

ORIGINAL ARTICLE

Stroke Survivors and Their Family Caregivers' Experiences of Health Information Seeking: A Qualitative Study

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ABSTRACT

Background: Stroke is a significant and unpredictable event that affects physical and mental functions. A useful approach to returning to a normal life is to seek out health information. This study aimed to explore the experiences from health information seeking in the stroke survivors and their family caregivers.

Methods: This study was carried out using qualitative content analysis. Participants included five stroke survivors and fifteen family caregivers who were selected purposively from the Rofideh Rehabilitation Center and private physiotherapy centers in Tehran. Data were collected from semi-structured interviews. Data analysis was performed using Graneheim and Lundman's method manually in Word software. Sampling was carried out in 2021.

Results: Two main categories were extracted: 1) adapting and learning resulting from awareness including optimization of living environment and disease management, and 2) fear and inquietude on the information way including confused and insolvent in receiving information, and doubts about the accuracy of information.

Conclusion: The health information seeking created adaptability and relative stability in some stroke survivors and their family caregivers. However, in others, there was still a sense of anxiety and uncertainty. Thus, understanding health information seeking experiences helps health policymakers and administrators to provide information and training based on evidence and individual needs of the client and family.

Keywords: Health information seeking, Qualitative content analysis, Stroke survivors

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INTRODUCTION

Stroke is an unpredictable event which suddenly disrupts a person's life.¹ It causes many deaths and disabilities and is a major concern in public health.² According to the report by US Center for Disease Control (CDC), in 2018, one out of six deaths due to cardiovascular diseases was related to stroke. Also, more than 795,000 people suffer from a stroke each year in the United States alone.³ According to the World Health Organization, this rate amounts to 15 million worldwide, of which 5 million are permanently disabled.⁴ According to the Iranian Ministry of Health, stroke is the second leading cause of death in Iran.⁵ This disease causes simultaneous involvement of the survivor and the family and causes caregivers, in addition to coping with the physical defects caused by the disease in the survivor, to learn new skills, adapt to the situation, and suffer many challenges to safely manage the survivor. Hence, the client and the family experience all kinds of role-related challenges, lack of care-giving skills, and supportive and financial tensions.⁶ These tensions and demands include the lack of proper health information and the ambiguity and confusion in the method and place of obtaining it. A review of the related literature also confirms this shortage and confusion.⁷ For instance, the results of a study in Australia revealed that stroke patients and their caregivers had great difficulty obtaining information for post-discharge care. Participants acknowledged that they were unaware of the location of the brochure containing the information, or that they did not know from whom they should receive post-discharge training, and that the information provided lacked the details that caregivers wanted to know.⁸ Therefore, one of the possible answers and the basic strategy to meet this need and eliminate the shortcomings is to seek health information.⁹ Given the multidimensional recovery and rehabilitation process following stroke, it is essential to understand the information needs of stroke survivors and their caregivers to engage them in the therapeutic decision-making process.¹⁰ In

addition to the above points, lack of information or lack of proper understanding affects the quality of care and safety of the client and causes complications such as pressure ulcers/bedsores, urinary tract infections (UTIs), joint contractions, aspiration pneumonia, depression, and anxiety in the caregivers.^{6, 11} Nonetheless, obtaining health information plays a role in increasing knowledge, deep understanding of the risks, and active participation in clinical decision-makings.^{12, 13} Review of literature indicates the improvement of the quality of life of patients with spinal cord injury by health information seeking.¹⁴ On the other hand, it may cause anxiety or the application of information avoidance strategy by some people.¹⁵ This is because avoiding information leads to hope and optimism or is a response to the discomfort of obtaining information.¹⁶ Therefore, different results have been obtained for the experience of health information seeking in patients with chronic diseases.¹⁷⁻¹⁹ Besides, a review of the studies revealed that most of studies that had examined the health information seeking were cross-sectional-descriptive studies, and naturalistic studies were rarely carried out. Thus, a deeper understanding of the experiences gained from health information seeking through qualitative studies has been proposed.²⁰ Of course, there have been several studies in the field of health information seeking; yet, most of them have dealt with cancer patients,²¹⁻²³ diabetics,²⁴ and heart patients.^{25, 26} Health information seeking studies on stroke survivors have emphasized the patients' needs, educational and motivational interventions, and patient and caregivers' support.^{11, 27} Hence, according to the lack of qualitative studies in this field in Iranian community, we decided to study the experiences of health information seeking in stroke survivors and family caregivers after treatment and completion of the acute stage of the disease in a sample of Iranian society.

