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Original Article

Barriers to Adherence to Post-stroke Exercise Program: A Qualitative Study into the Experiences of Patients with Stroke

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ABSTRACT

Background and objective: Approximately one-third of stroke patients remain disabled and post-stroke rehabilitation is required. Adherence to an exercise rehabilitation program is considered an important area of interest in the wake of optimizing long-term participation in physical activities after stroke. This study aims to explore the barriers to adherence to exercise program among post-stroke patients.

Methods: A qualitative study was conducted in the Physiotherapy units of Hawler and Rizgary Teaching Hospitals, Erbil, the Kurdistan Region of Iraq including twelve post-stroke participants with limited/ inadequate adherence to a post-stroke exercise program schedule from March to December 2018. Data was collected through face-to-face interviews. All of the interviews were conducted at a time and place that was the most convenient for the participants. Within two months, the categories emerging from the analysis of the interviews began to repeat, and no new categories emerged, leading to an enrollment of 14 participants. One month after the first interview, the second interview was conducted which included 12 participants. This was done to confirm their previous answers and ensuring that there were no new concepts about this limited adherence. Software for Qualitative Data Analysis was used for managing the data.

Results: More than half of the participants were over 70 years old, male, illiterate, married, and housekeepers from urban areas. Most of the participants had an ischemic stroke for more than four weeks. The barriers to adherence to post-stroke exercise program were categorized into the four main categories of the barriers related to environment and facility, personal (physical and psychological) factors, organizational policies, and contents of exercise program.

Conclusion: Barriers to adherence are different in nature. Environmental barriers and lack of facilities show that a well-organized rehabilitation program in health care system at directorate of health-Erbil is very important to improve and facilitate adherence to the post-stroke exercise program.

Keywords: Adherence**;** Barriers; Post-stroke patients; Qualitative research.

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INTRODUCTION

According to the definition proposed by the World Health Organization, stroke is “the interruption of the blood supply to the brain, usually because a blood vessel bursts or is blocked by a clot. This cuts off the supply of oxygen and nutrients, causing damage to the brain tissue”, which includes both main types of ischemic and hemorrhagic strokes [1]. Approximately one-third of stroke patients remain disabled; therefore, there is a dire need for post-stroke exercise rehabilitation programs [2] which is a dynamic process with the overall purpose of reducing disabilities from stroke complications in which collaboration between medical specialties and financial

and administrative systems in terms of establishing team working to provide post-stroke care can be required [3]. Stroke patients are vulnerable to the effects of a sedentary lifestyle and would benefit from increasing the amount of exercise they regularly obtain [4,5]. The significantly lower rate of adherence to and participation in regular exercise among disabled people is related to a variety of environmental and personal barriers which include architectural barriers, organizational policies and practices, discrimination, and social attitudes. These barriers effectively reduce personal options, inhibit participation in healthy and active lifestyles, and prevent people with stroke and other disabilities from full participation [6]. General examinations of personal and environmental barriers and facility mediators of physical activity in individuals with stroke require a better understanding of the contextual factors such as personal, environmental, and facility factors that are associated with the target population's participation in physical activity. Also, health conditions associated with stroke are barriers to these individuals' opportunities to engage in exercise programs. Without understanding the critical person-environment barriers associated with participation in exercise programs, it is difficult to establish effective programs that have sustainable outcomes [7]. In order to come up with better understanding of why post-stroke patients do not adhere to exercise programs designed specifically for them according to their needs, the researchers in the present study conducted this qualitative study on post-stroke patients that did not adhere to the randomized controlled trial of exercise program. Therefore, the purpose of the present study was to explore barriers to adherence to the randomized controlled trial of exercise rehabilitation program among post-stroke patients.

METHODS

Design

The present qualitative study used a conventional content analysis described by Graneheim and Lundman[8]. Qualitative content analysis allows for the subjective interpretation of data and helps better understand human emotions and the meaning underlying everyday experiences[9]. Conventional content analysis is generally used with a study design whose aim is to describe a phenomenon. This type of design is appropriate when the existing theory or research on a phenomenon is limited. Researchers avoid using preconceived categories [10]. This form of analysis was selected because the aim of the study was to explore the phenomenon of perceptions of post-stroke patients from barriers to adherence to the exercise program without using predetermined categories.

