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Factors influencing adherence to home-based exercises among community-dwelling stroke survivors in India: a qualitative study

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ABSTRACT

Purpose: To explore the factors influencing adherence to home-based exercises among community-dwelling stroke survivors using Intervention Mapping (IM) approach.

Material and methods: Qualitative interviews were conducted with ten stroke survivors living in semi-urban regions of India. The data were analysed using Atlas.Ti8 software and categorised using the Social Ecological Model.

Results: The mean age of the stroke participants was 61 ± 11 years. Key factors such as lack of awareness about stroke recovery and exercises, poor perceived recovery, hopelessness and lack of emphasis on exercises by healthcare professionals led to non-adherence while commitment, continued supervision, supportive family and society facilitated adherence. Some cultural specific factors such as opting for folk medicine over rehabilitation and social stigma were also identified.

Conclusions: The factors which influenced adherence to home-based exercises in stroke are existent at the individual, interpersonal, organisational and community level. This study can lead to the development of effective interventions for promoting exercise adherence among stroke survivors in low and middle income countries (LMICs).

Abbreviations: IM: Intervention Mapping; LMICs: Low and middle-income countries

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Introduction

Stroke is a leading cause of disability and mortality in India and worldwide. The prevalence of stroke in India is estimated at 559/100,000 persons per year [1]. An estimated 20% of people with stroke in developing countries have had a prior stroke, reflecting insufficient secondary prevention [2]. International clinical stroke guidelines strongly recommend therapeutic exercises to optimise recovery of function and continuance of physical activity to prevent further stroke [3,4].

In a low resource setting like India, stroke units and rehabilitation facilities are virtually absent in the Government sector, and those in the private sector are inaccessible for the semi-urban and rural population [2,5]. Therefore, home-based rehabilitation is a feasible and economical alternative, which has been shown to be equally effective as centre-based rehabilitation to promote function and quality of life in stroke survivors [6–8]. A recent large trial showed that cost-shifting rehabilitation to being family-led is not feasible or effective in the Indian context [9]. Adherence to prescribed treatment is essential for successful implementation of the intervention, [10] but many stroke survivors find it difficult to adhere to home-based exercises programmes [11,12]. Therefore, it is important to address the reasons for

non-adherence and thereby improve exercise adherence among stroke survivors.

Intervention Mapping (IM) is an iterative approach which provides the step by step guide in the development of health behaviour interventions [13]. The IM approach has been used for other cases of long term care [14], in low and middle income countries (LMICs) [15] and both [16]. IM is underpinned by the Social Ecological Model, which focusses on the multi-level health promotion programme [17,18]. It incorporates factors that are present at the individual level and environmental level [19] (see Figure 1). The IM approach is a stepwise approach and emphasises the importance of first understanding why people engage (or do not engage) in the desired behaviour before effective behaviour change can occur [13]. Thus, the aim of this qualitative study was to explore the reasons for adherence and non-adherence to prescribed home-based exercises among community-dwelling stroke survivors.

Materials and methods

Study design

Qualitative in-depth interviews were conducted based on the thematic descriptive approach. The interview guide was



Figure 1. Classification of determinants based on the socio-ecological model.

developed after a literature search and studies which explored the barriers and facilitators to home-based exercises were included. It was reviewed by five experts in the field of neurological rehabilitation and community care. The interview guide had seven domains; home-exercise programme, environmental, social, familial, personal and professional and any other factors.

Participant recruitment

Ethical approval was obtained from the Institutional Ethics Committee (IEC:335/2017). All eligible stroke patients admitted to the University hospital located in a semi-urban region and/or who attended outpatient clinics were invited to participate in the study from June 2017 to December 2017. Inclusion criteria were sub-acute and chronic adult stroke survivors who have been prescribed some form of home exercises during the study period, who were medically stable and had functional reading comprehension and communication in English, Hindi/or the regional language. The exclusion criteria were cognitive impairment (Montreal Cognitive Assessment Score <26), critical illness/end-stage diseases, conditions or impairment restricting their ability to exercise, known psychiatric disorder and, coexisting neurological disorders like Parkinson's disease. Participants were sampled purposively to include different socioeconomic status and duration of the stroke, employment status and gender to obtain maximum variation in the sample. After explaining the study purpose, written informed consent was obtained from the participants.

