A literature review on self-care of chronic illness: definition, assessment and related outcomes

Una revisione della letteratura sul self-care nelle malattie croniche: definizione, valutazione e outcomes associati

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ABSTRACT

Introduction. Chronic illnesses care represents a challenging issue for people well-being and future health systems' sustainability. Promotion of self-care is considered a key point for chronically ill patients' care. The aim of this literature review was to explore: how self-care of chronic illness has been theoretically defined; how self-care can be assessed in clinical and research settings; what associations exist between self-care and health outcomes of chronically ill patients. **Results.** A wide range of definitions and terminologies related to self-care of chronic illness has been found in the literature. Although some common elements useful to explain the concept of self-care have been identified, the physical, cognitive, emotional and social processes underlying self-care remain controversial and poorly defined. Valid and reliable disease-specific assessment tools have been developed and used in a growing number of studies; however, the lack of utilization of standardized instruments in clinical practice has been referred by many authors. Significant correlations between self-care of chronic illness and outcome measures e.g. general health status, quality of life and healthcare costs, are reported by a limited number of studies. **Conclusions.** Supporting patient self-care is recognized as a crucial factor in chronic illness care. A deeper analysis of variables and processes influencing self-care could help for a full description of the phenomenon. A systematic evaluation of self-care in health professionals' everyday clinical practice is strongly recommended. The development of general non-disease-specific assessment tools could facilitate the evaluation of complex patients, especially those with multiple co-morbidities. Although self-care has been recognized as a vital intermediate outcome, further large-scale studies clarifying the association between self-care and patients' and health systems' outcomes are needed.

Key words: self care, self management, chronic illness, health promotion, nursing assessment, nursing theories, nursing outcomes, patient outcomes

RIASSUNTO

Introduzione. L'assistenza alle persone con malattie croniche rappresenta una sfida per il benessere della popolazione e per la futura sostenibilità dei sistemi sanitari. La promozione del self-care è considerata un aspetto chiave dell'assistenza ai malati cronici. Lo scopo di questa revisione della letteratura è stato quello di esplorare: come il self-care nelle malattie croniche è stato definito dal punto di vista teorico; come il self-care può essere valutato nella pratica clinica e nella ricerca; quali associazioni esistono tra il livello di self-care e i risultati di salute dei pazienti con malattie croniche. **Risultati.** In letteratura si è riscontrata un'ampia gamma di definizioni e terminologie connesse con il self-care nelle malattie croniche. Sebbene nei diversi approcci siano stati identificati alcuni elementi comuni utili a spiegare il concetto di self-care, le variabili fisiche, cognitive, emotive e socioculturali sottese al self-care nelle malattie croniche risultano controverse e scarsamente definite. Un crescente numero di studi ha sviluppato o impiegato strumenti di valutazione del self-care validi ed affidabili per una specifica malattia cronica; tuttavia molti autori riportano la mancanza di utilizzo di strumenti di valutazione nella pratica clinica standard. Un numero limitato di studi ha mostrato delle correlazioni significative tra il self-care nelle malattie croniche e alcune misure di risultato come lo stato generale di salute, la qualità di vita e i costi dell'assistenza sanitaria. **Conclusioni.** Favorire lo sviluppo del self-care è riconosciuto come un aspetto cruciale dell'assistenza ai malati cronici. Un'analisi più approfondita delle variabili e dei processi che influenzano il self-care potrebbe contribuire ad una più completa descrizione di questo fenomeno. La valutazione sistematica del self-care nella pratica clinica dei professionisti sanitari è fortemente raccomandata. Lo sviluppo di strumenti generali e non specifici per singola malattia potrebbe facilitare la valutazione dei malati complessi, specialmente in presenza di comorbidità multiple. Sebbene il self-care sia definito come un outcome intermedio vitale per i malati cronici, sono necessarie delle ulteriori ricerche su larga scala allo scopo di chiarire l'associazione tra il self-care e i risultati dei pazienti e dei sistemi sanitari.

Parole chiave: self-care, self-management, malattie croniche, promozione della salute, valutazione infermieristica, teorie infermieristiche, risultati infermieristici, risultati dei pazienti.

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INTRODUCTION

Chronic illnesses are a burden for global health and represent one of the main expenditures for healthcare organizations all over the world (WHO, 2010; European Observatory on Health Systems and Policies, 2010; ISTAT, 2008; CDC, 2005; Department of Health, 2005a). Choice, respon-

sibility, empowerment and participation are considered key principles in chronic illness management and available reports suggest that future health systems' sustainability will mainly depend on people's ability to self-manage their chronic conditions (Regione Lombardia, 2014; Newman, Tonkens, 2011; Ministero della Salute, 2011; Department of Health, 2005b; Wanless, 2002).

Chronically ill patients need to implement a range of specific behaviors in order to adhere to complex therapeutic regimes, to maintain well-being and quality of life over time, to control risks, to manage disease symptoms and to reduce the incidence of complications (World Health Organization, 2008 and 2005). All these behaviors, requiring motivation, experience and skills, have been referred by many authors to the concept of self-care (Baumann, Dang, 2012; Ryan, Sawin, 2009; Hoy et al., 2006; Wilson, Mayor, 2006). Several studies observed that chronically ill patients show low levels of self-care ability in recognizing and managing their symptoms, in taking drug therapies and performing recommended behaviours including diet or exercise. (Gallagher, 2010; Schnell-Hoehn et al., 2009; Lerman, 2005; Department of Health, 2005c; Artinian et al., 2002; Carlson et al., 2001). Therefore, self-care promotion represents a relevant issue in chronic illness care both for research and clinical practice. In order to understand factors affecting self-care of chronically ill patients and to implement effective self-care promoting interventions, several authors underline the relevance of the following three issues. First, the development of chronic illnesses self-care theories is strongly required in order to explain the meaning of self-care and to guide self-care promotion programs in clinical practice (Ryan, Sawin, 2009; Schilling et al., 2002). Secondly, valid and reliable self-care assessment tools are needed in order to help professionals to determine individual's self-care abilities, to provide focused health education interventions and to monitor patients' behavior changes over time (Costantini et al., 2011; Pulignano et al., 2010; Hibbard et al., 2005). Finally, documented associations between self-care behaviors and patients' outcomes could contribute to develop effective health policies and clinical services' organization for chronic illness care (Sidani, 2011).