Study setting and participant

The study was conducted at the physiotherapy units in both Hawler and Rizgary Teaching Hospitals located in Erbil, the Kurdistan Region of Iraq. These units provide rehabilitation for patients with neuromuscular problems through physiotherapy and exercise programs. In a qualitative research study, researchers try to make sense of phenomena and interpret them in terms of semantics provided by people in their natural position[11]. According to the nature of qualitative research, the target participants were selected through the purposive sampling method. The inclusion criteria were ability to do exercise, no contraindications for physical exercise, agreement to participate in the study, age of 18 years or more, ability to establish verbal communication, and limited adherence to post-stroke exercise as determined by failure to regularly attend all sessions of the

exercise program.

ETHICAL CONSIDERATIONS

The formal approvals were obtained from both Ethical and Scientific Committees (Code No.58 in 2018.03.10) in the College of Nursing, Hawler Medical University. The patients were made sure about the confidentiality of their information and that the collected data would be used for this study only. Afterwards, they were provided with explanation about the purpose of the study. In addition, each participant was informed that their participation in the study was voluntary and they could leave any time even without completing the exercise program. Finally, written informed consent was obtained from each patient, including their signature on the informed consent form.

Data Collection

Interviews are among the most familiar strategies for collecting qualitative data and much qualitative research is interview based. This study data was collected through semi-structured in-depth interviews. In-depth interviews can provide rich and in-depth information about the experiences of individuals[12]. The researchers developed the interview guide specifically for the purposes of this study. It was a questionnaire that consisted of two main parts. The first part was related to socio-demographic and some clinical information which was aimed at collecting data on the participants' age, sex, education level, marital status, occupation, residency area, duration of stroke (since the diagnosis), and type of stroke. The other part contained open-ended questions regarding the barriers to adherence to post-stroke exercise program. Interview questions were asked about the participants' perception of the post-stroke exercise program and the barriers to adherence to the regular schedule as follows.

- What did you find concerning the organizational services in facilitating your exercise program?
- I'd like to hear from you about your experience of participating in the exercise program?
- What interested or disinterested you when you were involved in the exercise program?
- What do you think about the positive and negative aspects of the exercise program?
- Can you tell me more about the barriers that made you withdrew from the exercise program?
- How do you feel that the exercise program is affecting your activity limitations?
- How do you think exercise is managing and maintaining you?
- How did the exercise make you feel better?
- How did you solve the problems with the exercise program?
- What was your opinion about the content of the exercise program?

Interview Procedure

Data were collected by face-to-face interviews. All of the interviews were carried out at a time and place that were the most convenient for the participants. Two months after the initiation of the study, the categories emerging from analyzing the interviews began to repeat, and no new categories emerged. A total of 14 participants were recruited for the study. After one month of the first interview, the second interview was done on 12 (missing two) participants. Each interview lasted from 40 to 70 minutes, which was taken to indicate that most of the codes had been identified; therefore, sampling was discontinued. Field notes were written during and after interviews.

Trustworthiness

Based on the Lincoln and Guba's criteria [9], the credibility of the data was established through prolonged engagement in the research site for two years, learning and understanding all about the context, culture, social setting, and the phenomenon of interest, persistent observation for exploring all characteristics in the situation that are most relevant to the exercise adherence, individual interviews, choosing participants from various experiences with 5 younger participants for member checking, and maximum variation of age, sex, level of education, occupation, and place of living. The dependability of the data was established through constant comparative analysis of the data, clarifying the data analysis process, and peer review. To ensure the conformability of the data, there were experts in qualitative research from the School of Nursing, Tehran University of Medical Science who were asked to assess the congruence between the data and the findings. To facilitate transferability, a clear description of the characteristics of culture and context, the participants' characteristics, data collection, the analysis process, and provision of enough meaning units were used to ensure that the findings fitted the quotes.