MATERIALS AND METHODS

In this study, qualitative content analysis was performed by Graneheim and Lundman method

and using semi-structured interviews.²⁸ The interviews took place from January to July 2021 and were conducted with five stroke survivors and fifteen family caregivers in the Rafideh Rehabilitation Center and private physiotherapy centers in Tehran. The Rafideh Rehabilitation Center was chosen for the study because it is a specialized governmental rehabilitation center for clients with stroke in need of rehabilitation; moreover, the researchers had better and easier access to this center. The inclusion criteria for stroke survivors were passage of two months to two years since the incidence of stroke, not in the acute phase of stroke, discharge from the hospital, and entrance to the chronic phase and rehabilitation, stroke severity of mild to moderate, patient's awareness and consciousness, and ability to speak. The criteria for family caregivers were being a member of the client's family, and being responsible for caring for the client. Most of the clients' caregivers were their spouses and children. Interviews were conducted first with the family caregivers and then with stroke survivors who were able to speak. Exclusion criterion was the participants unwillingness to continue the study. Purposive sampling was performed. To collect the data, the researcher was present in the study environment. After the approval of the officials of the rehabilitation centers, the researcher was introduced to the head nurses of the rehabilitation, occupational therapy, and physiotherapy departments; with their guidance, the participants who were qualified for participation in the study were identified. Then, the objectives of the study were explained to them; after they agreed to participate in the research, an informed written consent form was signed, and the interviews were conducted. Semi-structured interviews were conducted in a separate and quiet environment. A number of interviews were conducted at the request of the participants in their homes. Interviews were recorded using a tape recorder and typed in Word immediately after the session. The interviews lasted between 20 and 60 min with an average of 40 min. The main questions of the interview included: What problems did you

have after the illness? What would you like to learn? In addition, exploratory questions such as "Can you explain more to me" were used as needed.

The transcripts of the interviews were analyzed based on a 6-step conventional content analysis method developed by Graneheim and Lundman.²⁸ First, the interviews were studied several times, immersion in the data was performed, and they were divided into meaning units based on the purpose of the study. Subsequently, the meaning units were abstracted and coded. Condensation of meaning units was performed by the process of reduction while preserving the core. Then, the categories were identified and their interrelations between them were formed. The categories and subcategories were labeled, and the basic meanings were extracted. In this study, data collection and analysis took place simultaneously.

Lincoln and Guba strategies were used in this study.²⁸ For these, the participants were contacted to give them a summary of the primary results to determine whether the concepts were true to their point of view (member check). As a further validity check, the transcripts and the analysis process were checked and verified by the research team and some experts as expert check. Two of the interviews were translated into English for two English experts who were members of the research team, as well as the whole analysis process, so that all co-authors could participate in the verification process of the emerging categories. Besides, the research team had a weekly routine meeting to evaluate the process of the study.

This research project was approved by the Ethics Committee of Tehran Islamic Azad University of Medical Sciences (IR. IAU.TMU.REC.1399.482). The principles of confidentiality and independence were observed in this study. All participants were informed about the purpose and design of the study and the nature of their participation. Prior to participating in the study and recording of the interviews, the subjects gave

their informed written consent. Participants were reassured that they had the right to withdraw from the study at any time, that their withdrawal or non-participation would have no effect on their treatment and care and that their anonymity would be maintained.