The aim of this scoping review was to explore: how self-care of chronic illness has been theoretically defined; how self-care can be assessed in clinical and research settings; what relationships exist between self-care and health outcomes of chronically ill patients.

METHODS

Nursing, medical and psychological literature published until January 2013 was searched using main scientific databases (MedLine, Cochrane Library, CINAHL, Psychinfo and Italian Nursing Literature Database). The search was performed both by free text and by MESH terms, where existing. Some used keywords were: self-care, chronic disease, assessment, theory, outcomes. Synonyms or alternative terms of main keywords were included using boolean operators. References of retrieved papers were checked and taken into account if relevant to the aim of the study. Monographs and books were also considered and retrieved when possible as well as position papers and documents published by authoritative associations or scientific societies. Papers were excluded if: self-care was a secondary or minor topic; self-care was considered within too specific clinical specialities like mental health or maternal, child and adolescents care; the language was not English or Italian; the quality of publication, evaluated through pre-defined critical appraisal criteria was uncertain or poor (JBI, 2011).

RESULTS

1. Self-care of chronic illnesses: definitions and terminologies.

Published analyses of the historical evolution of the concept of self-care showed a lack of consensus on definitions and terminologies (Ryan, Sawin, 2009; Hoy et al., 2007; Lorig, Holman, 2003). Terms like self-care, self-management, self-regulation, self-monitoring, self-efficacy, adherence, are often used interchangeably and a clear definition of this terms is not fully provided (Riegel, Dickson, 2008).

In the 70's the American psychologist Thomas Creer introduced the term "self-management" to indicate the active participation of the patient in chronic treatments (Lorig&Holman, 2003; Creer et al., 1976). Dorothea Orem built a nursing theory based on the concept of "self-care" defined as "the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health and well-being" (Orem, 1971). Levin and Idler (1983) referred to "self-care" as those activities undertaken in promoting health, preventing disease, limiting illness and restoring health. Even if these terms have been used for several years within the healthcare literature, a low level of agreement has been found about their meaning and implication for practice. Some authors suggest to interpret "self-care" as a preventive strategy performed by healthy people, while "self-management" should indicate one's ability to manage specific problems due to chronic conditions (Ryan, Sawin, 2009; Barlow et al., 2002). More recently other authors focused on the concepts of "self-help", "activation" and "patient engagement" to highlight the active role of the patient into the healthcare team (Braden, 1990; Hibbard et al., 2004; Hochhalter et al., 2010). Grey in 2006 was the first author to write about "self- and family-management"; more recently a middle range theory defined three key dimensions of self-care in chronic illness: self-care maintenance, self-care monitoring and self-care management (Riegel et al., 2012). A summary of the main terms and definitions has been reported in **Table 1** to give an overview of the complexity of the literature on this topic.

Seven conceptualizations further analyzed how self-care has been theoretically defined in healthcare literature. One of these models has a medical and psychological background (Hill-Briggs, 2003); the other ones consisted in nursing theories (Riegel et al., 2012; Ryan, Sawin, 2009; Riegel, Dickson, 2008; Grey et al., 2006; Burks, 1999; Braden, 1993). All the analyzed conceptualizations suggest different processes underlying self-care: Hill-Briggs (2003) focused primarily on problem-solving process, Ryan and Sawin (2009) focused on interactions between chronically ill patient and social environment, Braden (1993) focused on enabling skills owned by patients to perform self-help and to maintain health. Riegel and colleagues (2012) pointed that "the elements of self-care have not been specified in a middle-range theory that can be used across a variety of chronic conditions" and proposed a theoretical framework to explain