Procedure

The study was conducted in the semi-urban population of coastal India. Semi-structured face-to-face interviews were conducted with the participants at their residence in the local language. The interviews were focussed on the perceived barriers, facilitators and the contextual variables which could influence their adherence to the home-based exercise programme. The average duration of the interviews was 30–45 min.

Reflexivity

Interviews were conducted by two researchers who have five years of experience in physiotherapy and were pursuing their doctoral research on stroke rehabilitation at the time. The first investigator conducted the interview and the second investigator made field notes and audiotaped the interviews.

The second investigator is native of the study region and understands the cultural practices prevalent in this region.

Analysis

All the interviews were translated into English using the parallel back translation by a bilingual investigator (English-Kannada) who is native of the study region and is proficient in both English and local language (Kannada). The translated interviews were transcribed on Atlas.Ti8 software. The data were analysed using conventional content analysis approach [20]. The data analysis was done in two steps. In step 1, four transcripts were analysed, significant codes generated and each paragraph was open-coded. These codes were reviewed by all the investigators and were modified for final coding. Step 2 included the analysis and coding of all the transcripts. After the analysis of eight transcripts, no new codes were emerging [21]. Therefore, data collection was stopped after two more interviews to attain inductive thematic saturation [22]. Similar codes were grouped into categories based on the social ecological model [19].

Results

Sample characteristics

The mean age of the stroke participants was 61 ± 11 years with mean time since stroke of 41 ± 28 months. All the participants had been prescribed some form of home exercises during the interview period and were able to walk independently with or without an assistive device. Table 1 shows the participants' characteristics.

Factors influencing adherence

A total of 20 codes were generated from the interview data. The codes were categorised into personal and external agents based on the IM approach, Figure 1. The personal agents represented factors such as commitment, knowledge about recovery and distress of an individual. The external agents were further grouped into interpersonal, organisational and community factors. Key factors are summarised in Table 2.

Personal factors

Participants reported several personal factors for non-adherence to home-based exercise, including poor knowledge about stroke and exercises, frustration, hopelessness and, failure to do an activity independently. Almost all the participants opted for alternative and folk medicine over traditional/Western rehabilitation, after discharge from the hospital, continuing to utilise all forms of available treatment such as Ayurveda (alternative medicine rooted in Indian sub-continent that employs union of body, senses, mind and soul for health benefits), Naturopathy (alternative medicine based on healthy living and a drugless system of healing) (<http://ayush.gov.in>) and herbal medicine. Thus, engaging in

Table 1. Participant characteristics.

ID	Age in years	Gender	Time since stroke in months	Employment status	Stage of stroke
1	49	Male	60	Employed	Chronic
2	60	Male	30	Unemployed	Chronic
3	75	Male	48	Self-employed	Chronic
4	53	Female	72	Unemployed	Chronic
5	50	Female	46	Unemployed	Chronic
6	80	Female	6	Unemployed	Late sub-acute
7	55	Female	2	Employed	Early sub-acute
8	54	Male	84	Employed	Chronic
9	68	Female	12	Unemployed	Chronic
10	63	Male	48	Self-employed	Chronic

Table 2. Key factors influencing adherence to home-based exercises among community-dwelling stroke survivors.

Personal factors	External factors		
	Interpersonal factors	Organisational factors	Community factors
Awareness about stroke recovery	Supportive family	Emphasis on exercises by the treating doctor	Inclusive and supportive society
Knowledge about the benefits of exercises	Involvement of others in exercise sessions	Professional supervision	Socio-cultural beliefs on opting for folk medicine
Perceived recovery	Dependence on family and others	Meaningful exercises prescription	Social stigma
Motivation and commitment	Access to healthcare services	Participation in treatment planning	
Opting for alternative therapies over evidence-based treatment		Access to healthcare services	
Failure to accomplish a task		Healthcare costs	
Boredom, distress, frustration			

multiple interventions at the same time, created a barrier to exercise adherence.

