SELF-CARE: A CLARIFICATION OF MEANING
AND EXAMINATION OF SUPPORTIVE STRATEGIES

by

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A thesis submitted to the School of Rehabilitation Therapy
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the degree of Doctor of Philosophy

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Abstract

Background

Considering ~9 million Canadians have one or more chronic health conditions, and >3.3 million report some level of disability, the burden of care is substantive for individuals and health system. With such conditions, self-care is essential but may pose challenges to both individuals and providers of care. As a concept, self-care is poorly understood. Further, evidence for effective self-care support is diffuse and typically studied relative to specific conditions.

Objectives

To investigate the concept of self-care three objectives were undertaken: 1) explore and describe the construct of self-care as understood by individuals/families, health care professionals, researchers, policy-makers; and industry; 2) produce new knowledge for health care professionals about interventions for self-care across a range of population groups; 3) develop a provisional framework to inform practice and research.

Method

A multi-phase enquiry was undertaken. Phase 1 Concept clarification including: 1) synthesis of qualitative evidence on the experience of self-care reported by individuals/families; 2) content analysis and definitional study of the meaning of self-
care; 3) concept analysis of self-care; 4) creation of a conceptual schema encompassing these perspectives. Phase 2 Self-care Interventions: Integrative study of systematic reviews, synthesizing evidence for self-care interventions from multiple disease/impairment groupings.

Results

Three modes of self-care were revealed: ‘Care of self’ self-care performed on one’s own behalf; ‘care by other’ acknowledging individuals with disabilities who guide and direct care provided by another person; and ‘care of other’- care of families and others at a community level. Analysis of 30 self-care interventions across 16 conditions demonstrated that educational sessions and self-care management plans are emerging as effective strategies to support and guide self-care.

Conclusion

Self-care is a complex care concept that is becoming an expected element in today’s health care environment. A full understanding of how it is viewed, including the individual’s perspective, is vital for enactment and beneficial support. This comprehensive understanding of the concept along with evidence for effective interventions drawn from multiple groups will assist health care professionals to improve their assessments and provide them with strategies to support self-care needs.
–ultimately, contributing to enabling individuals to maintain their highest level of functioning.
Co-Authorship

The following individuals were involved as co-authors:

Dr Margaret Harrison  RN PhD
Dr Rosemary Lysaght  PhD
Dr Marianne Lamb  RN PhD
Dr Ian Graham  PhD
Patricia Oakley  MLIS

Christina Godfrey conceptualized the enquiry, developed the methodology, collected and analyzed all the self-care data, and developed the 1st draft of the four manuscripts. Dr Harrison and Dr Lysaght contributed to the conceptualization and analytical plan. Dr Lamb and Dr Graham contributed to the interpretation of the results of the enquiry. All reviewed final versions of the manuscript chapters. Ms Oakley assisted with the generation of the extensive search strategies to locate the literature on self-care.
Acknowledgements

I would like to thank my supervisors Dr. Margaret Harrison and Dr. Rosemary Lysaght for their unwavering dedication and mentoring throughout these last four years. In particular, thank you Margaret for preventing me from dashing off to any one of at least a dozen courses and conferences during the final months of writing. Although I kept trying and you remained insistent, once buckled down and writing I was so grateful for your greater wisdom in keeping me at my desk and focused. Rosemary, I would like to thank you for your support and your guidance through each step of this PhD process. You both allowed me to gallop ahead but when I needed to discuss some thoughts and ideas, you were always there to share your insights and wisdom. I appreciate your caring of me during this adventure.

To my thesis committee, Dr. Marianne Lamb and Dr. Ian Graham, thank you for your effort and time attending meetings and reading through the manuscripts. I valued your input and suggestions and the different perspectives you brought to the table. To both supervisors and committee, I thank you for your contributions to this enquiry as well as to my learning experience.

I would also like to thank Patricia Oakley for her help with the generation of the intricate search strategies that were needed to find the literature on this complex concept. Pat your expertise and assistance were a valuable contribution to this enquiry.
Thank you also to Dr. Craig Kuziemsky (Telfer School of Management, University of Ottawa) and Dr David Lamb (Queen’s University School of Computing) for several conversations, insights and articles on ontologies and Semantic Web applications that enriched my knowledge in this area.

I would like to thank the staff of the Queen’s Joanna Briggs Collaboration, Valerie Angus and Victoria Donaldson for their constant support. In addition, I would like to express my appreciation to Amanda Diegel and Kristen Dean for their contribution as second reviewers for the critical appraisal process in both reviews. Thank you also to my friend Eleanor Rosenzweig for her encouragement over the years and prompting to sustain my own self-care activities along this journey.

I would like to thank my family, always cheering from afar in England, New Zealand and South Africa, and who hopefully have forgiven me for being able to write a 400 page thesis but not being able to write a short email to let them know I love them.

I would like to acknowledge the Canadian Institutes of Health Research (CIHR) for funding support provided by a PhD Fellowship Knowledge Translation Award (KPD 85181).
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Chapter 1: General Introduction

Description of the Problem: the Need for Self-Care

It is estimated that 9 million Canadians have been diagnosed with one or more chronic health conditions,\textsuperscript{1,2} and over 3.3 million report some level of disability that poses a unique problem to their health.\textsuperscript{3} A robust and growing health care system is needed to support these individuals; however, instead, about 5 million people report that they do not have a regular medical doctor\textsuperscript{4,5} to address primary health care needs. It is not surprising to learn that of this group without primary physicians, 298,000 individuals (4\%) reported at least one of the following: hypertension, arthritis, diabetes, or heart disease.\textsuperscript{4} These conditions typify long standing chronic diseases which often require intricate medication regimes, constant assessment, monitoring and self-treatment in combination with regular consultations with health care professionals.

With medical resources and support dwindling, and at least 25.8 million Canadians with unmet health care needs,\textsuperscript{6} access to care has become an important issue in health care services. Caring for oneself or relying on family and other caregivers for assistance through recovery, chronic disease or disability is no longer just an option, it has become a necessity.
Challenges with Self-Care

Engaging in self-care activities may be challenging for individuals at different developmental stages, or with longstanding chronic conditions, disabilities or injuries. For example, learning new self-care regimes can be difficult for children and individuals who are cognitively compromised. For adults, performance of self-care may be hindered by economic conditions, constrained workplace situations, and cultural and lifestyle habits. The environment may have a substantial influence on the performance of self-care activities, and for individuals with disabilities the environment can be a major barrier to the performance of self-care.

For individuals with multiple morbidities, engaging in self-care activities can be an intricate task, as they are often required to follow conflicting and/or complicated regimes. Taking one aspect such as medication administration as an example, medications may have to be taken at different times or have specifications (with/without food) that are incompatible, or the medication routine itself may be forgotten because of the cognitive decline associated with the impairment. Hence, engaging in different self-care routines for coexisting conditions is complex, and ultimately may reduce the individual's and/or his/her family's ability to perform self-care.
Initiatives to Encourage Self-Care Behaviours

The growing presence of health issues in the media prompts people to be more aware of their health. Beyond the explicit involvement in therapeutic care which the individual may enter into contractually with their health care professional, there are several initiatives that act more implicitly to engage individuals in examining their health behaviours. Television infomercials on recognising the signs of stroke, ubiquitous media attention to obesity and heart disease, and the vast amount of information on the web, all serve to raise the population’s consciousness about health care issues, and the steps they can take to help themselves.