TERMS	DEFINITION	REFERENCES
self-care	A process through which people take responsibility for their own health understanding how to promote it and what can damage it. This health development process is performed in everyday life by individuals in order to maintain life, health and well-being through the practice of healthy behaviors and activities. It refers to one's potential to address needs, goals and health issues to improve functional ability, indipendence and satisfaction and to prevent dysfunction, disability and pain.	Orem (1971), Levin (1979), Hoy et al. (2006), Riegel et al. (2012).
self-management	An active, daily and flexible process in which individuals perform activities directed to a specific goal, modulating thoughts, emotions, decisions and behaviors through use of learned mechanisms and skills. Adapted to chronic illnesses, it refers to the process in which patients take responsibility and decision making for achieving disease control, health and well-being through a wild range of illness-related activities: recognizing symptoms, adhering to treatments, managing physical and psychosocial consequences and lifestyle changes due to their specific condition.	Creer et al. (1976), Riegel et al. (2000), Barlow et al. (2002), Schilling et al. (2002), Lorig&Holman (2003), Riegel&Dickson (2008), Ryan&Sawin (2009).
self-help	An informed process of facing definable, manageable adversities by maintaining control of everyday problems.	Braden (1993).
activation	Knowledge, beliefs and skills that a consumer needs to successfully manage when living with a chronic disease.	Hibbard et al. (2004).
self- and family management	A multidimensional, dynamic and complex phenomenon, involving chronically ill patients and their families, in which the process of self-management is modulated by the unique characteristics of individuals and family members. The physical and social environment may include condition specific risks and protective factors (knowledge and beliefs, self-regulation skills, social facilitations) that influence the functioning of individuals and of social groups in which they live.	Grey et al. (2006), Ryan&Sawin (2009).
self-care agency	The pool of individuals' acquired ability to plan and execute self-care activities on their own in order to maintain life and promote health and well-being. The concept of self-care agency differs from self-care that means the actual performance of self-care activities.	Orem (1971), Sousa et al. (2008).
self-care maintenance	Those behaviors used by patients with a chronic illness to maintain physical and emotional stability.	Riegel et al. (2012)
self-care monitoring	The process of observing oneself for changes in signs and symptoms; it is the link between self-care maintenance and self-care management.	Riegel et al. (2012)
self-care management	The response to signs and symptoms when they occur.	Riegel et al. (2012)
adherence	The extent to which a person's behavior in terms of taking medications, following diet or executing lifestyle changes corresponds with agreed recommendations from health care providers. It is an essential component of self-care maintenance whose achievement depends from the degree of collaboration between professionals and patients in negotiating the adoption of behaviors that the patient can tolerate and accept.	Lorig&Holman (2003), WHO (2003), Lerman (2005), Grey et al. (2006), Riegel et al. (2012).
self-efficacy	One's confidence in her or his ability in taking a specific action aimed to obtain a desired outcome and in persisting in that action despite obstacles or challenges. It is the sense of personal control over desired changes or the belief that an individual can accomplish a specific behavior. It is composed by self-efficacy expectations (person's perceived ability to perform a specific behavior) and outcome expectations (beliefs about whether a specific behavior will cause a certain outcome). Adapted to self-management, self-efficacy reflects the belief of patient capability to organize and integrate physical, social and emotional self-care behaviors to create their own solutions to everyday life problems.	Bandura (1977), Bandura (2004), Risser et al. (2007), Riegel&Dickson (2008), Du&Yuan (2010), Yoo et al. (2011).

Table 1: Main self-care related terms and their definitions in the literature.

self-care of chronically ill patients. A clear theoretical and operational definition of self-care key concepts has been provided by authors based on a large research experience on self-care in chronic heart failure. Furthermore, clear definitions of processes underlying self-care and factors affecting self-care could be found in this middle range theory. Decision making abilities and reflection were considered as processes underlying people self-care. Experience, skills, motivation, confidence, habits, functional and cognitive abilities represented some factors affecting patients' self-care as defined by the authors (Riegel et al., 2012).

Despite this plurality of terms and definitions, some elements were found to be common within analysed papers: complexity of chronic illness, knowledge, skills, self-efficacy, problem solving and adherence were found to be mentioned regarding patients' behaviours and characteristics. Social context and healthcare providers' role and availability were mentioned about the external context in which self-care should be achieved. A synthesis of these common elements, as they are defined in considered conceptualization, can be found in **Table 2**. About the external context, all these retrieved theories underlined the contribution of nursing and nurses in assessing and promoting self-care in chronic illness; one conceptualization in addiction to nurses and health care providers, pointed the important role and responsibility of the family, friendship network and community (Ryan, Sawin, 2009).

Lastly, only two theories have been verified in clinical settings through several empirical studies and used by many researchers as theoretical background when investigating

ELEMENTS	DESCRIPTION	THEORIES
Problem parameters	"Basic conditioning factors" serving as barriers and facilitators may affect the need and the efficacy of self-care, representing an essential part of nurse's assessment. These factors are : - individual factors like age, educational level, ethnic and cultural background, past experiences, beliefs, habits and values that may affect patient's approach to self-care and influence her or his perception of health; - environmental factors like families' socio-economic status, characteristics of the healthcare system and of the community in which the patient lives (place of residence, school, workplace); - factors related to health status like the complexity of illness and treatment regimens determining functional and cognitive deficits.	Grey et al. (2006) Burks (1999) Riegel et al. (2012) Braden (1993 Riegel&Dickson (2008) Hill-Briggs (2003) Ryan&Sawin (2009)
Knowledge and skills	A learned set of behaviors, cognitions, affects and beliefs allow the person to manage her health, not being overwhelmed by severity of illness, uncertainty and dependency, and maintaining hope and optimism. Knowledge acquisition should be a reasoned and reflective process: patients should develop approaches to become reflective and purposive about their self-care.	Braden (1993) Riegel et al. (2012) Riegel&Dickson (2008) Hill-Briggs (2003) Ryan&Sawin (2009)
Self-efficacy	Psychosocial characteristic of chronically ill patients are an essential component of self-care process because they represent the force driving persons to achieve their goals. Self-efficacy influences the choices made, the efforts expended, the actions taken and perceverance in the face of obstacles or failures in self-care. It has been seen as a mediator of the relationship between self-care and outcomes.	Riegel et al. (2012) Grey et al. (2006) Riegel&Dickson (2008) Chenoweth et al. (2008)
Decision making process	People exhibiting an active response to health difficulties can better seek solutions to problems by themselves. This response can be made implementing a problem solving process that is a construct used for conceptualizing and understanding the complex nature of chronic illness self-management. This classical, analytical and systematic problem solving method is rarely used by patients: they adopt a naturalistic decision making process in order to produce automatic, impulsive and contextual decisions in everyday situations. Assessment, planning, performance and continuous evaluation of self-care actions and situations are vital parts of self-care process that develop from the collaboration between the patient and the nurse.	Hill-Briggs (2003) Riegel et al. (2012) Burks (1999) Riegel&Dickson (2008) Braden (1993)
Social support	Chronically ill patients should receive contributions from relatives, neighbors, colleagues and friends in a process of "shared care". The families variables of closeness, caregiver coping skills, mutually supportive family relationships, clear family organization, and direct communication about the illness and its management are linked with better family and individual outcomes.	Riegel et al. (2012) Grey (2006) Riegel&Dickson (2008)
Professional support	When health needs overwhelm patient's self-care agency, there's a deficit of self-care so that the individual may need nursing interventions. Nurses and other team members help patients in evaluating conditions and planning self-care behaviors, but their role is to relinquish control of the client allowing him or her to act on his or her own. By understanding the dynamics of patients' reactions to chronic health problems, nurses would be better able to improve health and well-being, to promote indipendence, to prevent complications and to reduce health care costs.	Riegel et al. (2012) Burks (1999) Braden (1993)
Outcomes	Outcomes have been intended as the last dimension of self-care process. Early outcomes consist in actual engagement in healthy behaviours, symptom management and adherence to therapies; the long term outcomes are health status, quality of life and healthcare costs. Self-care itself has been suggested to be not only the process of managing one's condition, but also a major outcome of that process: maximizing the person's abilities in taking place in everyday activities despite the illness is a fundamental goal of health care.	Ryan&Sawin (2009) Riegel et al. (2012) Braden (1993)

