Chinese, and only a few can speak English, so it is difficult to speak with patients and spouses. (Registered Nurse 5)

Second, rehabilitation nurses perceived that nursing staffing shortages and their own heavy workloads impacted the recovery of their patients. Staffing shortages made it difficult for nurses to juggle routine care and to provide sufficient support to stroke couples in the clinical setting:

I think that human resources are lacking because we take charge of 16 to 18 patients and there are only two nurses to take charge. Let us say that one patient calls for the toilet, and another patient also calls for the toilet. Then there is really a lack of staffing. It is very difficult to address all patient concerns at the same time. (Registered Nurse 7)

One staff nurse is in charge of 17 patients, making the workload even heavier. (Registered Nurse 8)

Third, the rehabilitation nurses in this study were uncertain regarding how to develop a strategic care plan to meet the needs of spousal caregivers, many of whom were working. Nurses reported plans to engage stroke dyads in rehabilitation activities together. However, education to explore the coping of these dyads, including rebuilding their marriage after a stroke, was lacking:

So, some of them are working, some spousal caregivers are available in the morning, while others are available in the evening. So, when we conduct bedside education in the morning, we will miss those who can only come at night. If we come at night, we will miss those who can only come in the morning. (Registered Nurse 2)

If they want a regular time, we will arrange it on Fridays and Saturdays, which are not so busy. Because on Saturdays and Sundays, patients are so free, just lying down as there are no therapy sessions with physiotherapists and occupational therapists. They will also do nothing. So maybe we can provide some *entertainment and activities for them.* (Registered Nurse 4)

Discussion

The primary theme identified in this study was the diverse meanings of stroke recovery that prevailed because of limited conversations and failure of discussions between couples and rehabilitation nurses about care decisions. A secondary theme was the challenges in nursing responsibilities that hindered the recovery of patients with stroke. In particular, this study highlights the need for further exploration of how the diverse meanings of stroke recovery for patients with stroke, spousal caregivers, and nurses may be better explored and aligned to improve care coordination.

The experiences of rehabilitation nurses revealed that spousal caregivers were not interested in the care of patients with stroke at home in the community. To support the family financially, spousal caregivers prioritized the resumption of work over care for their spouse. King et al. (2010) recognized that most caregivers struggled to provide for their family while caring for patients who experienced disabilities after a stroke. Informal caregivers depend on nurses for assistance with issues with their daily lives such as how to balance caregiving schedules with other commitments, including work. Therefore, the utmost priority for rehabilitation nurses may be to discuss decisions about caregiver training, meaning, and planning stroke recovery for couples and the types of support required so that appropriate assistance may be rendered in a timely manner (Camak, 2015).

One way of ensuring coordinated care among patients with stroke, spousal caregivers, and rehabilitation nurses is to practice shared decision making in a clinical context. Shared decision making refers to collaboration among patients with stroke, spousal caregivers, and nurses that considers the preferences and values of each during the stroke recovery process as well as evidence to inform the best possible decisions (Armstrong et al., 2016). Shared decision making allows patients and their family members to choose the best option available based on their respective values and goals for care (Armstrong, 2017). In a recent systematic review, shared decision making was reported to improve patients' knowledge and understanding of their clinical condition and their satisfaction and trust in healthcare professionals, thereby leading to better health outcomes (Shay & Lafata, 2015). In another systematic review, results highlighted that "knowledge alone is not power," recognizing the need for shared decision making in clinical settings (Joseph-Williams et al., 2014).

