

Adherence to a Rehabilitation Regimen in Stroke Patients: A Concept Analysis

Abstract

Background: Adherence to rehabilitation regimens is a major issue in the treatment of stroke. Despite the agreement on the importance of adherence, there is still no clear definition of this concept in rehabilitation. The aim of this study was the concept analysis of the concept of adherence to rehabilitation regimens in stroke patients. **Materials and Methods:** This qualitative concept analysis was performed using Walker and Avant's method. English and Persian articles were searched using keywords such as "adherence", "compliance", "rehabilitation", "stroke", and other related keywords among articles published from 1997 to 2018 in PubMed, Scopus, Web of Science, Google Scholar, Iranmedex, Magiran, and Scientific Information Database (SID). Related textbooks were also searched and all articles containing definitions, attributes, antecedents, and consequences of the concept were included in the study. **Results:** The attributes of the concept included complex, multidimensional, and dynamic behavior in the treatment process, personal experience, and adaptive behavior in patients, changeable, situational, voluntary, and collaborative behavior, and active communication between the patient and the healthcare provider. Common antecedents of the concept of adherence to the rehabilitation regimen were classified into patient-related and environmental-related categories and the consequences were classified into the three categories of patient-related, healthcare professional-related, and healthcare system-related. **Conclusions:** This concept analysis can be useful in eliminating any ambiguity of the concept of adherence to rehabilitation regimens. It helps clarify the vague concepts used in nursing rehabilitation instead of adherence. The results of this study can be helpful for researchers for further studies in this context.

Keywords: Iran, patient compliance, rehabilitation, stroke

Introduction

Stroke causes many disabilities in patients worldwide.^[1,2] The majority of stroke survivors require many treatments, including rehabilitation.^[3] Stroke rehabilitation is a part of the therapeutic regimen prescribed by healthcare providers to help patients.^[4,5] Adherence to long-term treatments, especially rehabilitation, is a major issue in the treatment of chronic diseases.^[4] In the process of rehabilitation, adherence to regimen by patients promotes function, increases independence level, and improves Quality of Life (QOL).^[4-8] Most studies have reported less than 50% adherence to medication and rehabilitation treatment. Moreover, adherence in the chronic phase of diseases is less than their acute phase and most patients give up their treatment programs after 6 months.^[9] To improve adherence to treatment plans, the

first step is an understanding of this and the relevant concepts.^[1,10]

Adherence has different meanings in different contexts and few studies have analyzed the concept of adherence in relation to patient behavior.^[1] Two concept analyses have studied the concept of adherence.^[1,10] These studies show that several common terms have been used in the literature instead of adherence including compliance, concordance, cooperation, and participation. Despite the general consensus on the importance of the phenomenon of adherence to healthcare, there is still no clear definition of this concept within or among disciplines.^[1,10] According to the definition presented by the World Health Organization (WHO), adherence is the extent to which patients' behaviors are in accordance with the recommendations of healthcare providers regarding individual

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behaviors, medication intake, diet observance, or lifestyle changes.^[11] Despite the introduction of the term adherence by the WHO, there is no functional definition of adherence base of the theoretical framework, and more studies are recommended in this regard.^[11]

Analysis of the concept of adherence is the first step towards understanding the problems of treatment regimens for patients.^[1,10] There are some studies on adherence to medication regimens^[12,13] but studies on other therapeutic regimens such as rehabilitation programs are limited. Moreover, despite the essential role of nursing in this field,^[14,15] nursing studies have not been carried out to understand and interpret this concept. In this regard, qualitative studies can provide good information for a thorough examination of this concept.^[16,17] When a concept in the area of interest is unclear and unhelpful, concept development is necessary.^[18,19] The concept of adherence to rehabilitation regimen is a key concept and the most critical issue in nursing care provided for chronic patients with disabilities including stroke, theoretical and knowledge development in nursing rehabilitation are useful, and there is no clear definition of this concept.^[1,10] Therefore, this study was conducted with the purpose of analyzing the concept of adherence to the rehabilitation regimen in stroke patients to reduce the ambiguity of this concept and provide an operational definition of this concept using Walker and Avant's (2011) method.^[20]