At the policy level there was the establishment of self-care as an important focus of health care and health care reform in Canada today.\textsuperscript{9} In response, Health Canada instigated a research project that culminated in a major report, entitled \textit{Supporting Self-Care: a Shared Initiative 1999-2002}.\textsuperscript{9} In collaboration with several professional organizations, Health Canada highlighted the instrumental role of self-care nationally. A crucial insight arising from this initiative was the challenge of "educating health professionals in the support of self-care and in integrating self-care support into professional practice."\textsuperscript{9p.4} This challenge is compounded because different professions view self-care within their own domain of practice, and have varied expectations of their roles in supporting these behaviours.
Perspectives on self-care differ, partly due to the multiple facets of the concept and the range of different reasons for performing self-care behaviours. This is echoed in the various definitions of self-care. Self-care for example, could be viewed strictly within the context of ill-health as suggested by this 1997 definition from Health Canada\textsuperscript{10} which states that self-care is “the decisions and actions taken by someone who is facing a health problem in order to cope with it and improve his or her level of health.”\textsuperscript{10,p.1} In contrast, self-care is more broadly viewed in this more recent definition (2009) from the World Health Organization (WHO) that states: “Self-care is the ability of individuals, families and communities to promote health, prevent disease, and maintain health and to cope with illness and disability with or without the support of a health-care provider.”\textsuperscript{11,p.17} This notion of self-care includes health, illness and disability, and notes that interaction with health care professionals is an option rather than an expectation. Suggesting a more individual view of self-care, Hoy and colleagues (2007) propose that: “Self-care is rooted in a perception of health as functionality, responsibility, integrity and growth.”\textsuperscript{12,p.462} The variety of conceptualizations complicates research on self-care, both from a theoretical basis to the methods employed and makes the comparison of findings difficult.

In order to proceed with an enquiry when faced with these multiple conceptualizations, there is a need to comprehend self-care from key perspectives. What self-care means for individuals engaged in a short term recovery from injury is
quite different from the experiences of an individual with a long standing condition such as heart failure or a disability such as cerebral palsy. To build the emerging meaning and understanding of self-care, the initial step in this research was to explore the full range of components and attributes comprising the concept of self-care. In addition, it was important to understand the types of generic approaches to the support of self-care and the effectiveness of strategies designed to assist individuals to engage in and maintain self-care behaviours.

The aim of my thesis was to advance the use of evidence for health care professionals in supporting self-care in order to improve supportive care for individuals and families. To accomplish this I first explored the definition components of the self-care concept, and integrated a variety of perspectives on this concept. Next, using the rigorous methodology of integrative research, evidence on interventions for self-care across several disease/impairment groupings was synthesized to describe and evaluate strategies to support individuals as they engage in self-care behaviours. With the knowledge generated by these different enquiries, I formulated a provisional framework for practice and research on self-care. In addition to this provisional framework, a body of evidence on self-care has been made available for direct use by health care professionals and developers of practice guidelines.
Defining Self-Care

For the purposes of practice and policy, self-care poses both conceptual and practical challenges. Currently, no single definition of self-care behaviour is broadly accepted. Definitions vary as to (1) who actually engages in self-care behaviour (individual, family, community); (2) the purpose of self-care behaviours (i.e., health promotion, prevention, to restore health, or to limit the impact of illness or impairment); and (3) the extent to which health care professionals are involved. Moreover, self-care is a complex concept, meaning that it has multiple facets and has different meanings depending on the context. Self-care is also not limited to certain populations or stages of life. Levin, Katz & Holst outline one view of the term in relation to the health care system: “Self-care behavior can be defined as a characteristic attribute of whole populations; as a level or element in social competence to cope with health and disease, complementary, or alternative to the professional resources.”

Therefore, self-care can be viewed as both a substitute for and supplement to the overall health care delivery system. For the purposes of this thesis, the United Kingdom Department of Health’s comprehensive definition was used as a starting point because it incorporates many salient points, such as self-care as part of daily living, care of self as well as care extended to others, actions to promote physical and mental health, prevention of illness and the care of long term conditions.

Self care is a part of daily living. It is the care taken by individuals towards their own health and well being, and in their role as carers includes the care extended
to their children, family, friends and others, whether in their homes, neighbourhoods, local communities, or elsewhere. Self care includes the actions individuals and carers take for themselves, their children, their families and others to stay fit and maintain good physical and mental health; meet social and psychological needs; prevent illness or accidents; care for minor ailments and long-term conditions; and maintain health and wellbeing after an acute illness or discharge from hospital.\textsuperscript{15,p.5}

**Self-Care as a Research Focus**

Self-care has been a part of daily living since the beginning of time, and people have taken action to ensure personal safety and address illness, impairment and injury according to their capacity and available resources.\textsuperscript{16} Popular interest in self-provided health care has been regarded as a response to the changes occurring in the nineteenth century, such as the women’s liberation movement and the change in women’s role in the family and work force, changes in general thinking about the etiology of disease; and an increased interest in the effects of lifestyle on health.\textsuperscript{17,18} In America, the focus on self-care was “rooted in the traditional American values of self-reliant individualism, anti-elitism, popular democracy, common sense, and even nationalism.”\textsuperscript{17,p.182} A dramatic increase in the amount of information about health and healing created “an erosion in medicine’s mystique; a process of demystification of professional care”\textsuperscript{19,p.119} Furthermore, there was a growing recognition by laypersons of the dysfunctional aspects of the medical care system, such as fragmented, depersonalized care; limited ability to enforce cure; and negative effects of medical care (iatrogenic illnesses).\textsuperscript{18}
Additionally, the advances in diagnostic and treatment technology enabled changes in care-giving responsibilities.\textsuperscript{19}

In August 1975, the first international symposium on the role of the individual and families in the primary health care process convened in Copenhagen, Denmark, bringing together 29 scholars from four European countries, as well as Israel and the United States.\textsuperscript{14} The intent at the symposium was to clarify the role of laypersons and families in primary care and to examine the phenomena broadly grouped under the rubric of self-care.\textsuperscript{14} The symposium generated both interest and investigation of the topic and hence, marked the emergence of research on the topic of self-care. Consequently, a high proportion of studies on self-care are found in the late 1970s and 1980s.