A study by Charles et al. (2006) argued that shared decision making should only be practiced when the cultural context of patients and their family members is taken into consideration. Indeed, in this study, ethnic norms affected the meaning of recovery less than the cultural and societal norms and the spiritual beliefs of stroke dyads. Similarly, in a study conducted in an Indian Muslim community in Africa, 59% of stroke caregivers held shared beliefs that stroke etiology was God's will and that they were not in a position to question what God had planned for them (Bham & Ross, 2005). The study highlighted important findings regarding the effect of stroke-related cultural and religious beliefs on patient expectations during stroke recovery. In particular, the findings of this study in terms of the primary theme "diverse meanings of stroke recovery" support that the attitudes, values, and beliefs of the three key stakeholders (i.e., patients, their spouses, and nurses) affect poststroke recovery. Hence, the assertion that shared decision making is necessary for families in Asia is justified, as it facilitates overall understanding in terms of health awareness between patients and their caregivers (Deber, 1996; Saint-Germaine & Longman, 1993).

Shared decision making in stroke care is an evolving approach in which recent research has predominantly focused on treatment decisions involving the use of oral anticoagulants for stroke prevention (Eckman et al., 2015; Ferguson & Hendriks, 2017; Kaiser et al., 2015; Visvanathan et al., 2017). Less research has been conducted in psychosocial areas involving decisions such as the engagement of couples in social support and in strategies for rebuilding a marriage after a stroke. In a recent systematic review (Anderson et al., 2017), chaos in marriage was found to be a prominent factor affecting poststroke recovery. It was recommended that support be provided to couples affected by stroke and that marital relationships be reestablished by managing the expectations of ideal and current poststroke marital contexts (Anderson et al., 2017).

The rehabilitation nurses in this study expressed a need for more time for training on how to involve patients with stroke and their spousal caregivers in postdischarge care, including training in (a) setting the stage for life after stroke; (b) how stroke affects patients and their marriage; (c) shared decision making on social support after a stroke; (d) balancing the roles of spousal caregiver and marriage partner; (e) strategies for rebuilding a marriage after stroke; and (f) safe lifting, transferring, feeding, and blood pressure monitoring (Palmer & Palmer, 2011). Overall, training should enable nurses to better support spousal caregivers as well as patients before patient discharge from the hospital.

Study Limitations

Although the participants may have been underrepresented in each group, the themes that emerged out of the patients– caregivers–staff mix of data were sufficient, as the rigor of this study ensured discovery of experience on the recovery of couples after stroke in Singapore. Insights on the theorization of a suitable intervention for stroke couples in a Singaporean context were introduced. Even with the small number of participants in this study, data saturation does not depend on a large sample size but rather on the incidents or events identified from the collected data (Corbin & Strauss, 2014). Another limitation of this study is that relatively more independent patients with stroke (mean Barthel Index score of 18.4 points) were interviewed. A future study that includes more patients with stroke with disabilities such as dysphagia or dysarthria is recommended because of inadequate representation in this study.

Conclusions

The meaning of recovery differs between patients and their informal and formal care providers. This issue should be explored in patient-provider conversations, as conversations shape values and preferences in the stroke recovery trajectory. Enhancing shared decision making by patients, spousal caregivers, and healthcare providers during the stroke trajectory may allow the alignment of values critical to the stroke recovery experience. Further research is warranted as to whether and how to incorporate shared decision making as an interventional component to better support couples at the rehabilitation hospital before patient discharge.

Author Contributions

Study conception and design: All authors Data collection: SR Data analysis and interpretation: All authors Drafting of the article: SR Critical revision of the article: DL, VCLC

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References

- Anderson, S., Keating, N., & Wilson, D. (2017). Reconciling marriage and care after stroke. *Canadian Journal on Aging*, *36*(3), 386–401. https://doi.org/10.1017/S0714980817000241
- Armstrong, M. J. (2017). Shared decision-making in stroke: An evolving approach to improved patient care. *Stroke and Vascular Neurology*, 2(2), 84–87. https://doi.org/10.1136/svn-2017-000081
- Armstrong, M. J., Shulman, L. M., Vandigo, J., & Mullins, C. D. (2016). Patient engagement and shared decision-making: What do they look like in neurology practice? *Neurology Clinical Practice*, 6(2), 190–197. https://doi.org/10.1212/CPJ.00000000000240
- Bham, Z., & Ross, E. (2005). Traditional and western medicine: Cultural beliefs and practices of south African Indian Muslims with regard to stroke. *Ethnicity & Disease*, *15*(4), 548–554.

