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## **The experiences and evaluation of a complex intervention for couples coping with stroke**

### **ABSTRACT**

**Background:** Globally, stroke is a leading cause of death and disability. With a strong sense of filial responsibility, Asian caregivers are committed to caring for their ill family members. In response, the 3H (Head, Heart, Hands) intervention was developed and implemented in Singapore to support couples in their coping after a stroke. The purpose of this study is to explore the experiences of the participants taking part in 3H intervention, and evaluate the intervention after they had participated in it.

**Methods:** An interpretive descriptive design was used. Semi-structured qualitative interviews were conducted with 7 patients and 7 spousal caregivers. Data were analyzed using conventional content analysis.

**Results:** The participants' experience was described as one of *becoming more prepared to face the storm*. The 'storm' resulted from a stroke, where the participants were worried and uncertain about their future. After participating in the intervention, the couples' *coping processes* had improved. They coped by: *breaking the silence and engaging in conversations, cultivating a sense of support, and conveniently fulfilling their educational needs*. It was evaluated that *extending the 3H intervention for community nursing* is necessary to strengthen the care transition of couples from the hospital to home.

**Conclusion:** New knowledge has been gained that the 3H intervention is useful and may be implemented in a clinical context prior to a patient's discharge from hospital. As a result of participating in the 3H intervention, effective coping was evident where participants engaged in conversations, cultivated a sense of support, and fulfilled their educational needs. Primary healthcare professionals should pay more attention to the difficulties and needs of this group of people, provide more resources to support them, and to improve their quality of life.

**Keywords:** stroke, persons with stroke, spousal caregivers, interview

#### **Background**

Stroke is a chronic disabling neurological condition that renders survivors dependent on caregivers (1). The family caregivers of persons with stroke shoulder a great deal of responsibility, such as providing instrumental, social, and emotional support (2). Such caregivers experience a great burden due to the sudden onset of a family member's disability from stroke and the uncertain prognosis of a recovery (3). Given their long-term and heavy caregiving responsibilities, the needs of family caregivers are often neglected, leading to relationship strains (4). In most instances, the spouse becomes the main family caregiver of a person with stroke (5). Particularly, Asian caregivers have a strong sense of filial responsibility, family loyalty, and cultural commitment to spontaneously accept the caregiving role and accomplish their filial duty (6).

A recent scoping review (7) was conducted on couples coping in the community after their spouse's stroke. The most significant finding of this review is that couples battled with emotional challenges, role conflicts, poor coping strategies that consequently led to decreased life satisfaction. The review shed light on the need for hospitals to develop and implement policies to adequately support couples in their post-stroke coping (7).

There is a lack of emphasis on the support of persons with stroke and their spousal caregivers as a couple in stroke recovery. To fill the gap, the 3H (Head, Heart, Hands) intervention was developed and implemented in Singapore to facilitate stroke recovery. The intervention holistically focuses on informational support ("head"), shared decision making ("heart"), and the practical skills that stroke couples need in order to cope ("hands"). The 3H intervention was tailored to the duration of a stroke patient's stay in the rehabilitation hospital. A total of six sessions were carried out over a period of three weeks. The intervention was conducted

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face-to-face in groups (four sessions), and in individual dyadic sessions (two sessions). However, a deeper knowledge is still lacking about experiences of those family members who took part of the intervention. Therefore, we aimed to explore first persons with stroke and their spousal caregivers' experiences of taking part in the 3H intervention. Second, we evaluated the implementation of 3H intervention into community nursing.

## Methods

### *Design*

An interpretive descriptive (ID) design was used. It is an inductive method that moves beyond description to uncover possible, “associations, relationships and patterns within the phenomenon” (8). In this study, we focused on recognizing potential associations and relationships between the experiences of stroke couples after taking part in a 3H intervention and the subsequent perceived effects on their ability to cope after a stroke.

### *Participants and Setting*

Participants were purposively sampled and recruited in a stroke rehabilitation ward of a hospital in Singapore. The criteria for inclusion in this study were married couples aged 21 years old or older, where one member of the couple had received a medical diagnosis of either an ischemic or haemorrhagic stroke, both members were able to communicate in English, and agreed to participate after full explanation of the study. The characteristics of persons with stroke and their spousal caregivers are illustrated in **Table 1**.

### *Data Collection and Analysis*

Ethical approvals for the study were obtained from (anonymous for blind peer review at this stage). Informed and written consent was sought from all of the participants. Semi-structured interviews were conducted with 14 participants (seven patients and seven spousal caregivers)

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for the data collection, and included in the analysis. All of the interviews were performed face-to-face and audio recorded. The length of interviews ranged from 15-50 minutes. Audio recordings were transcribed verbatim by the first author (initials are anonymous for blind peer review at this stage), while the second author (initials are anonymous for blind peer review at this stage) double-checked the transcripts of the data.