**Theories of Self-Care**

There are a variety of theories and conceptual frameworks focused on the topic of self-care. A high proportion of these are disease/impairment specific, (e.g., Riegel’s\textsuperscript{20} situation-specific theory of heart failure self-care, or Raven’s\textsuperscript{21} conceptual model for care in developmental disability services); or related to a specific developmental stage (e.g., Backman’s\textsuperscript{22} model for self-care of home-dwelling elderly). There are also many health behaviour theories and health behaviour change theories (e.g., Becker et al.’s\textsuperscript{23} health belief model and Ryan’s\textsuperscript{24} integrated theory of health behaviour change). Purely generic
self-care theories and models tend to focus on one aspect of the self-care constellation. To illustrate the range of aspects addressed by such generic theories and conceptual models on self-care, I have included a description of six exemplar models in Table 1.

The essential contribution of Orem’s theory of self-care is the emphasis on the regulatory function of self-care. Orem viewed self-care as a learned behaviour deliberately performed in conformity with the regulatory requirements of the individual, for example, developmental stage, state of health or environmental factors. The theory of self-care has 3 conceptual elements: 1) Self-care – engaging in action to regulate functioning and development; 2) Self-care agency - operational powers or capabilities specific to performing actions of self-care; and 3) Self-care requisites - requirements that guide the selection, choice, and conduct of regulatory actions in the care of self. Orem’s theory was used to analyze the data in the study contained in chapter 2, and guided the inclusion criteria for the study reported in chapter 7. Orem’s theory is explained in more details in these studies.
<table>
<thead>
<tr>
<th>Theory of Self-Care</th>
<th>Focus</th>
<th>Defining Constructs</th>
<th>Basic Proposition of Theory</th>
<th>Contribution</th>
</tr>
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</table>
| Orem (1985;2001) | The theory of self-care refers to the purpose of taking care of the self, the how of taking care of the self and the outcome of taking care of the self. | • Self-care – engaging in action to regulate functioning and development  
• Self-care agency – operational powers or capabilities specific to performing actions of self-care  
• Self-care requisites – requirements that guide the selection, choice, and conduct of regulatory actions in the care of self | Self-care is learned behaviour deliberately performed in conformity with the regulatory requirements of the individual. Purpose for performing care, self-care requisites, have 3 types:  
• Universal – attend to basic human needs.  
• Developmental – promote or support process of development.  
• Health deviation – changes in self-care activities due to deviation from normal structure and function. | Essential contribution of the theory is the emphasis on the regulatory function of self-care. |
| Leventhal (1998) | The process involved in the representation, coping and appraisal of symptoms and associated emotional responses. Two tracks of processing:  
• Individual’s phenomenal reality – e.g., symptom recognition, assessment, and response;  
• Generation of emotional identity – symptoms and labels, time line – acute / chronic consequences, causes, controllability | Reality interpreted both abstractly and concretely – i.e., in the experience of an illness, there could be a conflict between what we know and what we feel. | Addresses the evolving nature of self-regulation process.  
• Recognition of role of emotion in self-care process. |
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<th>Focus</th>
<th>Defining Constructs</th>
<th>Basic Proposition of Theory</th>
<th>Contribution</th>
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</table>
| responses to this reality – e.g., reactions to threat and problem solving process. | • Symptom recognition  
• Symptom evaluation  
• Treatment consultation  
• Treatment implementation  
• Symptom outcome | • Framework identifies action to evaluate, classify and treat a symptom.  
• Evaluation and consultation may be performed as self-care with family, friends, or within alternate or traditional health services. | • Definition and recognition of symptoms can be analyzed in relation to consultation and the selection and use of treatment.  
• Stages in the process defined to allow empirical measurement. |
| **Sorofman (1990)**  
**Symptom Response Model** | The processes through which individuals identify and evaluate symptoms and decide on actions that have a perceived potential for amelioration of the symptom. | | |
| **Simmons (1990)**  
**The Health-Promoting Self-Care System Model**  
[based on a synthesis of Orem’s Self-Care Deficit Nursing Theory; the Interaction Model of Client Health Behaviour (IMCHB) (Cox 1982); and the Health Promotion Model (Pender 1987)] | • Health outcomes can arise from and impact health-promoting self-care.  
• A person’s total requirement for health-promoting self-care, therapeutic self-care demand, is affected by basic conditioning factors as well as by universal and developmental self-care requisites. | • Basic conditioning factors  
• Self-care requisites  
• Therapeutic self-care demand  
• Self-care agency  
• Nursing system  
• Health outcomes  
• Health-promoting self-care (behaviours to maintain health & enhance quality of life) | • Individuals are capable of developing knowledge, attitudes and skills necessary for deciding upon and performing health-promoting behaviours.  
• Due to the value of self-care in health promotion, nursing practice is directed toward fostering self-responsibility in the acquisition and maintenance of health-promoting behaviours.  
• This framework is an organizing perspective for explaining the cumulative and interactive relationships among factors which influence the decision-making, performance and outcomes of health-promoting lifestyles. |
<table>
<thead>
<tr>
<th>Haug (1989)</th>
<th>Focus</th>
<th>Defining Constructs</th>
<th>Basic Proposition of Theory</th>
<th>Contribution</th>
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| **Conceptual model for explaining self-care behavior for symptoms perceived by respondents** | • Self-care action will differ, depending on whether symptoms are perceived as not serious and amenable to self-treatment, or perceived as more serious and less likely to be treatable.  
• Self-care is viewed as care performed outside the traditional health care system. | • Health set - encompasses the respondent’s health behavior and mental and physical health status  
• Attitude set - involves attitudes concerning the efficacy of physician care, such as his or her level of faith in doctors, claimed experience with prior medical error, and self-reliance in health-care  
• Demographic variables  
• Accessibility of medical services | • Model explains the rates of self-care across all reported symptoms.  
• Negative views of physician care favor a choice of self-care.  
• Positive health facilitates self-treatment - people who are healthy should be able to distinguish between health issues that can be addressed by self-care and those that require doctor’s attention. | Conceptual framework to understand illness behaviour, and Self-care action. |

<table>
<thead>
<tr>
<th>Cammermeyer (1983)</th>
<th>Focus</th>
<th>Defining Constructs</th>
<th>Basic Proposition of Theory</th>
<th>Contribution</th>
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| **Growth Model of Self-Care** | Representation of a person’s growth through life, focusing on the individual’s quest for autonomy, through physical and psychological integrity. The goal is to be a fully functioning person. | • Physical and psychological integrity are influenced by age, development, and health and determine how a person meets basic needs.  
• Autonomy is the person’s ability to apply self-care to meet basic needs. The greater the physical and psychological integrity, the greater the ability to self-care. | • Assessment and diagnosis is made from knowledge of the physical and psychological integrity of the person, i.e., the expected abilities and limitations in self-care to meet basic needs.  
• Basic needs are concerned with oxygenative, metabolic, locomotive, hygienic and interrelative needs of individuals and families. | Useful model for assessment of neurologically impaired individuals. |
Thesis Plan

In order to improve health care support for a growing population dealing with self-care, several fundamental issues needed to be addressed. First, to understand the experience of self-care as reported by individuals and families and gain an awareness of the challenges and benefits of the performance of self-care, a synthesis of qualitative evidence was performed. Second, the diversity of perspectives on and definitions of self-care compelled a rigorous and systematic integration of the literature addressing this concept to elucidate the different points of view. Third, a greater clarity and understanding of the concept we refer to as ‘self-care’ was required. Thus, a rigorous concept analysis was necessary to delineate the attributes of the concept. Fourth, health care professionals’ need to access the best available evidence on the effectiveness of interventions to support self-care and this prompted the synthesis of evidence on interventions for self-care.

