

Definition of the perceived self-care ability in stroke survivors living at home in the Middle East : a protocol for a Systematic Literature Review

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Protocol

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Abstract

Background : A stroke brings about several adverse outcomes so that a stroke patient faces numerous physical, and sensory together with cognitive, and psychological disorders. These disorders influence patients' perceived self-care ability. There is no agreement on what the perceived self-care ability in stroke patients living at home is. Because of various cultures and medical systems, such an ambiguity may be more serious when it comes to the Middle East countries compared to advanced ones. This Systematic Literature Review aims to summarize the literature on this concept and propose a definition which might help similar research on the stroke in the future. **Methods :** The databases PubMed, Scopus, CINAHL, PsycINFO, PEDro, Web of Science, ProQuest, ScienceDirect, Index Medicus, EMRO, Google Scholar, Magiran, SID, IranDoc, and the stroke-related literature will individually be queried to retrieve related literature on the perceived self-care ability in stroke patients, using subject headings and appropriate MeSH terms. The inclusion and exclusion criteria will be developed and refined by the research team. Two independent reviewers will participate in each search stage including abstract/title and full-text screening, study selection, data collection, or quality assessment steps. We will restrict our search to articles published in the English language in biomedical journals since 1970 to 2018. The result will be tabulated, and meta-synthesis will be performed. **Discussion:** The results of this systematic literature review can present a more accurate definition of perceived self-care ability in stroke patients living at home in Middle East countries. **Systematic review registration:** CRD42018100520 **Keywords:** Perceived Self-care Ability, Stroke, Home, Systematic Literature Review, Definition, Middle East

Background

The perceived self-care ability is a dynamic, complicated, and multidimensional concept [1-5]. Being able to take care of oneself implies that the individual can understand the disease and knows how to manage it. Management refers to what patients do daily. Self-care comprises the activities and actions carried out by patients on their own [6].

Stroke is one of the most common causes of long term disability worldwide. It is a global health-care problem that affects about 16 million people [7]. During the past decades, there has been an increase in stroke incidence and mortality rates in the Middle East (ME) [8]. According to the National Geographic Atlas of the Middle East (2003) [9], the ME countries include Egypt, Iran, Turkey, Iraq, Saudi Arabia, Yemen, Syria, United Arab Emirates, Jordan, Lebanon, Oman, Kuwait, Qatar, Bahrain, Cyprus, and the State of Palestine. Therefore, this paper aims to review data on the perceived self-care ability in stroke patients living at home in the mentioned countries and compare them with ones in developed countries.

Stroke is a leading public health problem causing significant disability and premature mortality, particularly in low-and-middle-income countries [10].

According to the World Bank, the majority of countries in the ME region are classified as low-income states. Hence, it is predicted that complications arising from disability caused by chronic diseases such

as stroke are more prevalent in these areas. Extensive research on the topic of self-care in patients in the acute and chronic phases of stroke have been carried out in developed and high-income countries; thus, it seems that such studies have seldom been conducted in the ME region, and therefore, poses a significant knowledge gap regarding the subject.

In recent years, numerous epidemiological studies have been carried out in the Middle East and North Africa (MENA) regions on stroke and other chronic diseases such as diabetes [8-10]. Nonetheless, there is an evident shortage of studies on the concept of the perceived self-care ability in stroke survivors living at home, and such studies have briefly mentioned the concept and or utilized similar concepts [11]. In this section, it is attempted to reference the studies conducted in developed countries and outside of the ME region, which have briefly addressed the concept of the perceived self-care ability in stroke patients living at home.

Dale established the understanding and definitions of the concept of self-care are different based on theoretical, philosophical, and professional perspectives and approaches[12]. In Orem's theory, for example, self-care was defined as a function or activity the individual initiates and conducts to maintain his/her life, health, and well-being [13]. There are some similarities, overlaps, and differences between the concept of the perceived self-care ability and other concepts such as self-management, self-monitoring, self-efficacy, self-confidence, self-care maintenance, supportive self-management, self-maintenance, disease management, and symptom management, which make such concepts interchangeable [14]. Over time, self-care and its related concepts have evolved, and somewhat different definitions have been proposed based on different priorities of the field vis-à-vis the provision of health, therapeutic, and care services [6]. However, the multiplicity of definitions has led to some misinterpretations, and thus, there is an ever-growing need to identify and present these concepts.