Materials and Methods

This qualitative concept analysis is a part of a sequential exploratory mixed-method study. A concept is a complex idea or a complex image of a phenomenon. An analysis of a concept is a clear and appropriate approach to identifying the attributes of that concept.^[18] Moreover, this helps to distinguish the concept from similar concepts and results in a precise operational definition that helps to clearly define its problems and allows researchers to construct hypotheses that reflect the relationships between the concepts.^[19] In this qualitative study, Walker and Avant's eight-step method was used to reduce the ambiguity of the concept of adherence to rehabilitation regimen in stroke patients.^[20]

To find relevant articles, literature dated from 1997 to 2018 in databases such as PubMed, Scopus, Web of Science, Google Scholar, Iranmedex, Magiran, and Scientific Information Database (SID) was searched using keywords such as adherence, compliance, concordance, rehabilitation regimen, rehabilitation program, rehabilitation guideline, stroke, stroke patients, patients with stroke, cardiovascular disease, and other related keywords for example: (stroke OR apoplexy OR CVA) AND (rehabilitation) AND (adheren* OR nonadheren* OR complian* OR noncomplian* OR concord*) AND (regimen OR treatment protocol OR program OR guideline). Full-text articles in Persian and English containing the keywords in the title and abstract were selected. All articles containing definitions, attributes,

antecedents, and consequences of the rehabilitation regimen concept were included in the study; 34 papers and 2 books were selected [Table 1]. The quality of the selected articles was evaluated based on the author's credibility and scientific validity of the journals. The eight stages of Walker and Avant's (2011) method for concept analysis were selecting a concept, determining the aim of the analysis, identifying all uses of the concept, determining the defining attributes of the concept, constructing a model case, constructing additional cases, identifying the antecedents and consequences of the concept, and defining empirical referents.^[20]

Ethical considerations

This study was approved by the Ethics Committee of the University of Social Welfare and Rehabilitation Sciences, Tehran, Iran, with the code IR.USWR.REC.1396.203/18 October 2017.

Results

In the literature review, 34 papers and 2 books related to the topic were selected [Table 1]. The eight stages of Walker and Avant's method for analyzing the concept of "adherence to rehabilitation regimen" are described in the following sections.

Selecting a concept

The first step in Walker and Avant's method is selecting a concept.^[19,20] Adherence to rehabilitation regimen was selected because it is a key concept and the most critical issue in nursing care provided for chronic patients with disabilities including stroke. This is important and useful to theoretical development in nursing and contributes significantly to knowledge development in nursing rehabilitation.^[14,15]

In 2007, the National Council on Patient Information and Education (NCPPIE) issued several common terms in the literature to describe patient self-care based on a treatment regimen. This was done in response to the recommendations of therapists. Terms such as compliance, adherence, and concordance are often used in texts. The term compliance has been used since the 1950s and gained popularity in the 1970s. In the 1990s, researchers began to use the term adherence rather than compliance. Negative implications of the concept of compliance are associated with the patient's lack of independence and inactivity in the process of treatment.^[42,45] The concept of concordance is also found in some literature that shows more collaboration in the treatment program between the patient and the care-services provider and is particularly popular in the European Medical Community. However, the compliance and adherence of the terms are noted more frequently in different studies.^[10] Some authors state that the concept of adherence reflects an active, voluntary, and

Table 1: Studies reviewed for data extraction (n=36)