Camak, D. J. (2015). Addressing the burden of stroke caregivers:

A literature review. *Journal of Clinical Nursing, 24*(17–18), 2376–2382. https://doi.org/10.1111/jocn.12884

- Centers for Disease Control and Prevention. (2018). *Recovering from stroke*. https://www.cdc.gov/stroke/recovery.htm
- Charles, C., Gafni, A., Whelan, T., & O'Brien, M. A. (2006). Cultural influences on the physician-patient encounter: The case of shared treatment decision-making. *Patient Education and Counselling*, *63*(3), 262–267. https://doi.org/10.1016/j.pec.2006. 06.018
- Clarke, J. (1991). Moral dilemmas in nursing research. *Nursing Standard*, *5*(50), 22–25. https://doi.org/10.7748/ns.5.50.22.s64
- Conrad, P., & Barker, K. K. (2010). The social construction of illness: Key insights and policy implications. *Journal of Health* and Social Behavior, 51(Suppl.), S67–S79. https://doi.org/10. 1177/0022146510383495
- Coombs, U. E. (2007). Spousal caregiving for stroke survivors. Journal of Neuroscience Nursing, 39(2), 112–119. https://doi. org/10.1097/01376517-200704000-00008
- Corbin, J., & Strauss, A. (2014). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (4th ed.). SAGE.
- Deber, R. B. (1996). Shared decision making in the real world. Journal of General Internal Medicine, 11(6), 377–378. https:// doi.org/10.1007/BF02600052
- Eckman, M. H., Wise, R. E., Naylor, K., Arduser, L., Lip, G. Y., Kissela, B., Flaherty, M., Kleindorfer, D., Khan, F., Schauer, D. P., Kues, J., & Costea, A. (2015). Developing an atrial fibrillation guideline support tool (AFGuST) for shared decision making. *Current Medical Research and Opinion*, *31*(4), 603–614. https:// doi.org/10.1185/03007995.2015.1019608
- Feigin, V. L., Forouzanfar, M. H., Krishnamurthi, R., Mensah, G. A., Connor, M., Bennett, D. A., Moran, A. E., Sacco, R. L., Anderson, L., Truelsen, T., O'Donnell, M., Venketasubramanian, N., Barker-Collo, S., Lawes, C. M. M., Wang, W., Shinohara, Y., Witt, E., Ezzati, M., Naghavi, M., ... Global Burden of Diseases, Injuries, and Risk Factors Study 2010 (GBD 2010) and the GBD Stroke Experts Group. (2014). Global and regional burden of stroke during 1990–2010: Findings from the Global Burden of Disease Study 2010. *The Lancet, 383*(9913), 245–254. https:// doi.org/10.1016/S0140-6736(13)61953-4
- Ferguson, C., & Hendriks, J. (2017). Partnering with patients in shared decision-making for stroke prevention in atrial fibrillation. *European Journal of Cardiovascular Nursing*, *16*(3), 178–180. https://doi.org/10.1177/14745151116685193
- Forbes, D. A., Finkelstein, S., Blake, C. M., Gibson, M., Morgan, D. G., Markle-Reid, M., Culum, I., & Thiessen, E. (2012). Knowledge exchange throughout the dementia care journey by Canadian rural community-based health care practitioners, persons with dementia, and their care partners: An interpretive descriptive study. *Rural and Remote Health*, 12(4), 2201.
- Fouka, G., & Mantzorou, M. (2011). What are the major ethical issues in conducting research? Is there a conflict between the research ethics and the nature of nursing? Health Science Journal [Online], 5(1), 3–14. http://www.hsj.gr/medicine/whatare-the-major-ethical-issues-in-conducting-research-is-there-aconflict-between-the-research-ethics-and-the-nature-of-nursing. php?aid=3485
- Gillon, R. (1985). "Primum non nocere" and the principle of nonmaleficence. *British Medical Journal, 291*(6488), 130–131. https:// doi.org/10.1136/bmj.291.6488.130

Goffman, E. (2009). *Stigma: Notes on the management of spoiled identity*. Simon and Schuster.