Currently, the research on self-care is typically conducted on single disease/impairment groupings. However, individuals with complex conditions encounter issues related to several different diagnoses. Evidence that addresses this complexity is not easily available to health professionals. Evidence for self-care needs to be scrutinized and synthesized into a form useful for health care professionals in order for this knowledge to inform practice. To date this has not been done. For this thesis I accessed evidence across multiple disease/impairment populations rather than focusing
on a single disease/impairment, and in so doing, integrated the current knowledge about interventions for self-care.

Systematic reviews currently represent the highest level of evidence available. However, the integration of evidence from systematic reviews (overview of reviews or “umbrella reviews”) has only recently begun to emerge as a methodology to provide evidence. The explicit methods used in systematic reviews limit bias and improve reliability and accuracy of conclusions. To sustain and augment this level of rigor, and provide a comprehensive analysis of the best available evidence on interventions for self-care, an integrative study of systematic reviews was conducted across multiple disease/impairment groupings. The results of this integrative study have created a body of work from which self-care best practices can be developed.

The investigation was conducted in two iterative phases. Phase 1 was a process of concept clarification and entailed three studies: 1) a synthesis of qualitative evidence on the experience of self-care reported by individuals and families; 2) a content analysis and study of the meaning of the definition of self-care from research, practice, policy and industry perspectives (e.g., health products, self-medication industry); and 3) a formal concept analysis to delineate the attributes of the concept of self-care. From this phase a conceptual schema encompassing these perspectives was created to inform Phase 2. Phase 2 involved an integrative study of systematic reviews, synthesizing the evidence on interventions for self-care across multiple disease/impairment groupings.
Thesis Objectives

The overall objectives of this research enquiry were:

1. To explore and describe the construct of self-care as understood by individuals/families, health care professionals, researchers, policy-makers and industry.
2. To produce new knowledge for health care professionals about interventions for self-care across a range of population groups.
3. To develop a provisional framework to inform practice and research.

Format of Thesis

These objectives were addressed by a multiphase enquiry. The chapters are outlined below and include four manuscripts, (Chapters 2, 3, 4, and 7). There are two ‘bridging’ chapters (chapters 5 and 6) that explain the methods and serve as links in the thesis between the phases of enquiry and manuscripts. Chapter 8 concludes with a summation of the research phases, the contribution to knowledge, and finally, implications for practice, policy and research.

Chapter 2: The experience of self-care: a systematic review

The first manuscript contains an integrative study using systematic review methodology for qualitative evidence. The study describes the experience of self-care as reported by individuals and families. This provides a foundation for the enquiry.
Beginning with this perspective the enquiry then progresses to explore the understanding of self-care from other viewpoints.

**Chapter 3: Care of self – care by other – care of other: the meaning of self-care from research, practice, policy and industry perspectives**

The second manuscript contains an exploratory study of self-care definitions and the evolution of self-care meaning examined chronologically from the 1970s to 2000s. An operational definition of self-care for research purposes is proposed. The next stage in this enquiry involved a thorough analysis of the concept of self-care using formal concept analysis methodology.

**Chapter 4: Self-care: a concept analysis**

The third manuscript contains a concept analysis study following the methodology proposed by Walker and Avant. This phase of the enquiry delineates various elements that comprise the concept of self-care, deepening our understanding of the concept’s function and attributes.

**Chapter 5: Self-care concept clarification: direction for inquiry**

Based on the concept exploration and analysis reported on in chapters 2, 3, and 4, the findings are integrated to develop a broad multi-perspective synopsis. The structure and function of the concept revealed by the concept analysis provides a framework within which to view the various meanings associated with self-care, which
in turn, are epitomized in the essence of the experience of self-care from the synthesis study.

**Chapter 6: Methodological challenges and approaches used in this enquiry**

Moving to the next phase of the enquiry, two methodological elements are grappled with: a) Issues of locating literature on complex concepts are outlined, and after consultation with experts (library science and computer information services), an approach is suggested using ontology software and Semantic Web applications.

b) Issues arising in the method of synthesis to perform a cross-cutting integrative review using the Cochrane Database of Systematic Reviews as the primary data source are described in detail. Key points in this process are raised.

**Chapter 7: Intervention strategies that support self-care activities: an integrative study across disease/impairment groupings**

The fourth manuscript contains a study that addresses the second objective to provide evidence-informed self-care interventions for health care professionals. The study provides evidence drawn from multiple populations and provides a valuable composite on interventions for self-care support across multiple disease/impairment groupings. The intervention strategies can be understood within the context of knowledge translation and the Knowledge to Action framework by Graham and colleagues\(^{37}\) was used to guide the conceptualization of this data.
**Chapter 8: Knowledge about self-care: A multi-phase enquiry.**

In the final chapter, the results from the entire research enquiry were summarized and integrated. Implications for practice and policy were discussed as well as areas of future research.
References


(6) Statistics Canada. Table 105-0016 - Unmet health care needs, by age group and sex, household population aged 12 and over, Canada, provinces, territories, health regions (January 2000 boundaries) and peer groups, every 2 years. Statistics Canada; 2000. Report No.: 3226.


Chapter 2: The Experience of Self-Care: a Systematic Review

Executive Summary

Background

Self-care has been defined quite simply as “the set of activities in which one engages throughout life on a daily basis.”\(^1\, p.68\) Examining this ‘set of activities’ more closely, we see that a number of activities encompass “a person’s attempts to promote optimal health, prevent illness, detect symptoms at an early date, and manage chronic illness.”\(^2\, p.2\) Hence, engaging in self-care activities may result in a range of different experiences depending on the set of activities that are performed and the reasons for their undertaking.

Objectives

To integrate and summarize the experience of engaging in self-care activities as reported by individuals and/or their families.

Inclusion Criteria

*Types of Studies* – studies included, but were not limited to, designs such as phenomenology, grounded theory, ethnography, action research and feminist research.

*Types of Participants* – individuals and/or their families who engaged in self-care activities, or were assisted with their self-care activities, or provided support for self-care.
Types of Interventions – individual experiences of self-care in response to an intervention or where no intervention was introduced.

Types of Outcomes – individual experiences of self-care through self-report. Reports from family members who assisted or provided support for self-care were included.