Qualitative data analysis

To analyze the collected data, a qualitative conventional content analysis, guided by Graneheim and Lundman[8], was used; which was based on the following steps: 1. Transcription of the interviews verbatim and several revisions to understand the concept as a whole, 2. Breaking down the text into rational units that will be condensed, 3. Conceptualization of the compressed significant units and cataloging them with codes, 4. Categorization of the codes into subcategories and categories, depending on their similarities and differences, and 5.Devising themes based on the latent content of the text[8]. The process of data collection and data analysis was conducted concurrently. All of the interviews were audiotaped, transcribed verbatim, read, and reread in order to understand the meaning within the context of significant words or phrases then analyzed using content analysis. The texts were read through several times to obtain a sense of the whole meaning units, and those that corresponded to the purpose were highlighted, condensed, and coded. The codes and meaning units were compared to the context. The codes were grouped together to form categories and subcategories. The final four categories were examined by the researchers, and in order to ensure a clear difference between them, the meaning units within all subcategories were checked for accuracy. The MAXQDA version 2018 was used to manage the data.

RESULTS

Participants' Sociodemographic characteristics

Fourteen participants were recruited, but only 12 of them agreed to participate in the study. More than half of the participants were over 70 years old, male, illiterate, married, housekeepers, and from urban areas. Regarding the duration of stroke since the diagnosis, most of the participants had ischemic stroke for more than four weeks. The participants' characteristics are presented in Table 2.

Barriers to exercise program adherence

Analyzing the collected data led to identification of four major categories, namely of the barriers related to environment and facility, personal (physical and psychological) factors, organizational policies, and contents of exercise program. The main first two categories were established after the first three interviews, others were identified by the tenth interview. By then,

no new codes were added and the main categories were ensured during the last two interviews and existing categories were supported.

Quotes are shown in italic.Participants are identified with Pt. Code number, age per years, and sex inside double brackets.

Table 1: Steps of the content analysis process

Steps	Actions
1	Identifying excerpts which are related to the research questions
2	Descriptive categories of excerpts to describe the collected data
3	Examination of descriptive categories to determine relationships between them, developing main categories formed by groupings of sub-categories
4	Confirming of the transcripts for other relevant data, with continuing adjustment and finalizing the sorting of the major and minor categories

Table 2: Socio-demographic characteristics of the 12 participants in the experimental group

SN	Age	Sex	Level of education	Marital status	Occupational status	Resi-dency area	Dura-tion / weeks	Type of stroke
1	61	Male	Secondary school	Married	Keeping house/ homemaker	Urban	4	Ischemic
2	71	Male	Cannot read and write	Married	Retired	Urban	5	Ischemic
3	69	Male	Can read and write	Married	Retired	Urban	4	Ischemic
4	70	Female	Cannot read and write	Widowed	Unemployed (other reason)	Rural	3	Ischemic
5	72	Male	Cannot read and write	Married	Retired	Urban	2	Ischemic
6	70	Female	Cannot read and write	Married	Keeping house/ homemaker	Rural	4	Ischemic
7	63	Male	Secondary school	Married	Self employed	Urban	4	Hemorrhagic
8	63	Female	Cannot read and write	Widowed	Keeping house/ homemaker	Rural	3	Hemorrhagic
9	78	Male	Can read and write	Married	Keeping house/ homemaker	Rural	5	Ischemic
10	72	Female	Cannot read and write	Married	Keeping house/ homemaker	Rural	4	Ischemic
11	74	Female	Can read and write	Married	Keeping house/ homemaker	Urban	4	Ischemic
12	68	Male	Cannot read and write	Married	Self employed	Urban	4	Hemorrhagic

Category of the environment and facility barriers

The category "environmental and facility-related barriers" derived from the participants' description of some barriers related to this category. Participant 1 said "*I think there needs to be a new building with enough space for doing all types of exercise",* Participant 3 mentioned "*The hospital is so far from my home, I need to take a taxi"*. Most of the participants had a problem with the transportation and their financial shortage as Participant 8 explained "*Such daily prolonged exercises need more money to spend on transportation".* Some of the participating women explained that they had to take care of their children every day and that is why they could not attend all sessions of the exercise program every day. Participant 10 described *"I'm married with children, and most of my time during the day is devoted to them".* The emergence of this category is shown in Table 3.