The perceived self-care ability is derived from the concept of self-care. Sidani conducted a concept analysis to develop and validate the criteria for self-care ability measurement in patients in acute conditions. She emphasized the literature on self-care focuses on the acute care context and explicitly mentioned the necessity of analyzing this concept in patients suffering from chronic diseases [4]. Riegel expressed his ideas about self-care and stated self-care education and support should be addressed as a significant consideration of the healthcare system. However, the complexity of conceptualizing and employing the results of this concept in health clinics has led to less attention to self-care by physicians and other members of the health team. As a result, physicians do not emphasize on self-care, and the vast majority of people with chronic illnesses do not exhibit appropriate self-care behaviors, thereby they jeopardize their health condition and quality of life [14].

In a systematic review, Jones examined the effects of self-efficacy on post-stroke conditions. They also examined empirical evidence to support self-management interventions based on self-efficacy principles for the survival of patients with stroke. They attempted to offer a clear picture of these concepts despite the lack of adequate literature on the topic [15].

Although recent advances and extensive studies on the methods of caring for patients with stroke have improved their functional outcomes and survival rates [11], evidence indicates that stroke patients have limited participation in daily activities because of incapacitation and dissatisfaction felt by them with their lives after returning home [16-17]. In rehabilitation programs, particular emphasis is placed on physical activities, mobility, self-care to encourage patients to live an active life [18]. Patients with stroke may face limited perceptual functions which affect their self-care ability within five weeks after the occurrence of a stroke [19]. Studies have demonstrated within the first three months after a stroke, some patients may not experience improvement in cognitive functions, which may exert unpleasant effects on the patient's self-care ability. Along with the improvement in perceptual functions, the improvement in cognitive functions such as proper concentration, attention, and function of the upper extremity plays a significant role in maintaining the patient's independence [20].

Currently, for people with chronic diseases and those who must live with them for an extended period, the focus of nursing care is changing from acute care in hospital environments to chronic care at home and mobile aid care outside hospital environments [21]. In the transition from hospitals to home or other care environments, it is imperative for patients to have the ability to care for themselves.

In recent years, many studies have been conducted to explain and analyze the concept of self-care and its associated ideas, which have played an essential role in defining such concepts and differentiating them from other similar ones [1-3, 6, 15, 22-31]. For example, in a systematic and integrative literature review by Matarese it was aimed to define the analysis of the self-care concept and other relevant ones along with combine, and integrate them with each other. The results indicated the accurate identification of similarities and differences between the self-care concept and other associated ideas can lead to the more conscious use of such concepts in clinical and research contexts together with formulation of policies in the nursing field. It was also demonstrated identifying the various components of self-care related concepts could lead to the development, design, and use of tools which can accurately and comprehensively measure the dimensions of self-care. Matarese considered self-care as an activity, a capability (capacity), and a process [2].

Thompson introduced the self-efficacy theory as the foundation for developing and interpreting the concept measurement [32]. Godfrey examined the definitions and evolution of the concept of self-care, care by others, and care for others based on research, clinical observations, and industrial policies and approaches. She concluded the concept of self-care and many of its derivatives require an accurate analysis to reach a better clarification [3].

Matarese report was based on a study conducted by Marzband who had analyzed the self-care concept through Islamic sources. The researchers stated in the Islamic culture, self-care has been addressed as a moral necessity and a right so as taking care of oneself as well as doing self-care activities imply the human body has dignity and value as a means for achieving spiritual perfection [2]. Also, this study emphasized on the necessity of identifying the dimensions of the self-care concept, which are influenced by religions [33].

Although some studies have considered a degree of performance dependence on or independence from others as the self-care ability [34], these definitions have been presented, paying no attention to personal perceptions of the patients and the effects of the disease nature on these definitions [6]; therefore, they are not yet complete. Hence, this review will be carried out to fill this critical gap in the definition of the perceived self-care ability in stroke patients living at home in the ME countries compared with its prevalent definition in developed countries so that its findings could be applied as a basis for future research as well as a guidance to other researchers.

While the definitions and status of the perceived self-care ability in stroke patients living at home are unknown among many countries in the Middle East, current studies consider them variant regarding the economy, religion, and culture of the country.

Review Question

1. Which definitions have been proposed for the perceived self-care ability in stroke patients living at home in the Middle East countries?
2. Which definition is more comprehensive and practical?
3. Are there any variations in defining the perceived self-care ability between the Middle East and developed settings?

Methods

Eligibility criteria

In this systematic literature review, the researchers will intend to notice and investigate the findings of case series, cross-sectional, case-control, cohort, qualitative studies, books and review articles given that the studies present at least one definition of the perceived self-care ability. Studies concentrated on animals will be excluded.