Search Strategy

The search strategy aimed to find both published and unpublished studies (e.g., theses). A three-step search strategy was used in each component of this review. An initial limited search of MEDLINE and CINAHL was undertaken followed by analysis of the text words contained in the title and abstract, and of the index terms used to describe the article. A second search using all identified keywords and index terms was then undertaken across all included databases. Thirdly, the reference lists of all identified reports and articles were searched for additional studies. The databases searched included: CINAHL; MEDLINE; EMBASE; PsycINFO; AMED; Cochrane Library; Scirus; and Mednar

Methodological quality

Methodological quality of the studies was assessed using the JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research. Two appraisers independently reviewed each study.
Data Collection and Analysis

Qualitative data were extracted from included studies using an adaptation of the standardized JBI Data Extraction Template for Qualitative Evidence.

Data synthesis

The data were synthesized using narrative form.

Results and Conclusions

Engaging in self-care is a process involving being aware of self, acquiring knowledge and taking responsibility for meeting needs at whatever level they are presented. The performance of self-care behaviours can be influenced both positively and negatively by the attitudes of others. Throughout life, the purpose for performing self-care differs and individuals face challenges that interfere with their ability to master these self-care behaviours. Individuals who are able to find symbolic meaning in the disease/disability or reframe the implications positively are more capable of adapting and maintaining their focus on caring for themselves. Studies revealed that individuals may abandon self-care when overwhelmed by symptoms or disability and/or when they feel that they are not supported.

Implications for Practice

It is valuable for health care professionals to understand the struggle that individuals experience when trying to engage in self-care. Furthermore, health care
professionals need to be cognizant of how important their support is, in terms of encouraging individuals to adopt and maintain self-care behaviours.

**Implications for Research**

This review has provided an insight into the process of engaging in self-care through the different developmental stages of life, as well as the adoption of self-care behaviours to meet different requisites. Further research would be valuable to integrate the range of health care interventions provided to individuals across different disability or disease groupings who engage in self-care activities.

**Keywords** – self-care, self-maintenance, self-treatment, personal care, lay care

**Background**

Self-care has been defined quite simply as “the set of activities in which one engages throughout life on a daily basis.”1,p.68 Examining this ‘set of activities’ more closely, we see that a number of these activities encompass “a person’s attempts to promote optimal health, prevent illness, detect symptoms at an early date, and manage chronic illness.”2,p.2 Hence, engaging in self-care activities may result in a range of different experiences depending on the set of activities that are performed and the reasons for their undertaking. “Self-care theory operates on the assumption that each human has a need to care for himself or herself.”3,p.385 However, the individual’s recognition and response to this need is influenced by many different factors including
the individual’s perception of their health status, their developmental stage, self-concept, perceived competence and control over their health, as well as the self-care behaviour itself.\textsuperscript{1,4} Furthermore, self-care is context dependent, and socio-economic, environmental and cultural factors are also predisposing factors that affect the individual’s engagement in self-care activities and their experience of this engagement.

Self-care is seen to comprise two major components, therapeutic care (medication administration; self monitoring and self treatment) and personal care (activities of daily living – dressing, bathing, eating, etc.). With the increase in the numbers of individuals with chronic and longstanding conditions,\textsuperscript{5} much of the interest in self-care has focused on the performance of therapeutic self-care.\textsuperscript{6} However, it is also important to understand the challenges that personal care may pose for individuals with chronic conditions or impairments. Self-care may be performed for a variety of reasons including health promotion, prevention, restoration of health after illness or injury, detection and treatment of illness, management of chronic conditions or impairments, and in the case of personal care – the preservation of self. Orem’s theory of self-care specifically addresses the purpose for performing self-care and provides a framework with which to explore the research in this area.
Orem’s theory of self-care

Orem’s theory of self-care posits that self-care behaviours are learned behaviours that purposely regulate human structural integrity, functioning, and human development (Orem 1995). Orem defines self-care as:

Self-care is the continuous performance of sets of related actions by older children and adults that supply the materials and bring about the conditions that are regulatory of their own functioning and development. Such actions when performed by responsible adults for socially dependent family members are named dependent-care. Self care is human behaviour that is self-directed and self-permitted. It is conduct of deliberate action or ego-processed behaviour.8,p.212

The essential contribution of the theory is the emphasis on the regulatory function of self-care.8 Self-care is learned behaviour deliberately performed in conformity with the regulatory requirements of the individual, for example, developmental stage, state of health or environmental factors.9

The theory of self-care has 3 conceptual elements:10

1. Self-care – engaging in action to regulate functioning and development.

2. Self-care agency – operational powers or capabilities specific to performing actions of self-care.

“The theory of self-care expresses the purpose of taking care of self, referred to as the self-care requisites; the how of taking care of self, referred to as the self-care agency; and the outcome of these known as the self-care practices or self-care system.”11,p.104

The concept of agent is central to Orem’s theory, and refers to the ability to meet self-care requisites, such as acquiring knowledge, making decisions and taking action for change.7

Orem describes three types of self-care requisites:7

1. Universal self-care requisites – activities required by all people during all stages of life to maintain health, promote health and prevent disease including: air, water, food, elimination, rest and activity, solitude and social interaction, prevention of harm, and normalcy.

2. Developmental self-care requisites – requirements related to developmental processes, acquired conditions such as pregnancy, or associated with an event such as the death of a family member. This includes maintaining conditions that support and promote the process of human development and preventing conditions that would negatively affect the developmental process.

3. Health deviation self-care requisites – changes in self-care activities to regulate the effects of deviation from normal structure or function. This includes: seeking medical assistance; attending to the effects of the illness or condition; carrying out recommended therapeutic regimes; adapting self-concept to accept oneself as being
in a particular state of health; adjusting to life with a particular condition or deviation from normal structure and function.

Orem’s theory does have some biases. Her theory is confined mainly to Western professional medical practices without consideration of the contribution of complementary health practices or different cultural perspectives on health and health deviation. It is also not a holistic theory. However, it is valuable as a theoretical model with which to analyze the research literature on self-care because the three categories relating to the purpose of performing self-care (universal, developmental, and health deviation) provide a framework to analyze the research literature on this topic.

When dealing particularly with the health deviation requisite, research tends to focus either on one disease/impairment grouping or on one developmental grouping. Although the actual self-care behaviours performed when taking care of asthma differ from those activities necessary to care for arthritis, for example, the purpose, process and experience of engaging in these self-care activities may have common threads. Thus in performing this systematic review we sought to integrate individuals’ narratives about their experiences of engaging in self-care across disease/impairment groupings. Further to this, we explored the range of experiences of self-care across developmental groupings.

A strong interdisciplinary team was assembled as a review panel, bringing together the necessary theoretical, methodological, and clinical expertise to complete
this review. We have combined extensive experience from nursing (MBH, ML, CG), rehabilitation sciences (RL) and qualitative research (ML). Panel members are also active in health services and epidemiology (MBH, IDG), policy (ML, IDG) and evaluation research (RL). As part of our investigator group, library scientist PO specializes in health care and systematic review methodologies.

**Objectives**

To integrate and summarize the experience of engaging in self-care activities as reported by individuals and/or their families. The question that guided this review was: What is the experience of engaging in, or assisting a family member to engage in, self-care activities as reported by individuals and/or their families?