Table 3: Categories associated with environment and facility barriers

SN	Exercise Barriers and Evidence (n=12)	No. of excerpts	Code/ Age/ Sex of participant
	Environment and facility barriers		
1	"*I think there needs to be a new building with enough space for doing all types of exercise*"	4	**Pt.1 (61, Male)**
2	"*The lack of equipment made me attend less every day*"	8	**Pt.1 (61, Male)**
4	"*There was no one among my family, friends, and relatives supporting me to complete all exercises*"	5	**Pt.1 (61, Male)**
5	"*You know, the weather is so cold, so it's not good for me to go out of home*"	9	**Pt.1 (61, Male)**
3	"*The hospital is so far from my home, I need to take a taxi"*	6	**Pt.3 (69, Male)**
6	"*Prolonged waiting for my turn made me follow up less and more bored*"	6	**Pt.5 (72, Male)**
7	"*Such daily prolonged exercises need more money to spend on transportation*"	5	**Pt.8 (78, Male)**
8	"*I'm married with children, and most of my time during the day is devoted to them*"	3	**Pt.10 (72, Female)**

Category of physical and psychological-personal barriers

According to the findings in presented in Table 4, the personal barriers are the most frequent barriers that were mentioned by the participants. These barriers were mostly related to the physical and psychological barriers to exercise adherence, such that they feared and had negative feelings about adaptation, suitability, and outcomes of the exercises. Some evidence in this regard includes *" You know , I have heart problems and the exercise is not good for me"* (P. 2), Participant 4 said *"I feel fatigue and pain during the exercise",* Participant 4 explained *"My age is not helpful for daily exercise, and I don't have enough energy and power compared to when I was young"*, Participant 5 described *"I feel that the exercise will not be beneficial for my paralysis",* Participant 4 said *"I have many problems in my joints, and the exercise makes me worse",* and Participant 6 mentioned *"I don't have enough time because of my family and guests".*

Table 4: Categories associated with personal barriers (physical and psychological barriers)

SN	Exercise Barriers and Evidence (n=12)	No. of excerpts	Code/ Age/ Sex of participant
	Personal barriers		
1	"*I am not adapted to do exercise every day*"	7	**Pt.1 (61, Male)**
2	"*You know, I have heart problems and the exercise is not good for me*"	7	**Pt.2 (71, Male)**
3	"*I am so worried about my medical status and the future of my work*"	4	**Pt.3 (69, Male)**
4	"*Because I am better than before, I try to do my daily activities and it's like the exercise*"	6	**Pt.3 (69, Male)**
5	"*I am female and I cannot attend the exercise every day as males*"	3	**Pt.4 (70 ,Male)**
6	"*I feel fatigue and pain during the exercise*"	5	**Pt.4 (70 ,Male)**
7	"*My age is not helpful for daily exercise and I don't have enough energy and power compared to when I was young*"	4	**Pt.4 (70 ,Male)**
8	"*I have many problems in my joints and the exercise makes me worse*"	7	**Pt.4 (70 ,Male)**
9	"*I cannot control all my body during the exercise*"	3	**Pt.5 (72, Male)**
10	"*I need someone to hold me and help me to do exercise*"	6	**Pt.5 (72, Male)**
11	"*I feel that the exercise will not be beneficial for my paralysis*"	4	**Pt.5 (72, Male)**
12	"*I think that I cannot complete all sessions of the exercise*"	4	**Pt.6 (70, Female)**
13	"*I don't have enough time because of my family and guests*"	4	**Pt.6 (70, Female)**
14	"*My obesity makes me lazier to do daily activities*"	3	**Pt.7 (63, Male)**
15	"*I did not feel any good progress with my paralysis and you know, I did 2 weeks still my weakness has not been solved*"	4	**Pt.9 (78, Male)**

Category of organizational policies barriers

Some of the participants noted wanting to make the modifications in some of the organizational policies, regulations, and job descriptions which they stated made it more difficult to access some important services. This category can be seen in some evidence including *"The policeman at the gate of the hospital doesn't allow us to use our car inside the hospital. You know, the distance between the gate and the exercise hall is so far, and there are not enough wheelchairs and they do not work well"* (P. 10).Some of the participants blamed about the health care service outcomes inside the hospital , Participant 2 explained *"This is the second time that this hospital has tried to treat me with exercise, it was simple and did not made me better until I visited a private center outside of the hospital".* Table 5 describes this category.