Table 2. Common elements underlying self-care in analyzed theories.

patients' self-care (Riegel, Dickson, 2008; LeFort, 2000). According to Sidani (2011) "research on self-care has been hampered by a lack of consistent conceptualization which has resulted in variability in its operationalization and in a lack of well-established, reliable and valid instruments to measure self care". This issue will be further discussed in the next paragraph.

2. Self-care of chronic illnesses: assessment tools.

Several instruments assessing self-care in different chronic conditions can be found in the literature (Brady 2011, Sidani 2003, 2012; Cameron et al., 2009; Grey et al., 2006; Schilling et al., 2002). However, information on theoretical grounding, validity and reliability of these tools, were often fragmented and in many cases it was difficult to identify and retrieve papers reporting exhaustive empirical data. According to Sidani (2003), "the expected self-care behaviors vary across patient populations and across self-care settings" so that in most cases each measure has been developed and used in a single study for contingent and practical needs, instead of being derived from self-care theories.

Consequently, a lack of validation data was observed especially for non disease-specific assessment tools. However, we found a limited number of instruments assessing self-care which fully reported validity and reliability measures. Two of them, both developed by English-speaking teams of physicians, are general not disease-specific tools and aim to assess self-care in all chronic conditions (Hibbard et al., 2004; Petkov et al., 2010). Three other scales, proposed by American and European nurses, are specific for chronic heart failure (Riegel et al., 2004 and 2000; Jaarsma et al., 2009 and 2002). Another instrument measuring self-care in diabetic adults was developed by a team of psychologists (Toobert et al., 2000). The last one, designed by a Canadian team of nephrology nurses, is specific for adults on dialysis and it has been tested for validity but not for reliability (Costantini et al., 2011).

All these self-care measures investigate common domains including knowledge, healthy behaviours, management of illness, self-efficacy, collaboration with professionals and spirit of adaptability. Some examples of these common elements are reported in **Table 3.**

Other instruments focused on self-efficacy in chronically ill patients (Du, Yuan, 2010). Brady (2011) reported that some of them are widely used for the evaluation of the effectiveness of self-management interventions. One of these tools was not condition-specific (Lev, Owen, 1996); the others were developed specifically to measure self-efficacy in chronic pain (Nicholas, 2007), in medication adherence (Risser et al., 2007) and in fatigue (Hoffman et al., 2011). This kind of tools aimed to measure confidence in one's ability to cope with anxiety and stress, to make decisions regarding treatment alternatives and to enjoy life despite illness.

Finally, a range of tools were designed to describe self-care agency; as shown by Sidani (2011) we found that "the empirical evidence on the psychometric properties of self-care agency measures is rather limited"; however examples of self-care agency measures which reported good reliability and validity indexes were found (Sousa et al., 2010 and 2008).

Analyzed tools were mostly self-administered, self-report questionnaires, structured as Likert scales; some of them proved to be robust in direct interview or telephone administration too (Riegel et al., 2009). Only one of them allowed the caregiver to perform the evaluation; this one was specific for parents of children with diabetes (Harris et al., 2000).

A summary of the investigated variables, study population, validity and reliability measures of some robust self-care related assessment tools is provided in **Table 4.**

Despite the availability of a growing number of standardized tools, many authors reported a lack of systematic evaluations of self-care in clinical settings recommending the implementation of a valid and reliable tool in clinical practice (Costantini et al., 2011; Battersby et al., 2010; Schilling et al., 2002).

3. Self-care of chronic illnesses: self-care ability and related outcomes.

Promotion of self-care represents a valid approach to improve well-being and quality of life of chronically ill

DOMAIN	EXAMPLE ITEMS FROM SELECTED TOOLS
Knowledge and skills about chronic condition, treatments, signs and symptoms.	"If I take a new medication, I obtain information about the side effects to better care for myself" (Sousa et al., 2008)
Adoption of self-care behaviours like compliance to diet, drug therapies and exercise.	"On how many of the last seven days did you test your blood sugar?" (Toobert et al., 2000)
Management of illness: recognizing and evaluating signs and symptoms, implementing treatments.	"The last time you had shortness of breath, how quickly did you recognize it as a symptom of heart failure?" (Riegel et al., 2000)
Self-efficacy (or confidence in self-care ability).	"How confident are you that you can do something that will relieve your symptoms?" (Riegel et al., 2004)
Active collaboration in decision making with the health professionals.	"If I experience increased fatigue, I contact my doctor or nurse" (Jaarsma et al., 2002)
Spirit of adaptability.	"I try to find the ways that make my life as normal as possible" (Costantini et al., 2011)

Table 3. Common domains investigated by analyzed tools assessing self-care and some selected example items.