**Criteria for Considering Studies for this Review**

**Types of studies**

In this review we considered qualitative studies that illustrated the experience of individuals (and/or families) who actively engaged in performing self-care, or were assisted with their self-care activities or provided support for self-care. These studies included, but were not limited to, designs such as phenomenology, grounded theory, ethnography, action research and feminist research.
Types of participants

In this review we considered studies that explored the experience of individuals of any age and/or their families, who actively engaged in self-care behaviours, were assisted with self-care behaviours or supported self-care behaviours.

Types of intervention

Studies were considered if the focus of the study was a description of the individual’s experience of self-care in response to a particular intervention. Studies were also included that described the individual’s experience of self-care where no intervention was introduced.

Types of outcome measures

Outcomes of interest from qualitative studies included individual experiences of self-care through self-report. Reports from family members who assisted or provided support for self-care were included.

Search Strategy

The search strategy was performed with assistance from a library scientist (PO) with extensive experience in generating search strategies for systematic reviews. The search strategy was designed to locate both published and unpublished studies (e.g., theses) (Appendix A), and a three-step search strategy was used. An initial limited search of MEDLINE and CINAHL was undertaken followed by analysis of the text words
contained in the title and abstract, and of the index terms used to describe the article. A second search using all identified keywords and index terms was then undertaken across all included databases. Thirdly, the reference lists of all identified reports and articles were searched for additional studies. The databases searched included: CINAHL; Medline; EMBASE; PsycINFO; AMED; Cochrane Library; Scirus; and Mednar. The literature located by this comprehensive search strategy provided the evidence for the entire concept clarification process comprising the studies in chapters 2, 3 and 4.

Electronic database searching had an international scope and retrieved articles were limited to those in English. The search for unpublished studies included: Dissertation Abstracts; Sociological Abstracts; and Conference Proceedings. Electronic searching resulted in lists of articles with details of title, author, source, and sometimes abstract. All identified articles were assessed on the basis of the abstract (or full article if the abstract was not available), and full reports were retrieved for all studies that met the inclusion criteria for the review. When in doubt, the full article was retrieved.

Initial keywords included: Self-care; self-care skills; self administration; self medication; self efficacy; personal care; lay care; self maintenance; self regulation; self treatment; delivery of health programs; health prevention; health behaviour

Use of the term ‘self-care’ and associated keywords generates a large return of citations. To address this issue, a variety of search strategies were generated that targeted various aspects of the self-care concept. For example: search strategies were
generated to locate articles that included terms such as chronic illness, disability and impairment.

**Methods of the Review**

**Analysis of the review**

To analyze the findings using Orem’s theory, each study was classified according to one of the three self-care requisites: universal, developmental or health deviation. Self-care requisites indicate the *purpose* of taking care of self, hence studies were assigned according to their main focus or purpose. For example, studies focused on a particular condition such as spina bifida or diabetes mellitus were classified as ‘health deviation’ regardless of the age of the participants. Studies focused on health maintenance or health promotion, were classified as either ‘universal’ or ‘developmental’ based on the purpose of the study and developmental grouping of the participants. In instances where a particular health deviation (such as asthma) was studied within the context of a developmental grouping (such as children), these studies were classified as both ‘developmental’ and ‘health deviation’. For example, Pradel\(^{12}\) compared self-care behaviours of seven year olds to 12 year olds with asthma. Moore and Beckwitt\(^{13}\) analyzed their data by Orem’s self-care theory, and their results were therefore assigned all three self-care requisites. Studies were assigned these categories
by the lead author and then checked for appropriateness in consultation with the review panel.

In this review we integrated several contexts such as age, type of impairment, and culture. To capture these important aspects when recording the findings, each finding incorporated these contextual details. For example, a finding would be coded as ‘adults with schizophrenia and diabetes’, or ‘Australian adults with diabetes’. Likewise, each category or synthesis topic also incorporated the context according to Orem’s self-care requisites. An example of a category generated for universal requisites would be: ‘when addressing universal requisites, self-care requires an awareness of self and understanding of one’s body’. The inclusion of these details in the findings, categories and synthesized findings greatly facilitated the analysis of the data according to each requisite and the final integration across the three requisites.

In order to examine the influence of developmental grouping on the experience of self-care, the data were also analyzed across developmental groups (including children, adolescents, adults and elders) for the most common health deviation, diabetes mellitus (14 studies).

**Assessment of methodological quality**

Methodological quality of the studies was assessed using the Joanna Briggs Institute (JBI) QARI Critical Appraisal Checklist for Interpretive & Critical Research (Appendix B). Two appraisers independently reviewed each study. There are ten
questions on this checklist and a cut-off point of 6/10 was set to include studies into this review. This level was chosen because it was considered high enough to establish a level of methodological rigor, but still provide a representative set of studies to analyze.

Data extraction

Qualitative data were extracted from included studies using an adaptation of the standardized Joanna Briggs Institute (JBI) Data Extraction Template for Qualitative Evidence. (Appendices C and D).

In this review we integrated a variety of contexts, for example, different developmental stages, diseases/impairments and cultures. Consequently, findings extracted from the studies had to contain these details and the extraction form was adapted accordingly. For example, ‘elderly Mexican men with diabetes’.

Data synthesis

Qualitative research findings were pooled using the Qualitative Assessment and Review Instrument (JBI-QARI). This involved the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings (Level 1 findings) rated according to their credibility and appropriateness, and categorizing these findings on the basis of similarity in meaning (Categories or level 2 findings). These categories were then subjected to a synthesis in order to produce a single comprehensive set of synthesized findings (level 3 findings) that can be used as a basis for evidence-based practice.
Review Results

Description of the studies

The search strategy located 9,560 citations, of which 260 were obtained for full read to assess the articles (Appendix E). Ninety-six studies were off topic and discarded and 151 studies were excluded for not meeting the inclusion criteria. Four studies did not meet the methodological criteria, leaving a set of 50 studies to comprise the final set included in the review (Appendices F and G).

The citations and articles were reviewed by the lead author. In collaboration with the review panel, selected studies were checked to verify those accepted into the review and those excluded. Discussion with the review panel reinforced the boundaries of the review and maintained the focus of the analysis.

Fifty studies were included in this review (Appendix H). Studies ranged in publication date from 1993-2009. Ten countries (determined by the location of the lead author) were represented: USA (26); Australia (7); United Kingdom (5); Canada (3); Sweden (3); Finland (2); Brazil (1); Denmark (1); Taiwan (1); Thailand (1). Nineteen different cultures were represented, and 27 different conditions were addressed, the most common being diabetes mellitus (14 studies) and asthma (7 studies). Age of participants ranged from 3 - 92 years old, and sample sizes ranged from 4 - 258. Total number of participants was 1,478.
Methodological quality

The methodological quality was assessed with a cut-off point of 6/10. Four studies scored 10, ten studies scored 9, 16 studies scored 8, 11 studies scored 7 and nine studies scored 6. The most common areas where studies lost points was neglecting to provide a statement locating the researcher culturally or theoretically, and not addressing the influence of the researcher on the research and vice-versa. Fourteen studies did not mention having received ethical approval.