Participants

This study will include research projects comprising adult male or female participants all or some of whom are stroke survivors living at home, older than 20 years old. **Setting and time frame**

This systematic literature review will encompass all studies carried out at any health center (for example, conducted at hospitals, nursing centers, nursing homes, community centers, **the** general population, and even patients' homes).

Report characteristics

Only papers in the English language will be included in the review.

Exclusion criteria

An article or report which will be only abstract or summary and its full text will not be available will be excluded.

Information sources

Information resources will comprise the following categories: electronic databases, databases of clinical trials, different types of gray literature, researchers, and authors. Electronic search will be carried out in the following databases: PubMed, Scopus, CINAHL, PsycINFO, PEDro, Web of Science, ProQuest, ScienceDirect, Index Medicus, EMRO, Google Scholar, Magiran, SID, and IranDoc. Medical Subject Headings (MeSH) and popular expressions in the related literature will be used as keywords. The search strategy will be primarily developed and completed in PubMed. Then, the same strategy will be pursued in other databases. Other resources will also be investigated to identify the gray literature. Moreover, a thorough search will be conducted in ProQuest to find relevant theses and dissertations. Seminar abstracts will be studied via Scopus, Web of Science, and other related websites. The reference lists of published papers and systematic reviews and tables of key journal contents on this topic will also be investigated. The review will include studies conducted/published from 1970 to 2018 in order to track general trends in the definition of the perceived self-care ability in various periods.

Search strategy

Our initial search syntax for PubMed will be (Self-perceived [tiab] OR self-perceived [tiab] OR (perceived AND self) [tiab] OR "perception") [tiab] AND (ability [tiab] OR abilities [tiab] OR talent) [tiab] AND (selfcare [tiab] OR self-care [tiab] OR (care AND self) [tiab] OR self-management [tiab] OR "self-management" [tiab] OR "self-administration" [tiab] OR self-administration [tiab] OR "self-monitoring" [tiab] OR self-monitoring [tiab] OR "self-medication" [tiab] OR self-medication [tiab] OR self-reporting [tiab] OR self-reporting [tiab] OR "activity daily living" [tiab] OR "self-care agent" [tiab] OR "self" [tiab] OR "care" [tiab] OR "ability" [tiab] OR performance) [tiab] AND (stroke [tiab] OR cerebrovascular accident "[tiab] OR CVA [tiab] OR "cerebrovascular accident" [tiab] OR "cerebrovascular apoplexy" [tiab] OR (apoplexy AND cerebrovascular) [tiab] OR cerebrovascular stroke [tiab] OR (stroke AND cerebrovascular) [tiab]] OR apoplexy [tiab] OR "cerebral stroke" [tiab] OR (stroke AND cerebral) [tiab] OR "acute stroke" [tiab] OR (stroke AND acute) [tiab] OR (cerebrovascular accident AND acute) [tiab] OR "acute cerebrovascular accident" [tiab] OR (cerebrovascular accident AND acute) [tiab] OR "acute cerebrovascular accident" [tiab] OR "brain vascular accident" [tiab] OR (vascular accident AND brain) [tiab] AND (1970/01/01:2018/12/31[dp] AND (((((((((((((((Iran) OR Bahrain) OR Iraq) OR Oman) OR United Arab Emirates) OR UAE) OR Qatar) OR Saudi Arabia) OR KSA) OR Syria) OR Lebanon) OR Yemen) OR Palestine) OR Egypt) OR Jordan) OR Turkey) OR Cyprus) OR Kuwait) (Additional File 1).

Selection process

The search process will be completed using the appropriate syntax developed in PubMed, then, duplicate articles will be omitted. Two members of the research team will independently review the titles and abstracts of the articles to evaluate their eligibility. The references will be categorized into three groups:

“relevant,” “irrelevant,” and “uncertain” subcategories. Then, two researchers will independently review the full text of all the references under the “relevant” and the “uncertain” categories based on inclusion criteria. Any disagreement will be noticed and resolved through discussion among these two researchers so as to achieve consensus. If they could not reach any consensus, a third researcher of the research team will arbitrate. Also, if multiple reports of a study will be identified, they will be considered as one study but reference will be made to all the publications. If any discrepancies are found between these multiple reports, they will be marked to contact the authors for clarification.

Data extraction and data management

The two researchers will independently extract the related data from the collected papers, which will subsequently be recorded in data sheets. A third party will review the two data sheets. Possible disagreements between the two researchers will be discussed with the whole team. If no solution is obtained, the researchers will contact the authors of the paper to make the final decision (Additional file 2).

The following information will be collected from each paper: author(s), year of publication, journal title, format (summary or journal paper), design and setting, country, study objective(s), theory and/or hypothesis, definitions of the perceived self-care ability, instruments for data collection, samples' demographic information (age, gender, etc.), type of participants, sample size, geographical domain, and time of data collection.