- Hunt, M. R. (2009). Strengths and challenges in the use of interpretive description: Reflections arising from a study of the moral experience of health professionals in humanitarian work. *Qualitative Health Research*, 19(9), 1284–1292. https://doi.org/ 10.1177/1049732309344612
- Jeanfreau, S. G., & Jack, L. Jr. (2010). Appraising qualitative research in health education: Guidelines for public health educators. *Health Promotion Practice*, 11(5), 612–617. https://doi.org/ 10.1177/1524839910363537
- Joseph-Williams, N., Elwyn, G., & Edwards, A. (2014). Knowledge is not power for patients: A systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. Patient Education and Counselling, 94(3), 291–309. https://doi.org/10.1016/j.pec.2013.10.031
- Kaiser, K., Cheng, W. Y., Jensen, S., Clayman, M. L., Thappa, A., Schwiep, F., Chawla, A., Goldberger, J. J., Col, N., & Schein, J. (2015). Development of a shared decision-making tool to assist patients and clinicians with decisions on oral anticoagulant treatment for atrial fibrillation. *Current Medical Research & Opinion*, *31*(12), 2261–2272. https://doi.org/10.1185/03007995. 2015.1096767
- Kallio, H., Pietila, A. M., Johnson, M., & Kangasniemi, M. (2016). Systematic methodological review: Developing a framework for a qualitative semi-structured interview guide. *Journal of Advanced Nursing*, *72*(12), 2954–2965. https://doi.org/10.1111/ jan.13031
- Kim, J. S. (2014). Stroke in Asia: A global disaster. International Journal of Stroke, 9(7), 856–857. https://doi.org/10.1111/ijs.12317
- Kim, Y. D., Jung, Y. H., & Saposnik, G. (2016). Traditional risk factors for stroke in East Asia. *Journal of Stroke*, 18(3), 273–285. https://doi.org/10.5853/jos.2016.00885
- King, R. B., Ainsworth, C. R., Ronen, M., & Hartke, R. J. (2010). Stroke caregivers: Pressing problems reported during the first months of caregiving. *Journal of Neuroscience Nursing*, 42(6), 302–311. https://doi.org/10.1097/JNN.0b013e3181f8a575
- Lutz, B. J., Young, M. E., Cox, K. J., Martz, C., & Creasy, K. R. (2011). The crisis of stroke: Experiences of patients and their family caregivers. *Topics in Stroke Rehabilitation*, *18*(6), 786–797. https://doi.org/10.1310/tsr1806-786
- Marshall, C., & Rossman, G. B. (1999). *Designing qualitative research* (3rd ed.). Sage.
- Ministry of Health, Singapore. (2017). Community hospital care-Handbook for patients. https://www.moh.gov.sg/docs/ librariesprovider5/resources-statistics/educational-resources/ handbook-on-ch-care-for-patients_210617.pdf
- National Institute of Neurological Disorders and Stroke. (2018). *Stroke statistics*. http://www.strokecenter.org/patients/aboutstroke/stroke-statistics/
- National Registry of Diseases Office, Health Promotion Board. (2018). *Singapore stroke registry annual report* 2016. https:// www.nrdo.gov.sg/docs/librariesprovider3/Publications— Stroke/singapore-stroke-registry-annual-reprot-2016_upload_ nrdo_website.pdf?sfvrsn=0
- Palmer, S., & Palmer, J. B. (2011). When your spouse has a stroke: Caring for your partner, yourself, and your relationship. Johns Hopkins University Press.