P8: "After one year, I again went to UJ (health center for alternative medicine) for treatment. They taught me walking independently. In between, I went to DS (another health center for alternative medicine) for ten days. That is another form of treatment. I also went to Kerala and border of Karnataka to get different herbal oil. I feel, that if I seek treatment from many people, then some people may have more knowledge than the other so they can help me for better recovery."

Most of the participants had inadequate knowledge and understanding about the recovery after stroke and the benefits of continuing exercises. Several participants believed that complete recovery would occur spontaneously after stroke and exercises need not be continued in the long term.

P9: "I started exercises after six months of stroke. For six months, I did not do any exercise. I thought I would recover on my own."

P7 "... that time (at the beginning of stroke) exercises were very much required because there was no movement in this hand. But now there is some movement, so exercises are not required."

Some reported boredom, distress and frustration as reasons for non-adherence to home-based exercises. The participants lost interest in the treatment by continuing the same set of exercises every day. They also reported feeling like the exercises were of no use if they did not experience immediate improvement.

P4 "What I say is, it's very difficult to survive and rehabilitate, and it's very boring also, doing the same thing again and again. No motivation also because improvement is so slow. In 1 year you will see only this much improvement (shows through gestures), and that also is not visible, so you don't feel like working. So I am fed up with this."

P2: I get lazy sometimes, but there are other things also. I lose hope when I am not able to see any recovery. I feel upset and frustrated and feel it's of no use to do the exercises. I get

nervous when I see no improvement. I get bored doing exercises again and again."

Poor perceived recovery also hampered exercise adherence, which often led to a cycle of reported depression and low self-esteem, frustration, hopelessness and lack of motivation.

P4 "Only exercises, exercise, exercise, and improvement is so slow, years it takes. And first six months, it showed good improvement, and later it became slower. The lower limb has hopes and recovers but for upper limb... you can't say. No doctor can say that it will recover. They say do exercises thrice in a day, two- three times in a day, just giving it a try, hoping it can recover. Without hope, means without expectations, I have to do exercises."

P4 "I was doing exercises. There was no sign of improvement as far as fingers were concerned, so I got fed up, and I stopped doing exercises completely."

Another reported barrier to exercise adherence was the failure to accomplish a task successfully, for example, during prescribed task-specific training exercises. Some of the participants reported not being able to complete a task, impacting their confidence and reducing adherence.

P4 "I had to fold the blanket, and I was trying to fold the blanket so forcibly I had to force the blanket into my fingers, then I tried to do, but I couldn't do it properly, so I gave up and kept it."

Personal factors which facilitated exercise adherence included having good awareness about stroke recovery, perceiving the benefits of exercises, and determination to achieve a goal - participants who had strong willpower to recover continued exercises despite experiencing difficulties in the course of recovery.

P4 "Exercise is the only treatment for it. What I have achieved so far will deteriorate if I don't exercise, that's what the doctor told, so I should keep doing exercises to maintain whatever I have

achieved. There is no other medicine for it. I face difficulty, but I try to do it, because of strong will power."

P6 "Until now, whatever recovery happened is only because of physiotherapy; it was perfect. Now my daughter asks me to do exercises as no one else can help. It is only my efforts now ... Now the horse is brought near the water, but to the drink water, the horse has to do on its own."

External factors

Interpersonal factors. Family and friends played a crucial role in determining adherence to exercises. Dependence on a caregiver was one of the interpersonal factors, which led to poor adherence. The participants became so dependent on their families that they failed to do a simple task independently. They believed that they could exercise only if a family member helps or supervises.

P5 "Nobody is there to help or guide me to do exercise. My husband is a daily wage worker, and he leaves home in the morning and comes back in the evening, my daughter goes to the college and comes back in the evening, and my son has gone abroad to work. So, I was not doing anything as I was alone at home."

In contrast, a supportive family was recognised as the most important factor in promoting exercise adherence. Family members helped the participants to carry out a task, encouraged to continue exercises, and provided psychological support. They helped in building their self-image after stroke and enhanced their confidence to perform day to day activities.

P6 "Most of the time I am sitting on this bed, which my daughter doesn't like. She wants me to move and get involved in some activity and get rid of my "patient mode." She tells me to forget what happened and start getting involved in daily activities like before."