Risk of bias in individual studies

Risk of bias analysis will involve the exploration of limitations and appropriateness of study methods in addressing the research questions and objectives, and how they inform outcomes. Notably, studies will be critically assessed for their design, data collection and analysis methods, selection bias, integrity, confounders, attrition, and reporting. Thereafter, we will categorize and summarize the findings as uncertain, high, or low [35].

Also, the quasi-experiments, and systematic reviews will be assessed by risk of bias in non-randomized studies of the intervention tool (ROBINIS-I) [36]. In addition, Qualitative Assessment and Review Instrument will be used for appraising qualitative studies [37]. This step will independently be conducted by two members of the research team.

Data synthesis

In this study, data will be analyzed through a narrative approach, specifically thematic synthesis. The analysis will comprise two phases. For the first question of this review, we will present the domains of the perceived self-care ability definitions in stroke patients living at home in the Middle East Countries. Finally, we will report various definitions of the perceived self-care ability into a table based on their importance and the degree of satisfaction which will be determined considering the quality of studies and reliability of their results. For the other questions of this review, the thematic analysis will be used and it

will comprise three phases. First, each article will be considered as a unit of analysis and will be read several times by a member of the research team to understand the general meaning lied behind data. The words, sentences, or phrase related to the perceived self-care ability will be identified as a meaning unit considering study objectives. The primary codes will be developed from the meaning unit and will be checked by a second researcher. The research team will make the final decision if there is disagreement in coding. In the second stage of the analysis, the primary codes will be categorized into more definite categories or subcategories based on similarities and differences. Finally, themes will be extracted with regard to the underlying meanings in the studies . The themes will be entered into the columns and the codes will be entered into the rows of a table. The constant comparison of data with data and data with codes will be used to facilitate comparison within and between studies. At last, the descriptive and analytical themes will be recorded based on the entire research team agreement. We will share the results with a significant number of international experts to validate them on the basis of the Delphi method. The final report will be prepared relying on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA).

Discussion

The perceived self-care ability is defined in several studies in the form of separate concepts and dispersed components. Nonetheless, there is no single definition of this compound term [2, 4, 38]. A general conclusion from the existing studies indicates this subject (i.e., the definition of the perceived self-care ability concept) has been exposed to various types of heterogeneities due to different foreseeable causes (theoretical, philosophical, and professional approaches, different populations and the nature of the disease, research programs, research designs, and bias) [2].

The results of this systematic literature review can outline the exact meaning of the perceived self-care ability concept in stroke patients living at home. It can also be the basis for the design of subsequent primary or secondary studies. Moreover, it can also play a significant role in enhancing the reliability of evidence in the future.

Strengths and limitations

This systematic literature review will develop a consensus on the definition of the perceived self-care ability, a controversial term in medical articles. Two investigators with an extensive experience in systematic literature review will independently conduct primary screening of the articles, data extraction, and quality assessment to minimize the probability of personal biase. However, the review will not include databases in languages other than English. This limitation may cause language bias.

Abbreviations

ME: the Middle East; MeSH: Medical subject headings; PQDT: The ProQuest Dissertations & Theses Database; PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses; PROSPERO:

International Prospective Register of Systematic Reviews; ROBINIS-I: Risk of bias in non-randomized studies of interventions

Declaration

Declaration

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Authors' contributions

NJG was the primary investigator, carried out the study, and wrote the first draft. **AD** and **MAH** supervised the study and contributed to the writing process. **MFKH** and **AE** were the study advisors. **AD** helped with the preparation of the manuscript and critical revision of the draft. **NJG** and **MAH** contributed to editing the articles. **MR** was the study advisor and contributed to the draft. **SS** contributed to the searching process, manuscript writing and final edition. **AAK** contributed to the searching process, manuscript writing and final edition. All authors read and approved the final manuscript before submission.

Ethics approval and consent to participate

This study is a part of a doctoral thesis titled "Design and psychometrics of the questionnaire for assessment of the perceived self-care ability in stroke patients", approved at the Ethics Committee of the University of Social Welfare and Rehabilitation Sciences under the number IR.USWR.REC.1396.208. The respective results will be presented in scientific and research journals as well as at national and international conferences. No ethics approval was required given that the present study is a systematic review.

Consent for publication

Not applicable.

Competing interests

The authors declare they have no competing interests.

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Supplementary Information

1: The final syntax. (DOC kb) Additional file

2: The schematic presentation of the selection process of articles for the final systematic review. (DOC kb)

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