CHARACTERISTICS OF THE STUDY			RELIABILITY			VALIDITY		
measured variable	population	measurement tool (reference)	internal consistency	test-retest reliability	interrater reliability*	content validity	criterion validity	construct validity
self-care	dialysis	Costantini, 2011				•		
	chronic heart failure	Riegel, 2004	0.76			•		•
	chronic heart failure	Jaarsma, 2002	0.81			•		•
self-management	chronic illnesses	Petkov, 2010	0.82			•		•
	chronic heart failure	Riegel, 2000	0,79 / 0,92			•		•
	diabetes	Toobert, 2000	0.47	0.4		•	•	
activation	chronic illnesses	Hibbard, 2004	0.85	0.93		•	•	•
self-care agency	chronic illnesses	Sousa, 2008	0.9			•	•	•
self-efficacy	chronically ill patients with fatigue	Hoffman, 2011	0.92			•		•
	chronic pain	Nicholas, 2007	0.92	0.73		•	•	•
	chronic illnesses	Risser, 2007	0.9	0.62		•	•	•
	chronic illnesses	Lev, 1996	0.93	0.94		•	•	•

Table 4. Investigated variables, population of interest, validity and reliability data of some self-care and self-care related assessment tools found in the literature.

patients (Howard, Ceci 2012; European Observatory on Health Systems and Policies, 2010; World Health Organization, 2005).

Several educational interventions and programs have been developed worldwide in order to enable patients to assume a primary role in managing their condition and undertaking self-care behaviours.

Although the existence of conflicting data about the effectiveness of such interventions on long-term self-management (Jerant et al. 2009; Chodosh et al., 2005), several observational studies and systematic reviews suggest that these programs are effective to improve healthy behaviors, self-efficacy and perceived health status and to reduce re-hospitalization (Packer et al., 2011; Driscoll et al., 2009; Evangelista, Shinnick, 2008; Jerant et al., 2008; McAlister et al., 2004; Lorig et al., 2003). While studies on nursing educational interventions and adherence to healthy are numerous in the literature (Sidani, 2003), few studies measured directly the relationships between levels of self-care in individuals and health outcomes such as quality of life, pain or other symptoms. (Cramm, Nieboer, 2012; Lee et al., 2007) No studies investigating as primary objective the effect of self-care behaviors on single patients' and healthcare systems' outcomes were found in the literature (Sidani, 2003). However, retrieved studies showed through secondary analysis that good levels of self-care are positively correlated to general health status and quality of life and negatively correlated to pain, disability and costs; Cramm, Nieboer (2012), Mosen et al.(2007), Hibbard et al. (2004) and LeFort (2000) showed statistically significant correlations between self-care levels and health outcomes, as showed in **Table 5.**

In addiction Harris et al. (2000) found an association between self-management abilities and glycated haemoglobin in diabetic children showing the influence of self-care on the metabolic control of diabetes. Lee et al. (2007) reported that self-care in chronic heart failure hospitalized patients was inversely associated to costs due to hospitalizations suggesting that high levels of self-care can improve patients' and organizations' outcomes. The same authors found statistically significant associations between self-care and self-confidence and several stuides identify self-efficacy as a key factor to improve self-care behaviours enhancing health outcomes and reducing physical and psychological symptoms (Riegel et al., 2012; Borsbo et al., 2010; Lev, Owen, 1996; Yoo et al., 2011).

Although analyzed publications support the role of self-care in promoting outcomes and reducing the economic

CHARACTERISTICS OF THE STUDY			OUTCOMES MEASURES											
main variable	reference	population	perceived health	psychological well-being	quality of life	self-efficacy	pain and other symptoms	disability	vital signs	healthy behaviors	medication adherence	communication with health professionals	healthcare services utilization	costs
self-care	Lee, 2007	chronic heart failure				+				+				-
activation	Hibbard, 2004	chronic illnesses	+										-	
	Mosen, 2006	chronic illnesses	+		+			-		+	+			
self-help	LeFort, 2000	chronic pain			+	+	-	-		+				
self-management	Cramm, 2012	chronic illnesses	+				-			+				
	Harris, 2000	diabetes			+				+	+				
self-efficacy	Lev, 1996	chronic kidney disease and cancer		+	+	+	-							
	Borsbo, 2010	chronic pain	+	+	+	+	-	-						
	Yoo, 2011	chronic illnesses	+			+	-			+		+		

Table 5. Associations between self-care and outcomes: synthesis of results from analyzed studies. Relationships between the main variable and outcomes measures are indicated with + (if directly proportioned) or - (if inversely).

impact of chronic illnesses, available results are limited and adopted research designs (mostly cross-sectional) do not allow to infer causality.

Furthermore, convenience sampling and the use of self-reported methods to describe main study variables represent some of the limitations reported by authors. For these reasons, the need of large analytic epidemiological trials has been reported by authors in order to clarify associations between patients' self-care and achieved health outcomes (Yoo et al., 2011).