P9 "Family support is good. They helped with everything. They help in all activities, hospital, exercise, and everything. It was a joint effort by my family members. I was doing exercises, getting food and medicine on time. So together it helped me to recover. Otherwise, it would have been difficult."

Participants expressed the need for involving others in the exercise programme to facilitate adherence. They reported feeling encouraged to do the exercises along with someone. They also required physical support to carry out their activities and exercises as they were unable to do it alone.

P6 "I want my daughter to be with me when I am doing exercises. I do not exercise alone. I need someone to be with me when I do exercises."

Organisational factors. A crucial determinant of non-adherence was a lack of emphasis on exercises by the treating doctor. The majority of participants followed what their doctors told them to do. However, most of the time, participants have not been prescribed any exercises and were not informed about continuing exercises after discharge. When exercises were prescribed, often the importance of completing exercises regularly was not emphasised, nor were participants advised about the benefits of exercises.

P9 "No, they only gave massages, bath in hot water and lepa (balm). I did not know about physiotherapy at that time. My Doctor didn't tell me about it. According to him, physiotherapy was not required. He said I would recover in four months, and strength will return automatically."

Most of the participants gave up home exercises due to lack of professional supervision. Either they could not perform the exercises alone or needed regular feedback from the professional.

P5 "I have stopped doing all exercises after the physiotherapist stopped coming home, as there is nobody to help or guide."

Participants who were instructed by healthcare providers, other than doctors to continue exercises and had the mechanism of recovery after stroke and the importance of exercise explained to them, reported better exercise adherence.

P4 "I took Botox and doctor told me that only taking Botox is not enough. Botox means the dominant muscle is given an injection to make it weak. And strengthening the opposite group of muscles is required so that my fingers could become straight. So I started exercises again."

Meaningful exercise prescription and participants' involvement in treatment planning also influenced their exercise adherence. Participants were more likely to adhere if the exercises were salient to their requirements and context. Additionally, the participants felt more confident if they were actively involved in designing their treatment.

P2 "Yes, one therapist asked me what activity I want to do. So I told him that I want to use my arm for holding objects. He told me some exercises and gave me ideas to use my hand."

The participants reported doing exercises regularly if they had some form of professional supervision or regular contact with the therapist. They felt motivated to exercises and liked to get feedback on how they were performing the exercises.

P6 "One physiotherapist comes once or twice a week for supervision because I requested him to come. I get some feedback and encouragement from him."

P2 "I want a physiotherapist to look when I do exercises, whether I am doing right or wrong. I feel encouraged to do exercises in front of a therapist."

Community factors. Some social factors also influenced exercise adherence. Usually, people who live in a community follow similar practices and culture and have similar faith and beliefs. Therefore, opting for alternative therapies over evidence-based treatment for stroke management was also determined by the cultural norms that prevailed in the study region. Most of the participants followed what the neighbours and the community advised them to do, which in some cases prevented them from following the recommended rehabilitation after stroke.

P6 "I went to UW (health center for alternative medicine) for Ayurveda treatment; all my friends say that Ayurveda is best for this problem."

P8 "One of my relatives also got a stroke, and he is more than 70 years so, I went to see him. I went to tell him that Ayurveda is the best for this (stroke)."