N	Title	Author/year
1	A systematic review of measures of self-reported adherence to unsupervised home-based rehabilitation exercise programs, and their psychometric properties	Bollen <i>et al.</i> ^[21]
2	Adherence: A concept analysis	Gardner ^[10]
3	Adherence: A concept analysis	Bissonnette ^[1]
4	The importance of medication adherence in improving chronic-disease related outcomes: what we know and what we need to further know	Balkrishnan ^[6]
5	Predicting compliance with treatment following stroke: A new model of adherence following rehabilitation	Coetzee <i>et al.</i> ^[4]
6	Adherence of Family Caregivers of Patients with Stroke to Rehabilitation Regimen	Dehghan Nayeri <i>et al.</i> ^[8]
7	Investigating the effects of a family-centered care program on stroke patients' adherence to their therapeutic regimens	Dehghan Nayeri <i>et al.</i> ^[7]
8	Patient Adherence and Medical Treatment Outcomes: A Meta-Analysis	Dimatteo <i>et al.</i> ^[22]
9	Predictive validity of a medication adherence measure in an outpatient setting	Morisky <i>et al.</i> ^[12]
10	Psychometric Properties of the Thai Version of the 8-item Morisky Medication Adherence Scale in Patients with Type 2 Diabetes	Sakthong <i>et al.</i> ^[13]
11	Adherence to postacute rehabilitation guidelines is associated with functional recovery in stroke	Duncan <i>et al.</i> ^[3]
12	Therapeutic Alliances in Stroke Rehabilitation: A Meta-Ethnography	Lawton <i>et al.</i> ^[23]
13	Adherence to clinical guidelines improves patient outcomes in Australian audit of stroke rehabilitation practice	Hubbard <i>et al.</i> ^[24]
14	Stroke rehabilitation	Belagaje ^[5]
15	Adherence to Exercise Scale for Older Patients (AESOP): A Measure for Predicting Exercise Adherence in Older Adults after Discharge from Home Health Physical Therapy	Hardage <i>et al.</i> ^[25]
16	Patient adherence to treatment: three decades of research. A comprehensive review	Vermeire <i>et al.</i> ^[26]
17	Validation of the 8-Item Morisky Medication Adherence Scale in Chronically Ill Ambulatory Patients in Rural Greece	Plakas <i>et al.</i> ^[27]
18	Improving adherence to medication in stroke survivors: A pilot Randomized controlled Trial	O'Carroll <i>et al.</i> ^[9]
19	Multidisciplinary team care in rehabilitation: An overview of reviews	Momsen <i>et al.</i> ^[28]
20	Protection motivation theory and adherence to sport injury rehabilitation revisited	Brewer <i>et al.</i> ^[29]
21	Preliminary psychometric evaluation of a measure of adherence to clinic-based sport injury rehabilitation	Brewer <i>et al.</i> ^[30]
22	The Hopkins Rehabilitation Engagement Rating Scale: Development and Psychometric Properties	Kortte <i>et al.</i> ^[31]
23	The Pittsburgh Rehabilitation Participation Scale: Reliability and Validity of a Clinician-Rated Measure of Participation in Acute Rehabilitation	Lenze <i>et al.</i> ^[32]
24	Health-related quality of life in patients with the chronic rheumatic disease after a multidisciplinary rehabilitation regimen	Coupe <i>et al.</i> ^[33]
25	The perceived threat in compliance and adherence research	Carpenter ^[34]
26	A meta-analysis of the association between adherence to drug therapy and mortality	Simpson <i>et al.</i> ^[35]
27	Adherence and Quality of Life	Ridner <i>et al.</i> ^[36]
28	Adherence: A matter of self-efficacy and power	Buchmann ^[37]
29	Reconciling incompatibilities: A grounded theory of HIV medication adherence and symptom management	Wilson <i>et al.</i> ^[38]
30	Patient Adherence to Medical Treatment Regimens: Bridging the Gap Between Behavioural Science and Biomedicine	Christensen ^[39]
31	Threat and coping appraisal as determinants of compliance with sports injury rehabilitation: An application of protection motivation theory	Taylor and May ^[40]
32	Compliance to treatment in patients with chronic illness: A concept exploration	Rafii <i>et al.</i> ^[41]
33	Patient-centered care and adherence: Definitions and applications to improve outcomes	Robinson <i>et al.</i> ^[42]
34	Psychometric properties of the rehabilitation therapy engagement scale when used among individuals with acquired brain injury	Lequerica <i>et al.</i> ^[43]
35	Adherence to long-term therapies: Evidence for action (Book)	Sabaté ^[11]
36	Improving patient treatment adherence: A clinician's guide (Book)	Bosworth ^[44]

participatory relationship between the patient and the healthcare team.^[44] Despite the importance of the concept of adherence in many health studies, there is still no clear definition of the selected topic,^[1,9] especially in the field of rehabilitation in chronic diseases. Therefore, researchers selected this term to clarify this important concept in stroke rehabilitation.

