Adherence to rehabilitative programmes by patients living with neurological conditions: A South African context

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Abstract

The number of people living with disabilities is increasing. Good adherence to rehabilitative programmes is critical for optimal health and health systems in developing countries are under pressure to meet multiple health needs. Overworked practitioners assume that if the patients fail to show up for their appointments they have lost interest. The purpose of the study was to explore reasons for the poor adherence of patients with neurological disorders at rehabilitative services. This study used a phenomenological approach and purposive sampling. One-on-one interviews with patients booked to receive therapy at a South African public sector hospital and who failed to attend therapy were done (n=12). For triangulation purposes interviews were conducted with patients who had never missed sessions (n=5). A total of eight of the participants from both groups said that they had not accepted their condition. All five dimensions of adherence described in the literature were found. The participants gave very positive feedback on the rehabilitative programmes received at the hospital, but said circumstances beyond their control had caused them to miss a session. These included fear of losing jobs, unavailability of transport, and perception of poor services at primary health care clinics when down referred. The reasons for adherence or lack of it are not easily established. Contributing factors however were noted in this study. Information obtained from the study will assist health professionals to understand the patients' context and can inform rehabilitation programmes to support adherence.

Keywords: Adherence, rehabilitation, stroke, physiotherapy, quality.

Introduction

Adherence encompasses numerous health-related behaviours that extend beyond taking prescribed pharmaceuticals (World Health Organization [WHO], 2003). Stroke is a major source of mortality and morbidity in the world (American Heart Association, 2013), and its effects require good adherence to outpatient physiotherapy sessions to ensure optimal rehabilitation. Despite rehabilitation, 40% of stroke patients are left with moderate functional impairments and 15% to 30% with severe disability

(American Heart Association, 2004). The number of people with disabilities is increasing due to chronic diseases, war, HIV/AIDS, malnutrition, accidents and substance abuse (WHO, 2005). Population growth and medical advances that preserve and prolong life contribute to this increase in disabilities (WHO, 2005), with a resultant increased pressure on the health system.

South Africans aged five years and older were classified as disabled in 2011 and 2012 and women (5.4%) were more likely to be disabled than men (4.8%) (Census, 2011). The growing prevalence of people with disabilities places rehabilitation services under pressure and emphasises the need for adherence to post-acute rehabilitation guidelines as this is associated with improved patient outcomes (Duncan, Zorowitz, Bates & Choi, 2005). While health systems have a responsibility towards those with disabilities, disabled people should make use of the resources at their disposal. But the availability of resources such as rehabilitation services is not the only factor that affects adherence. According to the WHO, adherence is a multidimensional phenomenon determined by the interplay of five sets of factors (Figure 1) (WHO, 2003).
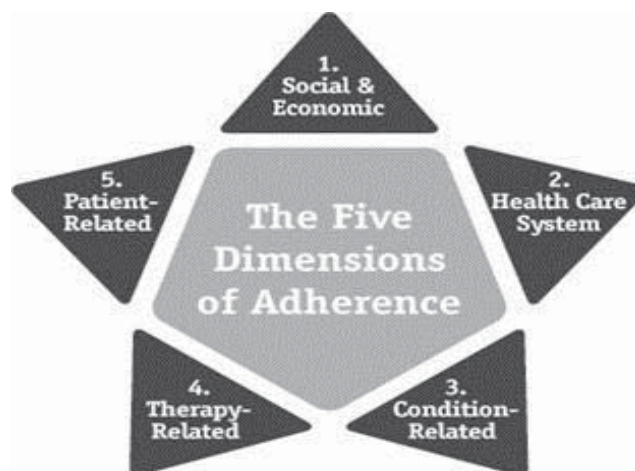

Figure 1: The five dimensions of adherence (WHO 2003)

Osamor and Owumi (2011) noted that *socio-economic* status was not found to be an independent predictor of adherence to treatment. It is feasible that in developing countries, low socio-economic status might put patients in the position of having to choose between competing priorities. Some socio-economic factors reported to have a significant effect on adherence are: illiteracy, low levels of education, unemployment, lack of effective social support networks, unstable living conditions, long distances from treatment centers, high cost of transport, high cost of medication, culture, lay beliefs about illness and treatment, and family dysfunction (Osamor & Owumi, 2011).