Category of the content of exercise program barriers

Some of the participants explained that they could not adapt to and cope with such an exercise program easily, because of their expectations and experiences regarding the content, sessions, and outcomes of the exercise program as in *"The duration of all exercises is very long, and you need several months to complete it"* and *"A huge amount of content is included inside a small exercise book"* (P. 4), Participant 10 explained *"What is presented for exercise in this small book is so difficult that you cannot follow all sessions correctly".* The data related to the emergence of this category are shown in Table 6.

Table 5: Categories associated with organizational policies barriers

SN	Exercise Barriers and Evidence (n=12)	No. of excerpts	Code/ Age/ Sex of participant
	Organizational policies barriers		
1	"*This is the second time that this hospital has tried to treat me with exercise, it was simple and did not made me better until I visited a private center outside of the hospital*"	7	**Pt.2 (71, Male)**
2	"*The hospital doesn't allow me to bring all my 3 sons with me*"	2	**Pt.10 (72, Female)**
3	"*The policeman at the gate of the hospital doesn't allow us to use our car inside the hospital. You know, the distance between the gate and the exercise hall is so far, and there are not enough wheelchairs and they do not work well*"	1	**Pt.10 (72, Female)**

Table 6: Categories associated with the content of the exercise program barriers

SN	Exercise Barriers and Evidence (n=12)	No. of excerpts	Code/ Age/ Sex of participant
	Exercise program barriers		
1	"*The duration of all exercises is very long, and you need several months to complete it*"	6	**Pt.4 (70 ,Male)**
2	"*A huge content is included inside a small exercise book*"	4	**Pt.4 (70 ,Male)**
3	"*The exercises were not comfortable or enjoyable, they were so boring*"	3	**Pt.5 (72, Male)**
4	"*From the first week I felt that this exercise would make worse and*	4	**Pt.6 (70, Female)**
5	"*What is presented for exercise in this small book is so difficult that you cannot follow all sessions correctly*"	3	**Pt.10 (72, Female)**

DISCUSSION

Summary of the findings and comparison with other studies

This study aimed to explore the barriers to adherence to exercise program among post -stroke patients. For this purpose, semi-structured interviews, which is an efficient way to investigate an under-researched topic, allowed interviewees to explain their opinions accurately in their own terms, and gain direct information from study participants without imposing preconceived categories or theoretical perspectives. These interviews were conducted to collect required data which were later analyzed by content analysis method based on the participants' unique perspectives and their actual data. There are limited theories and studies focusing on adherence to exercise program among post-stroke patients which is why the researchers selected conventional content analysis to derive the barriers directly from the post-stroke patients' own words as row data. Through qualitative interviews with post-stroke patients regarding their adherence to the randomized controlled trial of exercise program, it was found that there were many barriers that affected the post-stroke patients' efficient adherence to the exercise program until the end of the schedule that was planned according to their needs. The participants reported multiple barriers to attend all sessions of the exercise program that were interpreted as four main barriers of environment, personal (physical and psychological barriers), organizational policies, and some barriers regarding the content of the exercise program itself. In environment and facility barriers, the majority of the participants explained that cold weather, lack of equipment, lack of time, and problems with the transportation were the main barriers regarding the facilities to participate in such exercise programs . In the study carried out by Jack et al. (2010), about 70% of the participants referred to the lack of transportation as a major barrier [7]. The findings of the present study were consistent with previously out by Jack et al. (2010), about 70% of the published studies that involved post-stroke patients. Some of the interviewees wished to avoid the hassle of organizing another appointment or finding additional time out to attend, while others expressed anxiety about the potential for new tests to reveal more health problems. Also, time constraints were frequently cited as barriers to participation, generally construed as resulting carried from external forces beyond individual control [16]. Rimmer et al. reported several different categories of environmental or facility barriers related to participation in physical activity among people with physical disabilities; these barriers included the built environment, cost of services or programs, equipment, policies, information, and education and training of fitness facility staff [5]. The authors recommend that more facilities and organizational services should be provided in order to access the exercise programs easily. Regarding the personal barriers of physical and psychological aspects: health status problems, coping strategies and adaptation to exercise program, feeling undesirable symptoms, negative ideas, lack of energy, low confidence, low self-efficacy, feel of unsafely and injurious outcomes, lack of self-motivation, and dependency were the main barriers to adherence to an exercise program. The results of a study showed that one-fourth (26%) of the participants felt uncomfortable exercising in the facilities, and (39%) of them felt lack of energy [7]. In another study, five significant barriers were mentioned to exercise among older adults, including fear of injury/ falling, inertia, time constraints, negative effects, and physical ailments, the