Determining the aim of the analysis

The second step is the determination of the aim of the analysis. It essentially answers the question: "Why am I doing this?"^[19] The present concept analysis aims to help clear the concept of "adherence to rehabilitation regimen" in stroke patients and distinguish this from similar concepts

that are vague and are prevalently used in the practice. It results in a precise operational definition of this concept, which will accurately reflect its theoretical basis.^[19,20]

Application of the concept

In the treatment of chronic diseases, attention to adherence to the rehabilitation regimen is essential.^[15,43] Rehabilitation is a collaborative goal-oriented process that involves patients, caregivers, and healthcare providers over a period of time.^[28,46] It has an effective role in the treatment outcome of patients.^[21,29,47] Studies in the field of multidisciplinary rehabilitation show improvements in patients after receiving rehabilitation services as a result of adherence.^[43,46] In this regard, the results of the studies conducted in Iran and other countries showed a lack of awareness in stroke patients and poor adherence to rehabilitation regimen among the survivors and their families. The studies show a need for training and planning for adherence to rehabilitation treatment in stroke.^[4,26,45]

Determining the defining attributes

In this step, the attributes that are frequently related to the concept are determined. The defining attributes help to differentiate one concept from its related concepts and clarify its meaning.^[19,20] In the review of literature, the defining attributes of the rehabilitation regimen were identified. They included complex and multidimensional behavior in the treatment and rehabilitation process,^[1,21-23] dynamic behavior,^[1,24,35] personal experience and adaptive behavior in patients,^[1] and a changeable,^[22,23] situational^[22,35] voluntary, collaborative, and active communication between the patient and the rehabilitation team as the healthcare provider.^[23,39] The most common definition provided for adherence was the extent to which patients follow the orders they are given for a prescribed treatment^[1] including rehabilitation treatment.

Case model

The case model is a pure example of the concept studied and should have all the attributes that define the concept.^[19] *“A 70-year-old stroke patient, with hemiplegia of the right side of the body and aphasia for 9 months, hopes to be treated. He followed the rehabilitation team’s instructions regarding the use of medications and speech therapy, physiotherapy, occupational therapy, and other programs set by the rehabilitation team. He agreed to and attended physiotherapy, occupational therapy, and speech therapy meetings with his family. Due to his disease, sometimes he could not perform some of the exercises but he wanted to and tried to perform rehabilitation exercises at home ten times in the morning, evening, and night himself with the help of his family. His family support him and state that he is hopeful and wants to get back to work as soon as possible. According to them, he has significantly improved through exercising and following his rehabilitation regimen”.*

This is an example of a case model because it has all the attributes that define the concept. His behavior shows a complex and multidimensional behavior in the treatment process, dynamic and measurable behavior in the rehabilitation process, personal experience and adaptive behavior, a changeable, situational, voluntary, collaborative, and active communication between the patient and the healthcare provider. He follows all the instructions in the centre and at home. He believes in the treatment and healthcare provider. His adherence to the rehabilitation regimen is clear and his family, nurses, and therapists attest to it.

Borderline case

Identifying borderline cases reduces ambiguity between cases by clarifying attributes that are basic for the model.^[19] The borderline case has many attributes of the concept but it does not incorporate all of them.^[19,20,48] *“A 75-year-old woman had a history of stroke with right hemiplegia and aphasia. She was referred to the rehabilitation centre to undergo the rehabilitation process for stroke with her son’s help. She thinks that the rehabilitation process cannot help her and she does not have a good voluntary relationship with her healthcare provider, but her family is very supportive and follows her treatment programs. She is going to physiotherapy, occupational therapy, and speech therapy centres three times a week with her family. She performs her therapists’ programs at home. The family is very hopeful that she will recover with the help of rehabilitation services”.*

This patient has most of the defining attributes of the concept of adherence to rehabilitation regimen but she does not have good voluntary communication with her healthcare provider. She follows the rehabilitation team’s instructions because of her family.

Contrary cases

Contrary cases do not include any of the main attributes of the concept. Their definition indicates what the concept is not. This definition is so clear that most people can see with certainty that this is not an example of the desired concept.^[19] *“A 68-year-old man suffered from a stroke 4 months ago, resulting in paralysis of the left side of the body. In the examinations by physicians, he showed no sign of psychological, cognitive, and verbal problems but he does not speak to his family in the rehabilitation centres. According to the statements of his family, he understands what they say, but does not answer them because he does not like to adhere to his treatment programs. His son stated that he does not cooperate and pay attention to the instructions of the physician and the rehab team. His family forces him to take his drugs, and they believe that he will not be treated, and they cannot continue with his treatment”.* This is an example of a contrary case model because it has none of the attributes that define the concept.