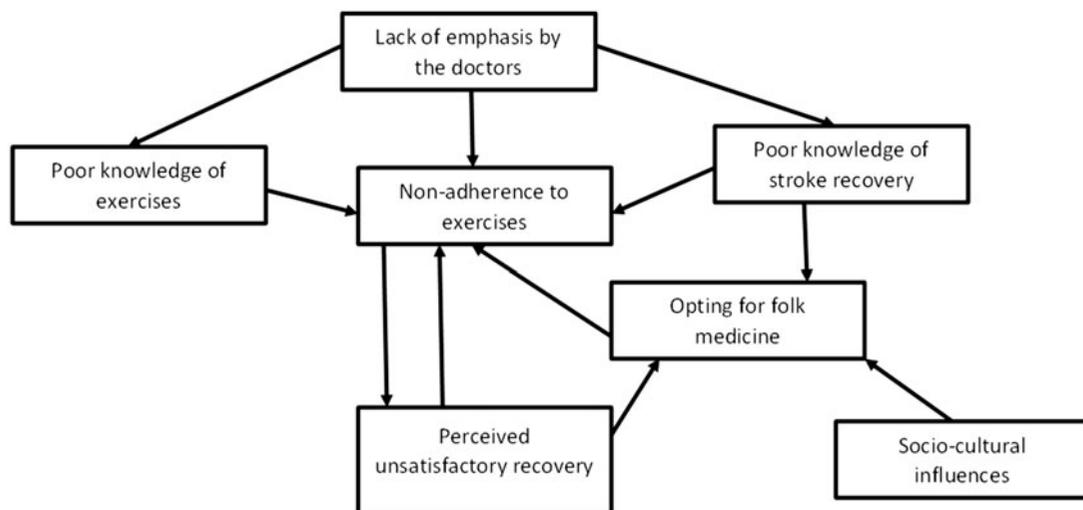


Figure 2. Link between factors leading to exercise non-adherence.

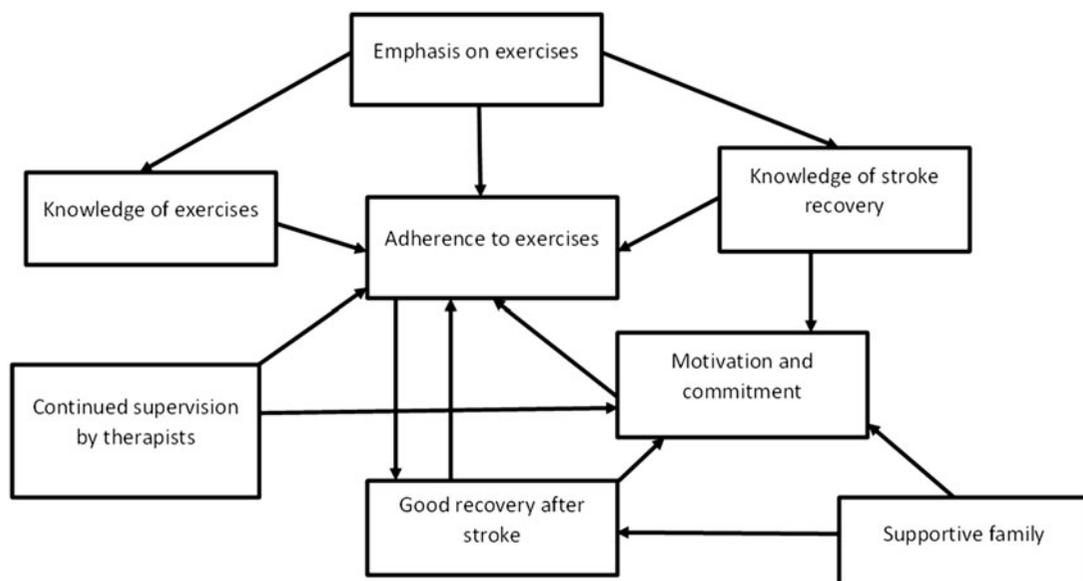


Figure 3. Link between factors promoting exercise adherence.

Social stigma also hindered in the re-involvement of the participants. In a developing country like India, people still believe that stroke is a punishment for your ill deeds, and the stroke survivor should be excluded from society. Many participants reported that they did not like interacting with society as it made them embarrassed, and they did not like to be treated as a victim. The attitude and perception of society predisposed the beliefs of the participants that they do not deserve to recover and to accept disability after a stroke as their destiny. Thus, such notions indirectly prevented them from making any attempts to recover and influenced their exercise adherence.

P6 "Yes earlier I was hesitant to go out; I used to feel what others will think of me. Because in India, there are concepts like if paralysis occurred then it must be due to your bad deeds or something."

The inclusive and supportive society helped substantially to improve the confidence and body-image of the participants. They were able to re-integrate in the community and were able to maintain an active lifestyle after stroke.