frequencies of responses were also noted.
Inertia, characterized by being "too tired"
Or "too lazy" or finding exercise to be "boring" was the most frequently mentioned barrier to the exercisers [15].
Some of the participants believed that the exercise program was too long and too difficult for post-stroke patients. They also expressed that the exercise program made their health status worse and caused injuries. Others confirmed that the program was not enjoyable or exciting. Considering that an estimated 80% of stroke patients are discharged home and most will be cared for by a family member following discharge from inpatient rehabilitation[17], families need to be involved in all aspects of care as early as possible. Stroke patients and their family caregivers would benefit from a collaborative, dynamic treatment process that includes an understanding of the social and environmental context of the family[18]. Including family as the central part of the rehabilitation process would ensure that all patients and families are given the opportunity to participate in and contribute to rehabilitation programs.
In the study, some of the participants explained that they could not adapt to and cope with such an exercise program easily. A qualitative study showed that key factors such as lack of awareness about stroke recovery and exercises, hopelessness, and lack of emphasis on exercises by healthcare professionals led to non-adherence while commitment, continued supervision, and having a supportive family and society facilitated adherence[18]. This is needed to develop effective interventions for promoting exercise adherence among stroke survivors in low and middle income countries.
Limitations of the study
The study had several limitations. Most of the participants in this study consisted of elderly patients with stroke; therefore, it is not clear whether young people with stroke have similar or different barriers to adherence. In this study, although we attempted to gain participants' trust during data collection, some might have had some reservations during interviews and hence, might have decided not to share some aspects of their experiences. The findings of this study may not be generalizable to countries with advanced transportation systems.
Implications for increasing adherence rates
The findings of this study may be useful for and applied by nurses, physiotherapists, and clinicians to identify these key barriers to exercise adherence in the development of exercise rehabilitation programs and deepen their understanding of the context of the strategies for overcoming all possible barriers among all diverse samples of post-stroke patients, which can in turn, increase exercise adherence. Another advantage of determining the barriers in this study is to improve performance in activities of daily living, and the overall quality of life might increase exercise adherence.

CONCLUSION

Exploration of the barriers to adherence to exercise program among post-stroke patients helps researchers, nurses, physiotherapists, and clinicians, and other health care providers to prepare an applicable exercise program and overcome the barriers that are mostly related to the content of the program, environment, organizational policies, and physical-psychological aspects. The authors recommend that most of the barriers be controlled through organizational regulation and policies, family support, health education on taking care of stroke patients, financial support, and provision of special facilities according to individualized needs.

These strategies may affect the perception, beliefs, expectation, and experience toward the positive direction and maximize the rate of exercise adherence among post -stroke patients. Further studies should focus on the content of the exercise programs with regard to the duration and frequency of each exercise and determine the impact of them on the exercise program adherence among different groups of post-stroke patients.

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CONFLICT OF INTEREST

The authors reported no conflict of interes

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