The effect of the *health care system-related factors* on adherence is inconclusive. Some system-related factors that have a negative effect on adherence to rehabilitative services include poorly developed health services, lack of knowledge and training for health care providers, overworked health care providers, lack of incentives and feedback on performance, short consultations, weak capacity of the system to educate patients and provide follow-up, inability to establish community support and self-management capacity, lack of knowledge on adherence and of effective interventions for improving it (Jack, McLean, Moffett & Gardiner, 2010). A growing body of evidence indicates that patients do better within a well-organized, multidisciplinary approach (Stroke Unit Trialists' Collaboration, 2007). Albaz (1997) concluded that organizational variables such as: time spent with the health practitioner, continuity of care, communication and interpersonal style of the practitioner are far more important than socio-demographic variables like gender, marital status, age, educational level and health status in affecting patients' adherence (Albaz, 1997). Despite this evidence, there is a tendency to focus on patient-related factors as the cause of adherence problems (WHO, 2003).

Condition-related factors represent particular illness-related demands faced by the patient. These influences on adherence may be related to severity of symptoms, level of disability (physical, psychological, social, and vocational), and the rate of progression. Lifestyle factors such as alcohol and drug abuse together with comorbidities such as depression are important modifiers of adherence. Gonzalez, Safren, Cagliero, Wexler, Delahanty, Wittenberg, Blais, Meigs and Grant (1997) suggest that even low levels of depressive symptomatology are associated with nonadherence.

Factors such as the duration of treatment are described as *therapy-related factors* (WHO, 2003). Most notable are those related to the immediacy of beneficial effects, side effects, and the availability of medical support to deal with them. Some of these factors challenge earlier findings which suggested that the improvement in performance is related to early initiation of treatment rather than the duration (Ottenbacher & Jannell, 1993). Two studies found a strong correlation between neurological conditions and time – recovery is seen within six months after incidence, and very little thereafter (Verheyden, 2008; Dhamoon, Moon, Paik, Sacco & Elkind, 2012).

Adherence is also influenced by *patient-related factors* such as personal resources, knowledge, attitudes, beliefs, perceptions and expectations. Furthermore patients' knowledge and beliefs about their condition, motivation to manage their condition, confidence in their ability to engage in illness-management behaviour, expectations regarding the outcome of treatment, and

the consequences of poor adherence interact in ways not yet fully understood to influence adherence behaviour (WHO, 2003). A patient's motivation to adhere to prescribed treatment is influenced by the value that is placed on following the regime (Casula, Tragni & Catapano, 2012). Patients remain the most important part of the multidisciplinary team and the literature on patient satisfaction generally confirms that utilisation of healthcare services and satisfaction are positively related (Keith, 1998).

This study explores the contributing factors of poor adherence to rehabilitative services at a district hospital. The significance of the study is to identify those dimensions within the WHO's five interrelated dimensions that affect adherence and are modifiable from a service provision perspective. The rationale of the study is to inform rehabilitation services in order to improve adherence to treatment.

Methodology

The study setting was the Department of Physiotherapy outpatient the Tambo Memorial Hospital (TMH), a public sector hospital, in the Ekurhuleni Metropolitan District, South Africa.

Research design

A phenomenological approach was used to understand the experience of adherence to rehabilitation from the patients' perspective. The target population was adult patients (eighteen years and older) who had neurological conditions that required physiotherapy rehabilitation and who had missed at least one session.

Study sample

The study sample consisted of 17 adult patients (Table 1) with various forms of neurological conditions; twelve of whom had been referred for physiotherapy services and failed to attend at least one session on an out-patient basis, and five neurological patients who had not interrupted their treatment were interviewed for triangulation purposes.

Sampling method

A purposive sampling method was applied and patients who met the inclusion criteria were identified from the out-patients appointment book. Purposive sampling is non-probability sampling and is suitable for in-depth qualitative research where the researchers aim to understand complex social phenomena (Small, 2009). Exclusion criteria included all in-patients receiving

rehabilitative treatment and those with severe speech and/or communication difficulties.

Measurements

The interview guide consisted of questions adapted from the Standardized Stroke Performance Measurement Implementation Guide and contained 10 open-ended questions and 21 close-ended questions (The Joint Commission, 2008). The interview guide was tested for clarity of the questions in the same study population.