CONCLUSIONS

Self-care of chronic illness has been studied since the 70's and the literature on this topic is broad and complex to analyze. The present contribution, far to be exhaustive, represents just an overview of three large and relevant areas of inquiry concerning self-care in chronic illness. However, based on analyzed literature we could draw the following conclusions in order to encourage further reflections and developments on this field.

Self-care has been differently defined in the literature but a recent middle-range theory clarified key concepts about self-care of chronic illness and related social and psychological processes (Riegel et. al., 2012). However, physical, cognitive and social processes underlying self-care – as much as relationships between these concepts – appear to be conflicting and fragmented in the literature, confirming results of previous publications (Hoy et al., 2006). A deeper analysis and theoretical definition of processes underlying self-care, starting from the existing theorization (Riegel et al., 2012), could contribute to the full description of the phenomenon. Furthermore, stimulating the use of a common language grounded on existing conceptual framework, could help professionals understanding self-care processes, evaluating patients and communicating clinical information.

Several self-care assessment tools have been developed but few of them were based on explicit theoretical backgrounds and further studies are needed to to improve available evidences of their validity and reliability.

The development of general non-disease-specific assessment tools could facilitate the evaluation of complex patients, especially those with multiple co-morbidities. A systematic evaluation of self-care in clinical practice is strongly recommended in order to identify uncaring behaviours and to address specific and weighted interventions.

Although self-care has been recognized as a vital intermediate outcome, further large-scale studies clarifying the

association between self-care and patients' and health systems' outcomes are strongly needed.

Knowledge and tools about self-care of chronic illness should be disseminated in educational, organizational, research and clinical settings in order to promote self-care assessment and to develop appropriate healthcare interventions to support patients and families living with chronic conditions.

REFERENCES

Artinian N., Magnan M., Sloan M. & Lange M.P. (2002). Self-care behaviors among patients with heart failure. *Heart and Lung*, 31 (3), 161-172.

Bandura A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review,* 84, 191-215.

Bandura A. (2004). Health promotion by social cognitive means. *Health Education & Behavior,*31(2),143-164.

Barlow J., Wright C., Sheasby J., Turner A. & Hainsworth J. (2002). Self-management approaches for people with chronic conditions: a review. *Patient Education and Counseling*, 48, 177-187.

Battersby M., Von Korff M. & Schaefer J. (2010). Twelve Evidence-Based Principles for Implementing Self-Mangement Support in Primary Care. *The Joint Commission Journal on Quality and Patient Safety,* 36 (12), 561-570.

Baumann L.C. & Dang T.T.N. (2012). Helping patients with chronic conditions overcome barriers to self-care. *The Nurse Practitioner,* 37 (3), 33-38.

Borsbo B., Gerdle B. & Peolsson M. (2010). Impact of the interaction between self-efficacy, symptoms and catastrophising on disability, quality of life and health in chronic pain patients. *Disability and Rehabilitation,* 32 (17), 1387-1396.

Braden, C.J. (1990). A test of the self-help model: Learned response to chronic illness experience. *Nursing Research,* 39, 42-47.

Braden, C.J. (1993). Research program on learned response to chronic illness experience: Self-help model. *Holistic Nursing Practice*, 8, 38-44.

Brady T.J. (2011). Measures of Self-Efficacy. *Arthritis Care and Research,* 63 (11), 473-485.

Burks K.J. (1999). A Nursing Practice Model for Chronic Illness. *Rehabilitation Nursing*, 24 (5), 197-200.

Cameron J., Worral-Carter L., Driscoll A. & Stewart S. (2009). Measuring self-care in chronic heart failure. A review of the psychometric properties of clinical instruments. *Journal of Cardiovascular Nursing*, 24 (6), 10-22.

Carlson B., Riegel B. & Moser D. (2001). Self-care abilities of patients with heart failure. *Heart and Lung*, 30 (5), 351-359.

CDC - Centers for Disease Control and Prevention (2005). *Chronic Disease and Health Promotion.* http://www.cdc.gov/chronicdisease/overview/index.htm Ultimo accesso 12-06-2014.

Chodosh, J., Morton, S. C., Mojica, W., Maglione, M., Suttorp, M. J., Hilton, L., Rhodes, S. & Shekelle, P. (2005). Meta-analysis: Chronic Disease Self-Management Programs for Older Adults. *Annals of Internal Medicine*, 143, 427-438.

Costantini L., Beanlands H. & Horsburgh M.E. (2011). Development of the Self-Care for Adults on Dialysis Tool (SCAD). *The CANNT Journal,* 21 (2), 38-43.

Cramm J.M. & Nieboer A.P. (2012). Self-management abilities, physical health and depressive symptoms among patients with cardiovascular diseases, chronic obstructive pulmonary disease, and diabetes. *Patient Education and Counseling*, 87, 411-415.

Creer, T., Renne C. & Christian, W. (1976). Behavioral contributions to rehabilitation and childhood asthma. *Rehabilitation Literature*, 37, 226-232, 247.

Department of Health (2005a). *The expert patient: a new approach to chronic disease management for the 21st century.* http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4006801 Ultimo accesso il 16-06-2014.

Department of Health (2005b). Self-care: a real choice. http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4101702.pdf Ultimo accesso il 16-06-2014.

Department of Health (2005c). Public Attitudes to Self-Care: Baseline Survey. http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4111263.pdf Ultimo accesso il 16-06-2014.

Driscoll, A., Davidson, P., Clark, R., Huang, N., Aho, Z. (2009). Tailoring consumer resources to enhance self-care in chronic heart failure. *Australian Critical Care,* 22, 133-140.

Du S. & Yuan C. (2010). Evaluation of patient self-management outcomes in health care: a systematic review. *International Nursing Review,* 57, 159-167.