RESULTS

Participants in this study were selected based on achieving maximum diversity. They included five stroke survivors and fifteen family caregivers. The demographic characteristics of the participants are presented in Table 1.

Two main categories were extracted: (1) adapting and learning resulting from awareness including, optimization of living environment and Disease management, and (2) fear and inquietude on the information way including confused and insolvent in receiving information and doubts about the accuracy of information. The results are displayed in Tables 2 and 3.

1. Adapting and Learning Resulting from Awareness

Most of the participants stated that after obtaining the required information, their view and performance changed, and they tried to

improve their physical and mental health by following the acquired knowledge.

1.1. Optimization of living environment: The goal of all efforts and searches is to materialize the independence of the client. Thus, most of the questions that stroke survivors and caregivers seek to answer, somehow end up with how to manage the disease. Participants concluded from health information seeking that stroke was a chronic disease that could not end in full recovery; thus, they will be always involved in some form of its complications. They learned to modify the living environment in a way that was appropriate for the clients' daily activities and tasks.

“We asked the doctor about exercises and physiotherapy and what we could do to work better with the patient at home, like two parallel horizontal wooden sticks in the yard for walking that worked like physiotherapy. It was such that the patient herself laid the hands on them and walked between them “(P 8).

1.2. Disease management: Survivors of stroke suffer from paralysis, numbness of the limbs, dementia, and reduced consciousness due to the disease. Thus, their independence and self-sufficiency are damaged, and they see themselves as helpless and dependent on others.

Table 1: Demographic characteristics of the participants (n=20)

| | Participant code | Sex | Age (Year) | Education level | Marital status |
|-------------------|------------------|--------|------------|------------------|----------------|
| Stroke survivors | P1 | Male | 63 | Secondary school | Single |
| | P2 | Female | 59 | Diploma | Married |
| | P3 | Male | 63 | Secondary school | Married |
| | P4 | Male | 54 | Secondary school | Married |
| | P5 | Male | 48 | Diploma | Married |
| Family caregivers | P6 | Male | 38 | Master degree | Single |
| | P7 | Female | 41 | Secondary school | Married |
| | P8 | Female | 53 | Secondary school | Married |
| | P9 | Male | 28 | Associate degree | Married |
| | P10 | Female | 40 | Diploma | Single |
| | P11 | Female | 35 | Secondary school | Married |
| | P12 | Female | 37 | Secondary school | Married |
| | P13 | Female | 60 | Secondary school | Married |
| | P14 | Male | 65 | Diploma | Single |
| | P15 | Female | 33 | Master degree | Single |
| | P16 | Male | 62 | Secondary school | Single |
| | P17 | Female | 35 | Illiterate | Married |
| | P18 | Female | 40 | Diploma | Married |
| | P19 | Female | 36 | Diploma | Single |
| | P20 | Female | 28 | Diploma | Married |

Table 2: Main category of adapting and learning resulting from awareness

| Meaning units | Subcategory | Category | Main Category |
|---|---|----------------------------------|--|
| - Use of home appliances for rehabilitation - Grip any possibilities to achieve recovery - Information seeking on buying medical equipment at home - Acquire information to purchase medical equipment for home care - The need for available medical equipment centers | Search for information to make most of the facilities at home Search for information on the use of appropriate medical equipment at home | Optimizing of living environment | Adapting and learning resulting from awareness |
| - Learning physiotherapy by family - Learning to work with NGT by the caregiver - Learning to install a full catheter by a caregiver - Follow-up and implementation of treatment plan by clients - The client's effort for daily life - Gaining more experience with less worry - Gaining experience in searching for health information - Consciousness of the client and caregiver - Awareness of the differences between clients in the recovery process | Self-learning care essentials in the information environment Self-care Increased health literacy | Disease management | |