Semi-structured in-depth interviews were conducted with all the participants and audio taped for transcription. Once the saturation of data was reached (no new information was forthcoming regarding the variables of interest) the collection of data ended after 12 interviews. On completion of the interviews, the audiotapes were professionally transcribed and checked by the researcher for consistency. The code L was used to represent the less adherent group, and the code A was used for the adherent group.

Analysis

Content coding was done using the socio-economic, health care system-related, condition-related, therapy-related, and patient-related factors in the WHO adherence model. Codes were grouped into sub-themes and themes.

Trustworthiness

Trustworthiness of the findings were ensured by addressing the four quality criteria for qualitative research: credibility, transferability, dependability and confirmability. Credibility was ensured using data triangulation (two discrete groups of patients) and member checking. Transferability was ensured by explaining the sampling strategy, thick description of the findings and comparison of the findings with literature. Dependability was ensured by the collection of data until saturation was reached and continuous analysis of the data to inform further data collection. Finally confirmability was ensured through peer debriefing and maintaining an audit trail.

Ethical considerations

Each potential research participant was given an informed consent form that outlined the purpose of the study, the length of the interview, risks involved with participation, anonymity, and benefits. Those who agreed to participate signed the consent form after explanation. Ethical approval was obtained from

the Ethics Committee at the University of Pretoria (S148/2012) and permission was obtained from the Chief Executive Officer of TMH.

Results

The demographic profile of the respondents is reported, followed by a description of the factors that affect the respondents' adherence to rehabilitative treatment. The WHO adherence model is used to structure the findings and quotes are used to illustrate the experience of the participants.

Demographic profile of respondents

The demographic data of both the adherent (A) and less adherent (L) groups is depicted in Table 1. More (n=8; 66%) of the L participants were males compared to only one (20%) in the A group. Group L had a large majority (n=9; 75%) of their patients in the relatively young age group (30–39) year age group.

Table 1: Demographic profile of the study participants

Variables	Categories	*Number of participants (n)*		Percentage (%)	
		L	**A**	**L**	**A**
Age	18–35	2	3	16.6	60.0
	36–45	9	2	75.0	40.0
	46+	1	0	8.3	0.0
Gender					
	Male	8	1	66.6	20.0
	Female	4	4	33.3	80.0
Diagnosis					
	CVA/Stroke	6	5	50.0	100.0
	Spinal injuries	2	0	16.6	0.0
	Cerebral Palsy	1	0	8.3	0.0
	TB spine	3	0	25.0	0.0
Disease Total		**12**	**5**		

The themes presented are a reflection of the WHO adherence model and are composed of some subthemes in some instances:

- socio-economic (subthemes: employment, education and family responsibilities);
- health care system-related;
- condition-related;
- therapy-related (subthemes: outcome and convenience; understanding their condition); and
- patient-related factors (subthemes: hopefulness, beliefs, substance use).

Social and Economic factors

Employment
Only one (20%) of the participants in group A was employed at the time of the interview, and five (42%) in group L. The largest proportion among the unemployed participants from both groups (35%; n=6) had been employed in the informal sector prior to becoming ill: *"Since I got sick, I was unable to work, and my madam hired another lady to clean her house and now my children are hungry"* (*A3*). Those who still have their jobs expressed the difficulty in fulfilling work duties: *"The grip on my left hand is still not strong enough, and I tire very easily" (L7)*, and taking time to attend the rehabilitation classes is a battle: *"I couldn't come because my boss refused to give me authority to come, what can I do, my children need to eat"* (L2).

Education
The highest level of education was similar between the two groups with seven (58%) reaching the level of high school and five (42%) never making it beyond primary school in group L. Three (60%) of the participants in group A received government grants compared to seven (58%) in group L but these were not always the disability grant: *"The child support grant for my two children is the only way we are putting food on the table. I am still waiting for the social worker response for my disability grant. We have filled up all the papers. I don't know how long we can wait. Life is very difficult right now."* (L4).

Family responsibilities
Four (80%) of the adherent participants had between one and five dependents in one family, compared to nine (75%) of the less adherent participants having between one and five participants in one family. The need to generate additional income and their ability to support their families was a concern*: "I can't even wipe my own bum right now so mixing cement is an impossible task"* (A1). Feelings of being abandoned were evident*: "Our system is very corrupt. I have spent my whole life working, and now that I am sick the system doesn't care to my needs"* (L4).