European Observatory on Health Systems and Policies (2010). Tackling Chronic Disease in Europe. http://www.euro.who.int/__data/assets/pdf_file/0008/96632/E93736.pdf Ultimo accesso il 16-06-2014.

Evangelista, L.S. & Shinnick, M.A. (2008). What Do We Know About Adherence and Self-care? *Journal of Cardiovascular Nursing*, 23(3), 250-257.

Gallagher R. (2010). Self management, symptom monitoring and associated factors in people with heart failure living in the community. *European Journal of Cardiovascular Nursing*, 9: 153-160.

Grey M., Knafl K. & McCorkle R. (2006). A framework for the study of self- and family management of chronic conditions. Nursing Outlook, 54 (5), 278-286.

Harris M., Wysochi T., Sadler M., Wilkinson K., Harvey L., Buckloh L., Mauras N. & White N. (2000). Validation of a Stractured Interview for the Assessment of Diabetes Self-Management. *Diabetes Care*, 23 (9), 1301-1304.

Hibbard J.H., Mahoney E.R., Stockard J. & Tusler M. (2004). Development of the Patient Activation Measure (PAM): Conceptualizing and Measuring Activation in Patients and Consumers. *Health Services Research,* 39 (4), 1005-1026.

Hibbard J.H., Mahoney H.R., Stockard J. & Tusler M. (2005). Development and testing of a short form of the patient activation measure. *Health Services Research,* 40 (6), 1918-1930.

Hill-Briggs F. (2003) Problem Solving in Diabetes Self-Management: a Model of Chronic Illness Self-Management Behavior. *Annals of Behavioral Medicine*, 25 (3), 182-193.

Hochhalter A.K., Song J., Rush J., Sklar L. & Stevens A. (2010). Making the Most of Your Healthcare intervention for older adults with multiple chronic ilnesses. *Patient Education and Counseling*, 81, 207–213.

Hoffman A.J., von Eye A., Audrey G., Given B.A., Given C.W. & Rothert M. (2011). The Development and Testing of an Instrument for Perceived Self-Efficacy for Fatigue Self-Management. *Cancer Nursing*, 34 (3), 167-175.

Howard L.M. & Ceci C. (2012). Problematizing Health Coaching for Chronic Illness Self-Management. *Nursing Inquiry,* [Epub ahead of print] 1-9.

Hoy B., Wagner L. & Hall E.O.C. (2006). Self-care as a health resource of elders: an integrative review of the concept. *Scandinavian Journal of Caring Science*, 21, 456-466.

ISTAT – Italian Institute of Statistics (2008). Condizioni di salute e ricorso ai servizi sanitari. http://www.istat.it/it/archivio/10836 consulted on 16-06-2014.

Jaarsma T., Stromberg A., Martensson J. & Dracup K. (2002). Development and testing of the European Heart Failure Self-Care Behaviour Scale. *The European Journal of Heart Failure*, 5, 363-370.

Jaarsma T., Arestedt K.F., Martensson J., Dracup K. & Stromberg A. (2009). The European Heart Failure Self-care Behaviour scale revised into a nine-item scale (EHFScB-9). *European Journal of Heart Failure*, 11, 99-105.

JBI – Joanna Briggs Institute (2011) Reviewers Manual 2011 Edition. http://joannabriggs.org/assets /docs/sumari/ReviewersManual-2011.pdf consulted on 6-06-2014.

Jerant, A., Moore, M., Lorig, K. & Franks, P. (2008). Perceived Control Moderated the Self-efficacy-Enhancing Effects of a Chronic Illness Self-management Intervention. *Chronic Illness*, 4, 173-184.

Lee C.S., Carlson B. & Riegel B. (2007). Heart Failure Self-Care Improves Economic Outcomes, but Only When Self-Care Confidence Is High [abstract]. *Journal of Cardiac Failure*, 13 (6) (suppl 2), 0-11.

LeFort S.M. (2000). A Test of Braden's Self-Help Model in Adults with Chronic Pain. *Journal of Nursing Scholarship*, 32 (2), 153-160.

Lerman I. (2005) Adherence to treatment: the key for avoiding long-term complications of diabetes. *Archives of medical Research* 36, 300-306.

Lev E.L. & Owen S.V. (1996). A measure of Self-Care Self-Efficacy. Research in Nursing and Health, 19, 421-429.

Levin, L.S. & Idler, E.L. (1983). *Self-care in Health. Annual Review of Public Health*, 4, 181-201.

Lorig K. & Holman H.R. (2003). Self-Management Education: History, Definition, Outcomes, and Mechanisms. *Annals of Behavioral Medicine*, 26 (1), 1-7.

McAlister, F.A., Stewart, S., Ferrua, S. & McMurray, J.J.V. (2004). Multidisciplinary strategies for the management of heart failure patients at high risk for readmission: a systematic review of randomised trials. *Journal of American College Cardiology*,44(4), 810-9.

Ministero della Salute (2011b). Relazione sullo stato del Paese 2009-2010. http://www.rssp.salute.gov.it/rssp/paginaMenuSezioneRssp.jsp?sezione=risposte&lingua=italiano consulted on 16-06-2014.

Mosen D.M., Schmittdiel J., Hibbard j., Sobel D., Remmers C. & Bellows J. (2007). Is Patient Activation Associated With Outcomes of Care for Adults With Chronic Conditions? Journal of Ambulatory Care Management, 30 (1), 21-29.

Newman, J. & Tonkens, E. (2011). *Participation, responsibility and choice: Summoning the active citizen in the Western European Welfare state.* Amsterdam: Amsterdam University Press.