Table 3: Main category of fear and hope through acquiring information

| Meaning units | Sub category | Category | Main Category |
|---|--|---|--|
| - Remaining a concern for the future - Ambiguity and confusion about the client's future - Doubt in the client's recovery - Insolvency in finding a qualified and dependable physician - Insolvency in finding reliable resources - Being unaware of the available resources for finding the required information - Expressing a pity to trust a single source - Feeling of failure to obtain appropriate information - Feeling sorry for the lack of appropriate information | Anxiety about uncertain future Insolvency and astonishment in making medical decisions Failure to obtain appropriate information | Confused and insolvent in receiving information | Fear and inquietude on the information way |
| - Providing conflicting information with the outcome of the disease by the treatment team - Giving useless hope to the client - Talking with uncertainty about the recovery time - Obtaining information from multiple and heterogeneous sources - Lack of confidence in health professionals - Lack of trust in scientific and medical content | Inadequacy of the information provided with the outcome of the treatment Lack of confidence in the acquired information | Doubts about the accuracy of information | |

Therefore, they seek health information for daily tasks and self-care

"I did not really know anything, but I could learn a lot by looking, such as connecting a

catheter or a gavage tube. I was able to learn how to feed my mother, but not the connection because I was afraid." (P20)

"I did the exercises they taught me at

home. I tried to do my own affairs". (P1)

2. Fear and Inquietude on the Information Way

This main category means that fear and anxiety prevail in most information seeking situations, as well as fear of the outcome of work. The question is whether this information, if appropriate, can be a response to the fears and unknowns of the stroke survivors and their families, and whether it can enhance the level and amount of information. This main category consists of two categories: "*Confused and insolvent in receiving information*" and "*doubtful about the accuracy of information*".

2.1. Confused and insolvent in receiving information: This category indicates that stroke survivors and their families were confused about the disease and its future. This ambiguity and lack of understanding of their position continued throughout life with stroke, and all the information-seeking behaviors were to resolve these ambiguities and doubts and achieve a comprehensive and reliable cognitive structure.

"I do not know, you see, what I should do after these three rehabilitation periods are over and I take her home. What should I do next? I mean, even now, I feel like we are all wandering about. There is no knowledgeable body around to let me know what to do and what not to do. In fact, it's as if I'm spinning around; we're not getting any particular results; I'm really worried about what the future will look like after that" (P20)

2.2. Doubts about the accuracy of information: According to interviews performed, obtaining contradictory and inconsistent information about the disease and the outcome of treatment from health professionals causes more confusion for stroke survivors and their caregivers; as a result, it causes their distrust, frustration, and disappointment with treatment and recovery.

One of the family caregivers said in this regard: "*Her doctor said that my mother would be better than before in six months. I was only told by the hospital to take physiotherapy*

equipment to our home and do it there. This gets better slowly by itself and there is no need for occupational therapy. Is it possible for a doctor who performs brain surgery to say such a thing? I do not know how we allowed the surgeon to operate on our mother. "(P10)

DISCUSSION

This study describes the experiences of health information seeking in stroke survivors and their family caregivers and provides a new understanding of the health information seeking experiences of stroke survivors and their family caregivers. The results show that two main categories: adapting and learning resulting from awareness, including optimization of living environment and disease management, and fear and inquietude on the information way including confused and insolvent in receiving information and doubts about the accuracy of information. The results of previous studies in this regard show that health information seeking behavior is highly effective in medical treatment selection, symptom management, prognosis, preventive behavior, survival, coping ability, physician-patient communication, end-of-life care, and conscious decision-making.^{22, 29} For instance, in a study conducted in 2013, the results showed that "acquisition of information" was correlated by five times or more with the patient's breast self-examination in the past year.³⁰ In other words, it causes more and better self-care. In another study conducted in 2015 in Saudi Arabia on patients with diabetes, the results suggested a high and significant positive relationship between obtaining online health information and self-care activities, especially glycemic control of the patient;³¹ this is in line with the results of the present study. Therefore, health information seeking leads to better disease management and increased health literacy. Research participants reported that seeking and obtaining health information alerted them to the diagnosis of symptoms and complications of the disease and caused them to perform many of the cares at home. In this regard, they have observed and searched in the medical environment and