Conventional content analysis (9) was conducted in this study, in which the use of preconceived categories was avoided but allowing them to emerge from the data (10). The analysis is also described as the inductive category (theme) development (11), where researchers immerse themselves in the data to synthesize new insights on the topic. The authors independently coded extracts from all of the interviews. Based on the codes, the authors developed an initial concept map. The themes that emerged were further reviewed and discussed until an agreement was reached. Computer-aided qualitative data analysis software (CAQDAS) NVivo 10 (12) was utilised to organise and facilitate the data analysis. Trustworthiness of this qualitative study was assured through researchers who have expertise in conducting qualitative studies (13). Peer debriefing were held with authors during the phases of data collection and analysis that improved the researcher triangulation. The interviewer reflected on her dual role as a registered nurse and an interviewer, and recorded her thoughts in a reflexive diary that aided the data analysis and emergent of the resulting themes.

## **Results**

### ***Becoming more prepared to face the storm***

After participating in the 3H intervention, the participants mostly described a process that they had experienced as *becoming more prepared to face the storm*. The term 'storm' denotes the feelings of worrying and uncertainties as a result of a stroke situation in the family.

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*It was a scary experience for me when my husband had a stroke. I was in shock. Now, I begin to realize more about stroke condition and how to care for my husband after attending the 3H intervention. (Stroke caregiver 2)*

Regarding the storm prior to the 3H intervention, couples struggled to adapt and cope with the aftermath of a stroke. Stroke persons were worried about their uncertain future with disabilities while spousal caregivers' lives were in turmoil as they did not understand the behavioral changes of persons with stroke:

*I feel uncertain and worried about my own future...I also feel fearful about my life after a stroke...My spouse has lost four to five kilograms of weight ever since I had a stroke...(patient cries) (Stroke patient 2)*

#### ***Coping processes of the couples***

Couples coped better with stroke situation after attending 3H intervention through: (a) breaking the silence: engaging stroke couples in conversation, (b) cultivating a sense of support, and (c) conveniently fulfilling their educational needs.

##### *(a) Breaking the silence: engaging stroke couples in conversation*

Couples felt that it was easier to engage in conversations with their partner, hence strengthening their post-stroke marriage relationship:

*I am very fortunate that there is someone here in the ward to tell us more about stroke and how to better relate with our spouses through communication. Otherwise, I wouldn't have understood all of the hidden issues that my husband is facing within himself, and more misunderstandings between us might have occurred. (Spousal caregiver 1)*

##### *(b) Cultivating a sense of support*

Group sessions of the 3H intervention cultivated new friendships. Besides emotional support, affirmative support was also evident, where participants freely shared and validated their stroke experiences with other participants:

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*...this intervention is where many patients and their spouses can come together and participate. We can share our problems and feelings openly and learn from one another. (Stroke patient 1)*

*I spoke to the wife of one of the stroke patients. She was sharing with me her experiences of caring for her husband with stroke. It also improves my insight of how I can prevent some problems like falling at home and care for my husband better. (Spousal caregiver 2)*

Spousal caregivers were the “forgotten” care recipients who tended to neglect their own health and well-being while providing care to their partner with stroke. Through the discussions with other spousal caregivers in the 3H intervention, spouses learned the importance of cultivating self-care:

*I learned that it is important to take care of myself after taking part in the 3H program. Many a time I forgot about myself. My life used to be for my husband. Now, I think that when I am good and healthy, I can care for my husband better. (Spousal caregiver 3)*

Participants suggested the continuation and extension of “cultivating a sense of support” from hospital to home. They felt that there are many other couples suffering from stroke in the community who have little support:

*Stroke is getting so common nowadays in Singapore. I know many people who are having stroke and they are suffering by themselves. They don't share their pain with anyone. If we don't attend such programs, we will not be informed about stroke at all. (Spousal caregiver 2)*

#### *(c) Conveniently fulfilling their educational needs*

An accessible venue and the right timing of the intervention made it convenient for the couples to participate in the intervention:

*The timing of the education is good, as it matches the visiting hours of our family members. Therefore, both the patient and spouse can attend. (Stroke patient 1)*

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Participants appreciated that they were given 3H intervention bags with a specially designed logo, which contained stroke prevention pamphlets, and a stress ball. The potential tensions of patients and their partners stemming from a lack of information on stroke eased as the participants were able to access all of the necessary information on stroke management in the 3H intervention bags:

*My wife and I feel happy to have received the 3H intervention goodie bag...When I see the bag, it reminds me of what I have learned here. (Stroke patient 4)*

### ***Extending the 3H program for community nursing***

Several participants stated that they preferred to have a tailored intervention for participants whose native language was either Chinese, Malay, or Tamil:

*I prefer if the education can be conducted in the Tamil language in the future. is a personal touch to the education if it is conducted in our own native languages. (Stroke patient 1)*