Health care system related factors

The participants in both groups expressed conflicting views about rehabilitative equipment used at the TMH: *"This place has everything from training bicycles, weights for the arms, those walking bars we use to support us when we are walking"* (A3). But the availability of the equipment did not necessarily imply that the equipment was functional: *"The things here sometimes don't work. Like the other day we had to use my sock to tie my foot to the footrest of the bicycle. It was really uncomfortable but the therapist*

tried her best. She is great. (Smiling)" (L6). All of the participants from both groups were NOT satisfied with the current frequency of a fortnightly session. Two (16%) participants from the less adherent group were referred to a primary health care clinic used for down referral purposes, and neither were happy: "*I decided that going there [new site] would be a waste of my time. First you wait for a long time, and then when you finally go through, they just put you on a machine, few minutes, they say goodbye see you next time. Oh no!*" (L11).

Condition-related factors

All twelve (100%) of the participants from the group L were all diagnosed with a stroke in the past six months, compared to two (40%) in group A. None of the participants (both groups) reported being aware of any side effects due to the medication received, and none (both groups) reported any drug and alcohol abuse. Furthermore, none of the participants from both groups were aware of being on any prescribed anti-depressants. "*The doctor prescribed a lot of pills for me, so if I am getting those anti what what, then I wouldn't even know*" (L5). Participants required an explanation on what anti-depressants are before answering. Once explained, nine (75%) of the group L, thought that they would benefit from anti-depressants compared to only one person in group A: "*So you say these pills will help improve my mood? So can I ask just ask the doctor to give them to me at the clinic?*" (L7).

Therapy-related factors

Outcome and convenience
When participants were asked about their views on the rehabilitation received, and the impact rehabilitation has had on their condition, all the participants from both groups (n=17) gave overwhelmingly positive feedback. All the participants had noted great improvements in their mobility and ability to perform general daily activities since commencement of their rehabilitation journey. Four (80%) of the participants in group A had expressed their desire to have longer sessions but no-one in group L had a similar wish. Group A participants reported that the therapists checked with them for suitable dates and times for future bookings and always tried to synchronize their sessions with that of any other hospital appointments (n=4; 80%) compared to group L (n=5; 42%).

Understanding their condition
Explanation about their condition was viewed as poor in both groups (40% for group A and 50% for group L). Little effort was made to ensure that any explanations were understood: "*The doctor used very big words to explain I think. I didn't understand a word obviously (laughing), so I later asked the*

nurse on duty for an explanation. She just said "there has been bleeding in your brain, and the doctor is not sure what caused it" (L11). Only one (20%) of the group A participants was diagnosed more than 6 months ago compared to nine (75%) in group L.

Patient-related factors

Hopefulness
Every single participant showed a sense of optimism about their prospective levels of functionality: *"When I walk again I will appreciate all the small things that I used to take for granted"* (A4). When the patients were asked whether they had accepted their condition, four (80%) of group A participants said they have not accepted their condition compared to four (33%) in the group L.

Beliefs
Eight (66%) of the group L participants believed that their sickness was due to witchcraft compared to two (40%) of group A: *"Once the bad spirits have been cleared from my house, things will improve for me, but I need money to slaughter a cow and I need to make at least three buckets of African beer"* (L11). *"Lots of bad things have been happening in my neighbourhood, so many witches walk amongst us every day. I never thought they would get me but they did"* (L2).

Substance use
Four of the participants (33%) in the less adherent group reported consuming alcohol compared to none in the adherent group. None of the participants in the study reported the use of any illegal drugs.

Reasons for missing a session/s

The participants in group L had several reasons for missing a session/s: five (42%) said they forgot about their appointment; three (25%) said they had to work; and four (33%) said they were not feeling well on the day: *"I really don't know what happened. I guess I just forgot about my appointment. There is always a lot on my mind"* (L5). Changing circumstances were another influence: *"A lot has changed at home. My wife had to work on that day. She is the one that makes it possible for me to come here every time"* (L10).