Nicholas M.K. (2007). The pain self-efficacy questionnaire: taking pain into account. *European Journal of Pain,* 11, 153-163.

Orem D. (1971). *Nursing Concepts of Practice*. St. Louis: Mosby.

Packer, T.L., , Boldy, D., Ghahari, S., Melling, L., Parsons, R. & Osborne, R.H. (2011). Self-management programs conducted within a practice setting: Who participates, who benefits and what can be learned? *Patient Education and Counseling*, 87, 93-100.

Petkov J., Harvey P. & Battersby M. (2010). The internal consistency and construct validity of the Partners in Health scale: validation of a patient rated chronic condition self-management measure. *Quality of Life Research Journal*, 19, 1079-1085.

Pulignano G., Del Sindaco D., Minardi G., Tarantini L., Cioffi G., Bernardi L., Di Biagio D., Leonetti S. & Giovannini E. (2010). Translation and validation of the

Italian version of the European Heart Failure Self-care Behavior Scale. Journal of Cardiovascular Medicine, 11, 493-498.

Regione Lombardia (2013). Determinazioni in ordine alla gestione del servizio socio-sanitario regionale per l'esercizio 2014. http://www.sanita.regione.lombardia.it/cs/Satellite?c=Redazionale_P&childpagename=DG_Sanita%2FDetail&cid=1213643130132&pagename=DG_SANWrapper. consulted on 12-06-2014.

Riegel B., Carlson B. & Glaser D. (2000). Development and testing of a clinical tool measuring self-management of heart failure. *Heart and Lung* 29 (1), 4-15.

Riegel B., Carlson B., Moser D., Sebern M., Hicks F. & Roland V. (2004). Psychometric Testing of the Self-Care of Heart Failure Index. *Journal of Cardiac Failure, 10* (4), 350-360.

Riegel B. & Dickson V. (2008). A Situation-Specific Theory of Heart Failure Self-care. *Journal of Cardiovascular Nursing,* 23 (3), 190-196.

Riegel B., Lee C.S., Vaughan Dikson V., Carlson B. (2009) An update on Self-Care of Heart Failure Index. *Journal of Cardiovascular Nursing,* 24(6), 485-497.

Riegel B., Jaarsma T. & Stromberg A. (2012) A Middle-Range Theory of Self-Care of Chronic Illness. *Advances in Nurses Science,* 35 (3), 194-204.

Risser J., Jacobson T.A. & Kripalani S. (2007). Development and Psychometric Evaluation of the Self-Efficacy for Appropriate Medication Use Scale (SEAMS) in Low-Literacy Patients With Chronic Disease. *Journal of Nursing Management,* 15 (3), 203-219.

Ryan P. (2009). Integrated Theory of Health Behavior Change: Background and Intervention Development. Clin Nurse Spec. 23 (3), 161-172.

Ryan P. & Sawin K.J. (2009). The Individual and Family Self-Management Theory: Background and perspectives on context, process, and outcomes. *Nursing Outlook,* 57, 217-225.

Schilling L.S., Grey M. & Knafl K. (2002). A review of measures of self-management of type 1 diabetes by youth and their parents. *The Diabetes Educator,* 28 (5), 796-808.

Schnell-Hoehn K., Naimark B. & Tate R. (2009). Determinants of self-care behaviors in community-dwelling patients with heart failure. *Journal of cardiovascular nursing,* 24 (1), 40-47.

Sidani, S. (2011). Self-care. In D. Doran (Ed.), *Nursing Sensitive Outcomes: The State of the Science.* Sudbury: Jones & Burtlett Learning.

Sousa V.D., ZausZwnieski J.A., Zeller R.A. & Neese J.B. (2008). Factor analysis of the Appraisal of Self-care Agency Scale in American adults with diabetes mellitus. *The Diabetes Educator,* 34 (1), 98-108.

Sousa V.D., ZausZwnieski J.A., Bergquist-Beringer S., Musil C., Neese J.B. & Jaber A.F. (2010). Reliability and validity and factor structure of the Appraisal of Self-Care Agency Scale – Revised (ASAS-R). *Journal of Evaluation in Clinical Practice,* 16, 1031-1040.

Toobert, D.J., Hampson, S.E. & Glasgow, R.E. (2000). The Summary of Diabetes Self-Care Activities Measure. *Diabetes Care,* 23, 943-950.

Wanless D. (2002). *Securing Our Future Health: Taking a Long-Term View.* http://webarchive.nationalarchives.gov.uk/+/http:/www.hm-treasury.gov.uk/consult_wanless_final.htm consulted on 16-06-2014.

Wilson P. & Mayor V. (2006). Long-term conditions. 2: supporting and enabling self-care. *British Journal of Community Nursing,* 11 (1), 6-10.

WHO - World Health Organization (2005). *Preventing Chronic Diseases: a Vital Investment.* http://www.who.int/chp/chronic_disease_report/en/ Ultimo accesso il 16-06-2014.

WHO - World Health Organization (2008). 2008-2013 Action Plan for the Global Strategy for the Prevention and Control of Noncommunicable Diseases. http://whqlibdoc.who.int/publications/2009/9789241597418_eng.pdf Ultimo accesso il 16-06-2014.

WHO - World Health Organization (2010). *Report on Chronic Disease.* http://www.who.int/topics/chronic_diseases/en/ consulted on il 16-06-2014.

Yoo H., Kim C.J., Jang Y. & You M. (2011). Self-efficacy associated with self-management behaviors and health status of South Koreans. *International Journal of Nursing Practice,* 17, 599-606.