Results

Analysis according to Orem’s theory of self-care

The Joanna Briggs Institute (JBI) defines a finding as: “A conclusion reached by the researcher(s) and often presented as themes or metaphors.”\(^{14, p.35}\) Meta-synthesis of studies included in this review generated 326 findings which were aggregated into 29 categories and 9 synthesized findings. Four additional meta-synthesis findings were generated when integrating the three requisites together.

The relationships between study findings, categories and synthesized findings are listed in Appendices I-K.

Universal self-care requisites

Activities required by all people during all stages of life to main health and life (basic human needs) (Figure 1). This analysis was based on six studies\(^{13,15-19}\) which
generated 28 findings; five categories and two synthesized findings (Appendix I). Two synthesized findings emerged:

- Supporting the self
- Balancing inner and outer worlds

**Supporting the self**

A precondition of meeting this requisite and engaging in self-care was gaining an awareness of self. Studies reported how their participants ‘developed a sense-of-self’ or had ‘an understanding of the body’ prior to taking action and satisfying universal needs. For example, for Native women, knowing themselves and their own bodies was a precondition for knowing when something was wrong.

And that’s part of health, being healthy. Is knowing your own body. Knowing yourself well enough to know when something’s out, when something’s wrong, something’s out of balance. Something’s not right. So really being in touch with yourself and with your body. And with your mind and with your spirit world.\(^{15, p.421}\)

For these women, understanding the body influenced their efforts toward taking care of self. “I think Native women are more in touch with their own souls. Understanding their own bodies. Healing themselves.”\(^{15, p.422}\)

Likewise, for homeless youth, the first step to self-care was becoming aware of themselves within the circumstances of family life which they had left, and the street life which they had entered. In the grounded theory study on homeless youth, some of
the participants came from abusive home-lives and grappled with developing a sense of self. One youth stated “I made my decision not to be around them [family]. I had to learn to build my self-confidence.” ¹⁸,p.237 Once on the street, developing self-awareness was enhanced by gaining self-respect. "I’m not scared of no one [sic] . . . To an extent I’m very proud of myself because I’ve come a long way. I need to learn to respect myself and care for myself."¹⁸,p.238 Youth reported that learning to be self-reliant on the street helped them to engage in self-care. “I’m taking care of myself now better than I ever have in my life.”¹⁸,p.238

Taking responsibility for meeting basic needs involved initiating and sustaining the self-care activities. For homeless youth, part of their self-care involved planning for self-protection. “I’ve got my big huge dog and I know how to fight and I carry weapons [knife].”¹⁸,p.239 In the case of Brazilian garbage workers,¹⁷ many of the workers were aware of the need to protect their hands when touching garbage, but very few actually wore gloves. Lack of access to gloves was the reason most frequently cited, but for others, not wearing gloves was a preference. When questioned about this self-care behaviour however, “arguments emerged in favor of using gloves, such as avoiding the accumulation of dirt under one’s nails and protecting oneself from ‘little animals that appear in the garbage, mainly in summer.’”¹⁷,p.733 In a study of children with cancer, both the parents and children did all they could to protect against risks to health or
safety. “Mark was burned by the IV system, and after that happened, I would only let
certain people [care for him].”  

**Balancing inner and outer worlds**

When meeting universal requisites, self-care activities also entailed balancing
both the inner world of mind, body and emotions, and time spent sharing oneself with
others. For homeless youth, self-care was facilitated by interacting with other people.
“I’m constantly around people so it’s not so lonely.”  For Native women being
healthy and caring for self meant feeling the balance between the physical, mental and
spiritual realms of their lives. “In my opinion health is like a three-legged stool. It’s body,
mind, and spirit. If one is out of balance or not up to par, then the rest follows. And an
unhealthy spirit and mind can affect the body.”

Children with cancer also desired to maintain a balance between solitude and
social interaction while in hospital. One child described being frustrated when friends
avoided her because of her cancer: “People would say to me later, ‘Well, I didn’t call or I
didn’t write because I didn’t know what to say.’ Well, get over it. That’s kind of how I
feel.”  A study of six-year-old children indicated that these children also
acknowledged the importance of sharing time with others. “When asked ‘What sort of
things do you do to look after yourself at school?’ Felicity and Kylie designated ‘playing
around with my friends’ to be a form of self-care because it kept them feeling ‘happy.’
When prompted to describe ‘How is being happy self-care?’ Kylie stated, ‘Because when you’re sad, you feel sick.’

16,p.73
Figure 1: Relation of Synthesized Findings, Categories and Findings for Universal Self-Care Requisites

<table>
<thead>
<tr>
<th>Synthesized Findings</th>
<th>Categories</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Supporting the self:</strong> When meeting universal requisites, self-care activities require self-awareness; discernment of basic needs; taking responsibility for attending to those needs; and protecting oneself from harm</td>
<td>When meeting universal requisites, self-care requires an awareness of self and understanding of one's body</td>
<td>7 findings</td>
</tr>
<tr>
<td></td>
<td>When meeting universal requisites, self-care involves taking responsibility for one's own health or for someone else's health</td>
<td>6 findings</td>
</tr>
<tr>
<td></td>
<td>When meeting universal requisites, self-care is about self-protection</td>
<td>8 findings</td>
</tr>
<tr>
<td><strong>Balancing inner and outer worlds:</strong> When meeting universal requisites, self-care activities entail balancing both the inner world of mind, body and emotions, and time spent sharing oneself with others</td>
<td>When meeting universal requisites, self-care involves striving for balance between mental, physical and spiritual aspects of life, and between social interaction and solitude</td>
<td>4 findings</td>
</tr>
<tr>
<td></td>
<td>When meeting universal requisites, self-care is facilitated by interacting with other people</td>
<td>3 findings</td>
</tr>
</tbody>
</table>
**Developmental self-care requisites**

Requirements related to maintaining conditions that support and promote the process of human development and preventing conditions that would negatively affect the developmental process (Figures 2-4). This analysis was based on 16 studies, \(^{12, 13, 16, 20-32}\) which generated 100 findings; 12 categories and four synthesized findings. (Appendix J) Four synthesized findings emerged:

- Influence of outer and inner worlds
- Continued engagement in self-care
- Positive experience of self-care
- Abandoning self-care activities

**Influence of outer and inner worlds**

When meeting developmental self-care requisites several factors influenced the individuals’ engagement in self-care. For example, one study reported that due to the influence of mother’s time on daily routines, children with disabilities either lost or retained independent self-care activities. "When confronted by time pressure, Karen's mother adapted their daily routine in a way that retained the element of self-feeding independence. Karen ate her sandwich in the car 4 days a week while her mother traveled to pick up an older sibling from school."\(^{27, p.256}\) Mothers’ anticipation of the future could influence the acquisition of self-care behaviours. Some mothers looked
ahead and perceived self-care goals and values for children with disabilities in terms of the children's future, such as preschool that requires the child be potty trained. “This mother identified Allison’s self-dressing as a goal, stating, ‘Maybe if she can dress herself and take her pants off, it would help potty train her.” 27,p.256 Mothers’ values could also determine which self-care skills were mastered. Some mothers placed a higher value on skills (such as eating) which have the potential for public scrutiny. “Dressing is not a subject that you talk to other moms about. It’s a privacy issue, I guess. Even in just talking to my family….No one says, ‘Is he dressing?’” 27,p.255