Discussion

According to the WHO adherence is a multidimensional phenomenon determined by the interplay of five factors (WHO, 2003). Socio-economic factors such as employment status seemingly affect the participants' ability to

attend the sessions because the employers and colleagues complain when they take time off to attend rehabilitation services. The majority of the participants were/are employed in the informal sector and has no sick leave benefits, so absence from work results in a loss of income. In this study, socio-economic factors did not seem to be the most important factor in adherence. This observation is supported by Osamor and Owumi (2011) who reported that socio-economic factors were not a predictor of adherence to treatment. Rather it is likely that time spent with the health practitioner, continuity of care, communication and interpersonal style of the practitioner is more important (Albaz, 1997).

In the study issues of broken exercise equipment were raised as a concern by a few participants, whilst some were satisfied. This seeming contradiction makes it difficult to identify the state of the physiotherapy equipment as a contributor to lack of adherence. Down referral to primary health care clinics is a possible barrier to adherence with both the less adherent participants referred complaining of the services. An interruption in the continuity of care and perceived inadequate service contributes towards lack of adherence (Albaz, 1997). The schedule for each of the participants was one physiotherapy session a fortnight which is inadequate to achieve the general goals of rehabilitation. The adherent group seemed aware of the benefit of having more sessions, but due to the uncompromising patient to therapist ratio, a more regular schedule is unlikely.

In this study, few condition-related differences emerged. All the participants in the adherent group were stroke patients which presented with serious physical impairments, and subsequently increased their dependency on others. Depression cannot be ruled out in all the patients regardless of them not receiving anti-depressants. The interest in the benefits of anti-depressants among the less adherent participants suggests that depression is overlooked by medical personnel or is merely not a concern. Gonzales et al. (1997) found that even low levels of depressive symptomatology are associated with nonadherence.

The therapy-related factors were similar in both groups, and none of the participants could fault the therapy they received. All the participants (both groups) wanted to increase the frequency of their sessions. However, only the adherent participants expressed a desire to have longer sessions, possibly because the adherent participants placed more value on physiotherapy. This finding is similar to that of Albaz (1997) who reported that time spent with the health practitioner influences adherence. The majority of the less adherent participants reported that their sessions were not booked to synchronize with that of the other health services in the hospital – a possible contributor to poor adherence as patients do better within a well-organised, multidisciplinary

approach to rehabilitation (Stroke Unit Trialists' Collaboration, 2007). In the South African context, patient-to-therapist ratios are high making rehabilitation a challenge but good patient-provider relationship assists to improve adherence (Jack et al., 2010). The less adherent group participants had been diagnosed more than six months ago and further improvements in their physical abilities are unlikely (Verheyden, 2008; Dhamoon et al., 2012). It is possible that the decline or halt in their rate of improvement since the start of rehabilitation was a contributing factor to poor adherence.

Patient-related factors which include the participants' personal resources, knowledge, attitudes, beliefs, perceptions and expectations about their condition and treatment were found similar in both groups. Differences however were noted in the acceptance of their condition and diagnosis. Many in the less adherent group had not accepted their condition, and patients' knowledge and beliefs about their condition affect their motivation to manage their conditions (WHO, 2003). A possible explanation for non-acceptance of their condition among the less adherent participants might be due to the lack of a simple and understandable explanation by a healthcare professional. The less adherent participants' belief in witchcraft is suggestive of yielding control to outside forces resulting in a feeling of helplessness. Until the "powers" are removed little value is placed on the regime and motivation to adhere to prescribed treatment will be poor (Casula et al., 2012).

The reasons for missing sessions given by the less adherent group in this study; namely: working, forgetfulness, and not feeling well gained more meaning through probing. The little inconsistencies that were found between the adherent and less adherent groups regarding the condition-related and patient-related factors suggest that all the participants had similar challenges but some were more able to overcome these challenges.

Conclusion

Adherence is a very simple idea. A patient can adhere, not adhere, or adhere somewhat to a prescribed rehabilitation programme. The reasons for this adherence or lack of it are not easily established. Contributing factors however were noted in this study. These include participants not being able to go to their therapy sessions due to a fear of losing their jobs, unavailability of a mode of transport, poor services at primary health care clinics when down referred, inadequate therapy sessions (one session in a two week period), untreated cases of depression, lack of good understandable education about their condition and treatment. One implication is for practitioners is to emphasise and re-enforce the patients' understanding of their condition and the role of rehabilitation. A second is to screen patients for signs of depression and to refer appropriately. Two health system implications are to synchronise

rehabilitation sessions with other hospital appointments and to increase the frequency of the sessions within the first six months.

Acknowledgements

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