Some spousal caregivers recommended an online 3H intervention. They felt that having the intervention accessible online would make it easier to access information related to coping and recovery after a stroke:

*Some days it is difficult for me to come down to the ward. I feel sick and I need to rest myself. I suggest that online teaching will be good. (Spousal caregiver 7)*

### **Discussion**

This study first explored the experiences of couples *becoming more prepared to face the storm* – stroke situation. During the storm, for instance, the spousal caregivers in this present study juggled returning to work to support their families with taking full responsibility in caring for their partner with stroke. A large number of people are suffering from moderate to severe disability as a result of stroke (14). Persons with stroke suffer from fatigue (15), physical disability (16), and depression (17), which disrupts both their physical and mental functioning



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and contributes substantially to the economic burden of stroke. Consistent results presented by Arwert et al. (2017) (18) indicated that the inability to work is a major consequence of stroke. To maintain a flow of income, most spousal caregivers of persons with stroke took up part-time jobs. In several studies where people were living longer with chronic debilitating conditions, spousal caregivers continuously strove to achieve continuity and normality, by resuming work part time, for example, to minimize the disruption to their marriage and life (19,20). Spouses from various cultural and religious backgrounds were expected by society to be responsible for caring for a partner who had been diagnosed with stroke (21). Literature (22) in the Asian context indicated that marital obligations and an ethical responsibility to provide care prevented caregivers from leaving an ill spouse. Similarly, in Korea, four in 10 older adults found themselves in the position of being the primary caregiver for their chronically sick spouse (23). Supporting spousal caregivers in their efforts to balance work and caregiving tasks is of paramount importance to prevent them from feeling overwhelmed with responsibilities after their spouse has had a stroke.

Other experiences of participants included their struggling with stroke situation, and the *coping processes of the couples* that they needed to deal with for themselves. Persons with stroke were worried about a future with disability. On the other hand, spousal caregivers were stressed, as they could not comprehend the mood fluctuations and behavioral changes of the person with stroke, contributing to caregiver strain. The diagnosis of a chronic disease can serve as a significant stressor for persons suffering from such diseases and their family caregivers, most notably spouses. Persons with chronic disease and their spouses must therefore learn about ways to gradually adjust to the challenges of living and coping with a chronic disease (24). Couples coping with a chronic disease tend to feel close as they empathize and converge emotionally with each other. Previous study (25) has shown that when couples coping with chronic diseases were unable to detach themselves from the spouse's suffering, this would lead

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to personal distress, with detrimental effects on their physical and psychological health over time.

It has been evaluated that *extending the 3H intervention for community nursing* is possible as participants coped better with stroke situation after participating in the 3H intervention. Consistent with the findings of the current study, previous literature (26) reported that spousal caregivers cried alone and concealed their frustrations from the person with stroke to establish a sense that life is going on as usual in the family. Consequently, spousal caregivers felt suppressed and overwhelmed, as they were unable to express their emotions openly (26). Family-oriented psychoeducational interventions and support groups are increasingly being utilized to deal with the concerns of families and persons who have been diagnosed with chronic health conditions. The interventions can be delivered either on a one-day, weekly, or biweekly basis over three to six sessions (27). These interventions enable persons suffering from chronic diseases and their families to confront the demands related to the disease. Likewise, the 3H intervention provided the study participants with the opportunity to voice their personal concerns in relation to coping with the processes of the disease and to form cross-family alliances with other spouses in similar caregiving roles. Cultivating a sense of support through structured services improves a family's networks and reduces their isolation (27).

The participants in this study suggested ways of extending the 3H program for community nursing in the future. In another study by Tsai and Lee (2016) (28), it was reported that Southeast Asian immigrants in Taiwan were at a higher risk of poor health outcomes due to language and communication barriers that affected their access to healthcare. Although English is the official language in Singapore, participants' preference to have the 3H intervention delivered in their own native languages of Chinese, Malay, and Tamil must be taken into full consideration in the future development of the intervention.

### **Limitations of the study**

Eleven out of 14 participants were older adults with their age ranging from 60- 79 years old in this study. There may not have adequately represented middle-age working adults between 40 to 49 years old. It was challenging to recruit spousal caregivers who were working for jobs. Future studies should consider the special concerns and needs of spousal caregivers and persons with stroke who were previously working for full time jobs.

### **Conclusion**

Persons with stroke and their spousal caregivers initially struggled with the stroke situation. After participating in the 3H intervention, they were found to have improved their coping processes together to deal with stroke in the family. Appropriate support programs such as the 3H intervention allows healthcare professionals to understand and alleviate the difficult life situation and needs of persons with stroke and their spousal caregivers. To ensure a seamless healthcare transition for stroke couples from hospital to home, generation of quantitative evidence from implementation of the 3H intervention is also warrant before extending the intervention for community nursing.

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