- Petera, E., & Liaschenko, J. (2004). Perils of proximity: A spatiotemporal analysis of moral distress and moral ambiguity. *Nursing Inquiry*, 11(4), 218–225. https://doi.org/10.1111/j.1440- 1800.2004.00236.x
- Polit, D. F., & Beck, C. T. (2010). *Essentials of nursing research: Appraising evidence for nursing practice* (7th ed.). Lippincott Williams & Wilkins.
- Saint-Germaine, M. A., & Longman, A. J. (1993). Breast cancer screening among older Hispanic women: Knowledge, attitudes, and practices. *Health Education Quarterly*, 20(4), 539–553. https://doi.org/10.1177/109019819302000412
- Sandelowski, M. (1986). The problem of rigor in qualitative research. Advances in Nursing Science, 8(3), 27–37. https://doi. org/10.1097/00012272-198604000-00005
- Satink, T., Cup, E. H. C., de Swart, B. J. M., & Sanden, M. W. G. N. (2018). The perspectives of spouses of stroke survivors on selfmanagement—A focus group study. *Disability & Rehabilitation*, 40(2), 176–184. https://doi.org/10.1080/09638288.2016. 1247920
- Savage, T. A. (2006). Ethical issues in research with patients who have experienced stroke. *Topics in Stroke Rehabilitation*, 13(4), 1–10. https://doi.org/10.1310/tsr1304-1
- Shay, L. A., & Lafata, J. E. (2015). Where is the evidence? A systematic review of shared decision making and patient outcomes. *Medical Decision Making*, 35(1), 114–131. https://doi. org/10.1177/0272989X14551638
- SingHealth Group. (2019). *Stroke*. https://www.singhealth.com. sg/patient-care/patient-education/stroke
- Spillett, M. A. (2003). Peer debriefing: Who, what, when, why, how. https://www.thefreelibrary.com/Peer+debriefing%3a +who%2c+what%2c+when%2c+why%2c+how.-a0111848817
- Stevenson, K. N., Jack, S. M., O'Mara, L., & LeGris, J. (2015). Registered nurses' experiences of patient violence on acute care psychiatric inpatient units: An interpretive descriptive study. *BMC Nursing*, 14, 35. https://doi.org/10.1186/s12912-015-0079-5
- Stroke Foundation of Australia. (2019). *Grief after stroke*. https:// strokefoundation.org.au/Blog/2015/05/19/Grief-after-stroke
- Thorne, S. (2008). Interpretive description. Left Coast Press.
- Thorne, S., Kirkham, S. R., & MacDonald-Emes, J. (1997). Interpretive description: A noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing* and *Health*, 20(2), 169–177. https://doi.org/10.1002/(SICI)1098-240X (199704)20:2<169::AID-NUR9>3.0.CO;2-I
- Tobin, G. A., & Begley, C. M. (2004). Methodological rigour within a qualitative framework. *Journal of Advanced Nursing*, *48*(4), 388–396. https://doi.org/10.1111/j.1365-2648.2004.03207.x
- Venketasubramanian, N., Yoon, B. W., Pandian, J., & Navarro, J. C. (2017). Stroke epidemiology in South, East, and South-East Asia: A review. *Journal of Stroke*, *19*(3), 286–294. https:// doi.org/10.5853/jos.2017.00234
- Visvanathan, A., Dennis, M., Mead, G., Whiteley, W. N., Lawton, J., & Doubal, F. N. (2017). Shared decision making after severe stroke—How can we improve patient and family involvement in treatment decisions? *International Journal of Stroke*, *12*(9), 920–922. https://doi.org/10.1177/1747493017730746
- World Health Organization. (2019). *Stroke, cerebrovascular* accident. http://www.emro.who.int/health-topics/strokecerebrovascular-accident/index.html