Antecedents

Antecedents are those events that must occur before the concept's occurrence.^[19] Common antecedents for realizing the concept of adherence to rehabilitation regimens are patient-related antecedents and environmental-related antecedents. Patient-related antecedents include patients' cognitive and emotional level,^[33] education and awareness level,^[7] attitudes, characteristics,^[1] beliefs in the benefits of treatment, adaptation,^[22] motivation, perception, and trust in healthcare providers.^[39] Environmental-related antecedents include financial and social support,^[1] family support,^[22,35] behavior of the healthcare providers, and communication between patient and therapists.^[22,39]

Consequences

Consequences are those events that occur as a result of the concept's occurrence.^[19] The consequences of adherence to rehabilitation regimens are classified into the three categories of patient-related, healthcare professional-related, and healthcare system-related.^[11] Patient-related consequences include improved treatment outcomes,^[1,3,22,24,49] improved QOL,^[36-38] reduced depression and complications of the disease,^[22] reduced recurrence of the disease,^[3,22] improved abilities,^[1,35] and increased acceptance of responsibility for improving^[28] physical^[7,30,34] and mental performance.^[7] Healthcare professional-related consequences include job satisfaction, improvement of rehabilitation services provided for patients, and communication of patients and the rehabilitation team.^[7,8,37] Healthcare system-related consequences are decreased in costs and improvement of healthcare services.^[11,35] Figure 1 shows attributes, antecedents, and consequences of the concept of adherence to rehabilitation regimens.

Empirical referents

The last step in analyzing a concept is defining empirical referents for the main attributes of the concept. According to Walker and Avant, if the concept is abstract, the attributes of the concept are also abstract, and thus, cannot be considered as good empirical symbols.^[19] Empirical referents that are classes or categories of actual phenomena can demonstrate the occurrence of the concept itself by their existence or presence.^[20] The purpose of the definitions of empirical referents is to facilitate the measurement of the concept, identify the concept, and to help the production of research tools.^[19,20,30,36-38]

Adherence to rehabilitation is demonstrated by active participation in rehabilitation programs. Very few studies have been conducted on rehabilitation adherence in patients with brain injuries.^[43] Most of the existing tools have been investigated for medication adherence^[9,12,26,34,50] and are not specific to rehabilitation adherence in stroke patients.^[25,27,31,32,40] However, the Functional Independence Measure (FIM) for evaluating the primary results of adherence, Instrumental Activities of Daily Living (IADL), Physical Functioning Scale of the 36-item short-form (SF-36), and Stroke Impact Scale (SIS) for measuring secondary outcomes of adherence

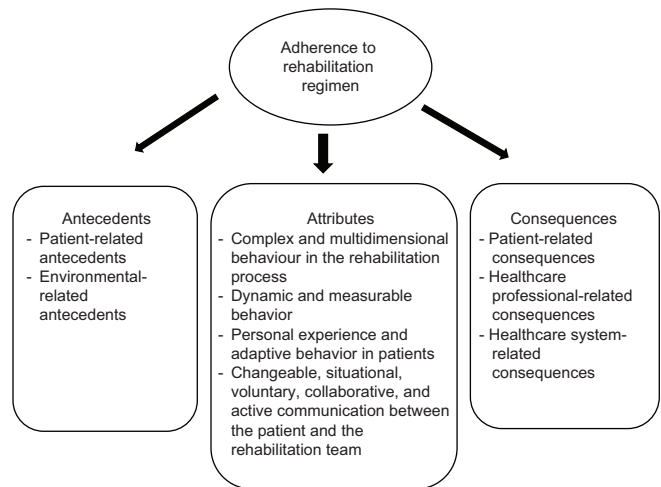


Figure 1: Attributes, antecedents, and consequences of the concept of adherence to rehabilitation regimen

to rehabilitation programs^[24,33,41] evaluate adherence to rehabilitation programs.