P6 "My daughter takes me to church every week. She also takes me to the park downstairs, where I meet people and talk to them. I like interacting with people. I also walk for 20 minutes every day."

The factors leading to non-adherence were linked to each other, Figure 2. For example, lack of education by the health-care professional led to poor knowledge about stroke recovery, which further led to non-adherence. Similarly, a lack of knowledge about stroke recovery led to the opting of folk medicine over evidence-based rehabilitation and reduced adherence to exercises. Figure 3 shows the link between factors which facilitate exercise adherence.

Discussion

In this study, we used IM approach to identify and understand the factors influencing adherence to prescribed home-based exercises among community-dwelling stroke survivors.

We broadly classified the determinants into personal and external factors which promote or impede adherence.

Opting for traditional medicine, poor knowledge about stroke and exercises, anguish, slow recovery, dependence on others, difficulty in accessing healthcare centres, and lack of emphasis on exercises and attitude of the society hampered exercise adherence. We found that awareness about stroke recovery, perceived improvement in condition, self-efficacy, commitment, involvement of family, continued supervision by the healthcare professional and supportive society facilitated exercise adherence. The factors influencing exercise adherence were interlinked to each other, thus, making it a multidimensional phenomenon [23].

Some of the previous studies have also reported factors such as motivation, social support [24] and self-efficacy [25–27] had a role in exercise adherence. A recent study identified the caregiver's perception of the barriers and enablers of exercises in stroke [28]. However, this study identified additional factors specific to stroke, such as the crucial role of healthcare professionals in treatment delivery, knowledge about benefits of exercise and progress in recovery, which determined exercise adherence. Some culture-specific barriers were also recognised, such as faith in alternative and complementary medicine, societal trends to utilise different forms of intervention and stigmatisation of the disease.

Interestingly, forgetfulness was not identified as a determinant of non-adherence. This finding is significant as the current methods employed to ensure adherence to home-based interventions are reminders or weekly telephonic calls [29–32]. Thus, only providing reminders may not be a useful tool to overcome barriers of exercise adherence [33].

Based on the findings of this study, the adherence interventions should target at improving self-efficacy, imparting knowledge about the disease, adequate emphasis on the prescribed treatment and patients' involvement in treatment planning. It is the responsibility of the treating therapist to individualise the treatment for the stroke survivors, which is feasible in their context. Involving family, neighbours and society would also strengthen exercise behaviour.

The IM approach offers a comprehensive method to identify the salient determinants for the desired behaviour to design health promotion interventions where patients, family, community, healthcare providers and society at large should be intervened to ensure that desired health behaviour [13]. Therefore, the interventions should be planned in a way which targets key factors of non-adherence and should incorporate interventions using the socio-ecological model [19]. The results of this study will lead to the development of programme design to facilitate adherence to home-based exercises among stroke survivors.

Using IM approach as a framework for understanding the various aspects of exercise adherence is a key strength of this study. This study offers deeper insight into the multifaceted components of adherence among the stroke survivors. The interviews were conducted during the afternoon at the participants' residences. An equal number of men and women were interviewed for identifying the gender-specific factors influencing adherence. To obtain a variation of

experiences, we included participants in their acute and chronic stage of stroke as well as from different socio-economic strata. Most of the women were unemployed and stayed at home. Data were obtained from both mildly affected to majorly disabled adults with stroke to understand the array of challenges in continuing home-based exercises. Discussions between all the investigators and thorough reviewing of analysed data established the credibility of the results.

There are several limitations of this study. Only the perceptions of the stroke survivors were included. Including the perspectives of caregivers and healthcare providers towards the issue of non-adherence would have provided a broader perspective. Another limitation was the cultural practices prevalent in the study region, which may confine the findings to this setting. However, people in different regions demonstrate different health practices based on their culture and context [34]. Therefore, future studies should also incorporate their culture-specific determinants to assist in exercise adherence.

Conclusion

This study revealed key factors of adherence to home-based exercises among community-dwelling stroke survivors. The dynamics of adherence are not only related to an individual but are also existent at the interpersonal, organisational and community level. Therefore, these elements should be considered to design and plan future studies aimed at facilitating exercise adherence among stroke survivors living in LMICs.

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