have tried to learn many principles of care. In this regard, and similar to the results obtained in the present study, the results of a qualitative study (2012) showed that stroke survivors try to regain independence and try to learn new skills or relearn the old skills, so that they can achieve independence and create balance in their daily lives.^{1, 27} In addition to better self-management and self-care and increased health literacy, other experiences of health information seekers included optimizing the living environment by taking advantage of available facilities, seizing all kinds of opportunities, searching for equipment, and creating a safe environment at home for improvement and rehabilitation. One of the tasks of health professionals is to provide advice on adaptations and improvements in the living environment to improve the performance of client participation at home. Home modification involves any changes in the home environment that increase performance and independence in daily activities and tasks.³²

On the other hand, according to the results of studies conducted so far on families whose patients have survived a stroke, lack of time leads to confusion and insolvency.¹ In the present study, the participants experienced confusion at all stages of the disease and in daily life and were worried about the future. In the same line with the results obtained, a content study found that the participants were unsure about the disease recurrence, signs and symptoms, risk management, and post-stroke care resources.³³ According to the results of studies, uncertainty in stroke survivors and their caregivers remains a recurring issue although the cause and type vary over time.³⁴ Moreover, the results of a grounded theory study also revealed that there was uncertainty even up to 1 year after the disease in the daily life of patients with mild stroke.³⁵

Elements of uncertainty identified by Michel, i.e. ambiguity, lack of information, uncertainty, and unpredictability which provides a framework for classifying the dimensions of uncertainty, also identifies intervention opportunities to deal with and promote stroke survivors. Therefore, they

are expected to gain a lot of awareness and knowledge to take appropriate action.³³ Yet, problems such as difficulty in predicting stroke outcomes; inadequate communication between stroke survivors, caregivers, and health professionals; and lack of transparency in the information provided lead to a purgatory along with relative improvements in them.³⁴

On the other hand, other aspects include uncertainty in the participants, existence of contradictory information, and lack of confidence in the information provided. Consistent with the results of the present study, participants in a qualitative and longitudinal study state that if a physician provides them with unfavorable information after a stroke, they lose trust in their physician. As a result, it negatively affects the doctor-patient relationship. Then, six months after the illness, patients explained that they wished the doctors had given them realistic information as it could have improved their current poor functioning. There does not appear to be a correlation between the patients' needs to maintain hope for performance improvement and their desire to have realistic information in the early post-stroke period. The authors referred to it as the "information-hope contradiction".³⁶ These feelings are quite similar to those of regret due to not receiving comprehensive, complete and appropriate information observed in the participants of the present study as they expressed it. The reason for providing disproportionate and contradictory information in the studies is visits by different physicians and lack of continuity of care and communication.³³ Consequently, to reduce the degree of uncertainty after a stroke, there should be a direct and continuous relationship with health professionals. Moreover, goals based on creating a sense of confidence and tranquility should be included in the client's health plan.³⁷

In this study, health professionals such as nurses, physicians, physiotherapists, etc. were not interviewed. Therefore, it is suggested that members of the treatment and rehabilitation staff should be used in future

studies. Besides, the findings of this study are specific to Iranian patients and the Iranian health care system. Hence, it is recommended that this study should be replicated in other communities and ethnicities. Also, according to the obtained results, it is recommended that health professionals and policy-makers should consider and implement strategies to provide better and wider information, improve the quality of education to clients, assess various needs of clients and their families, and provide adequate support to them.

CONCLUSION

The health information seeking created adaptability and relative stability in some stroke survivors and their family caregivers. However, in others, there was still a sense of anxiety and uncertainty. Therefore, it is recommended that the health professionals should provide the stroke survivors and their family caregivers with support and counseling to achieve independence, relative stability in life, and adaptation to the conditions and self-care. Through providing the necessary facilities to obtain the required information, challenges such as post-stroke uncertainty for stroke survivors and their families will be eliminated and will lead to reorganization of life and improvement of skills.

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Conflict of Interest: None declared.

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