Based on the literature review, no specific tool for measuring adherence to rehabilitation regimens in stroke patients was found. The concept of adherence to rehabilitation regimens is associated with the attitude and beliefs of patients; therefore, attention to the accurate measurement of this concept and development of appropriate tools for all kinds of patients seem essential.

Discussion

In this study, ambiguity related to the definition of adherence to rehabilitation regimens in stroke patients was discussed and the common attributes, antecedents, and consequences were mentioned. The first defining attribute of adherence to rehabilitation regimens was complex and multidimensional behavior in the rehabilitation process, which depended upon cognitive, emotional, and environmental factors in the treatment process.^[1,10,24] The second defining attribute of adherence to rehabilitation was dynamic behavior. Adherence is a dynamic concept and is influenced by the social context in which it is used.^[1,24,35] Adherence to rehabilitating changes over time and will not remain stable throughout a program of rehabilitation treatment. The third defining attribute was a personal experience and adaptive behavior in patients.^[1] Patients' agreement and participation in the rehabilitation therapy process is an important key to the improvement of the quality and effectiveness of their treatment.^[21,46,49] The last defining attribute was changeable, situational, voluntary, collaborative, and active communication between the patient and the rehabilitation team. The relationship between patients and rehabilitation team members is an important attribute of patients' adherence in the process of treatments.^[22,23,35,39]

Common antecedents for realizing the concept of adherence to the rehabilitation regimen in this study were classified into patient-related and environmental-related

factors. Patient-related factors included beliefs, attitudes, the emotion of patients, and financial, social, and family support,^[22,35] healthcare providers' behavior, and communication between patient and therapists were environmental-related factors^[1,7,33,35,39] that are essential factors in the process of patients' adherence.

In the present study, consequences were classified into the patient-related, healthcare professional-related, and healthcare system-related categories.^[1,3,7,8,11,35] In the process of rehabilitation, patients' adherence improves the outcome.^[4-8,36] Lack of participation in rehabilitation treatments may lead to a decrease in functional goals and patients' prolonged stay in the medical centres. Studies estimated that adherence to treatment is usually less than 50% and patients give up their treatment programs after 6 months.^[9] Healthcare providers and the healthcare system have important roles in improving patient's adherence.^[7,8]

Finally, the operational definition obtained in the study was a changeable, situational, voluntary, collaborative, and active communication behavior that reflects the patient's participation in the planned rehabilitation regimen to prevent complications and recurrence of stroke, and improve daily living activity, QOL, and outcomes in the patients. In the definition presented by the WHO, adherence is the extent to which patients' behaviors are in accordance with the recommendations of healthcare providers regarding individual behaviours, medication intake, diet observance, or lifestyle changes.^[11] Bissonnette, in her study, also stated that adherence is the extent to which patients follow the orders they are given for a prescribed treatment.^[1] The definition provided in the present study was in agreement with that presented in previous studies but it focused on rehabilitation.

Ambiguity related to adherence to rehabilitation regimens in stroke patients has been discussed in this study but further studies are required on the recognition of this concept in stroke rehabilitation. By understanding this concept, nurses and other healthcare providers can plan better rehabilitation treatment programs for stroke patients, which lead to patients being more coordinated and aligned with their rehabilitation team members. There were a limited number of articles on adherence and clarifying this concept in stroke patients. Further studies in stroke patients using other qualitative concept analysis methods are recommended. The limitation of this concept analysis was the lack of literature that directly defined adherence to rehabilitation regimens in stroke patients as a separate and distinct concept.

Conclusion

This study provided an operational definition of adherence to rehabilitation regimens. It helps clarify the vague concepts that are used in the context of rehabilitation instead of adherence. This concept analysis has identified the attributes, antecedents, and consequences of adherence to rehabilitation regimens using Walker and Avant's model.

The operational definition of this concept reflects the patient's participation in the planned rehabilitation regimen.

Studies regarding concept development of adherence to rehabilitation regimens can help nurses and other stroke rehabilitation teams to understand this concept better and pay attention to this in the rehabilitation process to promote patients' cooperation in this process. Furthermore, it can be helpful for researchers to further study and evaluate rehabilitation adherence in patients with tools that can be developed based on this concept analysis to improve stroke patients' outcomes. Further researches in this regard are necessary.

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Conflicts of interest

Nothing to declare.

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