Not all mothers directed their children’s acquisition of self-care behaviours. When introducing new self-care activities, one mother described allowing her child with disabilities to take the lead. "When she wants to do something, she tries. She just tries, and that's how I know she's ready. I let her tell me.” 27,p.256

For children with asthma the influence of adults was not always positive, as one child described struggling with having someone else decide the legitimacy of his/her asthma symptoms. “In 6th grade I had a teacher who questioned me like 'you're faking it.'” 26,p.602 A study that explored self-care activities in children with diabetes noted that mothers’ expectations also influenced the acquisition of self-care behaviours. Mothers of girls expected them to master the skill whereas mothers of boys were more protective of their sons and performed the task for them. 31
Three studies noted that for children and adolescents, the availability of adult support that was present but not overwhelming, contributed to their ability to adopt self-care activities. Children with asthma enjoyed the support that allowed them the responsibility to perform the necessary self-care behaviours. "Usually my mom doesn’t get involved with it unless it’s really serious, like when I have to go to the hospital. Usually she lets me handle it because she knows I know how to." For some adolescents with spina bifida, engaging in self-care activities was helped by sharing decision making with parents. "Sometimes [my parents’ advice is] dumb, but I listen to it anyway. And sometimes it’s very good advice and all. I’ll take it and I’ll follow it." In a study on middle aged Thai women, the researcher noted that when the demands of the outer world decreased and they spent less time raising children, women felt justified in focusing on their own health and engaging in self-care.

My children are old enough. Now they go to school. I have more free time than I had before so I turn to thinking about myself—my health, my work, my future life. I recognize that my work and my future life will be good if I have good health. I won’t be a burden to others if I start taking care of myself now. I used to care for others a lot; now it’s time for me to think about myself.

Continued engagement on self-care

The study that interviewed mothers of children with disabilities, described how the mothers fine-tuned daily routines and expectations in accordance with their perceptions of their child’s abilities at that moment. Behaviours and self-care skill
acquisitions were not seen as static. “Does he feed himself? Yes, he does. But sometimes he does, and sometimes he doesn’t. I feel I want to be realistic about the things he does. It’s not just black and white.”^27,p.256

A study of adolescents with diabetes who routinely engaged in self-care behaviours reported that these adolescents had mixed views on this experience. Some adolescents perceived the disadvantages of performing self-care activities as being the added burden of responsibility. “Just a lot of responsibility because if something bad happens . . . that was my fault.”^25,p.170 However, others saw no disadvantage, “I can do it all. I don’t have to, but I do . . . I’m responsible.”^25,p.170 In general, most of the adolescent participants perceived benefits of engaging in diabetes self-care in terms of having the knowledge of or confidence in their abilities. "Just feeling that you can take care of it yourself."^25,p.169

The study on middle aged Thai women described how for some of these women, continued engagement in self-care meant overcoming daily obstacles and responsibilities.

I go to work by bus in the early morning. I go back home in the afternoon to take care of my paralyzed husband. I cook for him and my children. After I wash dishes, I take my husband to bed. I spend a few minutes after I’m free from my housework doing Buddhist meditation or sometimes I listen to Buddha’s teaching. In this way, I feel good in the morning and ready to go to work."^20,p.902
Positive experiences of self-care

Several studies\textsuperscript{20,28,29,31} discussed the reinforcement of positive experiences on the performance of self-care activities. For example, one study mentioned that children most frequently identified 'feeling good' as their motivation to adhere to diabetes self-care behaviours. Avoidance of punishment or being concerned about the future were not strong motivators.\textsuperscript{31} For some adolescents with asthma engaging in self-care was facilitated through positive experiences. "I think what benefited me the most is working out . . . working out benefits my body, keeps me physically fit . . . I don’t breathe hard . . . it puts my asthma away [in control and] I don’t kinda come dependent on it—the nebulizer (13-yr male).\textsuperscript{28,p.76}

For adults and elders, positive attitudes to aging, and positive reinforcement of self-care behaviours assisted them to take charge and be responsible for their own self-care. This explanation from one middle aged Thai women exemplifies the “joy of self-care”:

> I think self-care is more than self-centered things. I do it because of my desire. I do it for myself. I do it for my own enjoyment. I do it for my personal growth. There is no one forcing me to do it; I swear. It’s my trial to test the effectiveness of self-care. If I feel good, I will do it forever.\textsuperscript{20,p.900}

A study on Finnish primary care patients noted that the participants’ self-care practices were reinforced by positive experiences of social support and feelings of belonging. Feelings of togetherness with family, friends and colleagues were considered
important. Giving social support as well as receiving it, was reported as a means of health maintenance and self-care. “We had a picnic together, the whole family. It is the best therapy for a person.” 29,p.736

**Abandoning self-care activities**

A study on primary health care patients remarked that individuals abandoned self-care when they felt helpless in the face of aging or when overwhelmed by symptoms. “Every day I feel helpless. I am only 53 years of age and I feel that there are still lots of things that would be nice to do, but I have to leave a lot undone. I simply cannot do any more.” 29,p.738
Figure 2: Relation of Synthesized Findings, Categories and Findings for Developmental Self-Care Requisites

<table>
<thead>
<tr>
<th>Synthesized Findings</th>
<th>Categories</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Influence of outer and inner worlds:</td>
<td>When meeting developmental requisites, a child or adolescent's acquisition and mastery of self-care behaviours is influenced by mother's values, schedules and child rearing styles</td>
<td>13 findings</td>
</tr>
<tr>
<td>When meeting developmental requisites, a child or adolescent's vigilance with self-care behaviours is influenced positively or negatively by their developmental stage and level of maturity</td>
<td>11 findings</td>
<td></td>
</tr>
<tr>
<td>When meeting developmental requisites, a child or adolescent's engagement in self-care behaviours is facilitated by supporting adults</td>
<td>2 findings</td>
<td></td>
</tr>
<tr>
<td>When meeting developmental requisites, control over the care behaviour is an issue for children, adolescents and parents</td>
<td>8 findings</td>
<td></td>
</tr>
</tbody>
</table>
Abandoning self-care activities: When meeting developmental requisites, self-care activities may be abandoned when overwhelmed by symptoms and disabilities or when feeling helpless in the face of aging.

Continued engagement in self-care: When meeting developmental requisites, continued engagement in self-care is facilitated by actively taking responsibility for one’s care, a positive attitude and the reinforcement of a sense of balance and vitality after performing self-care activities.

When meeting developmental requisites, positive consequences of self-care behaviours reinforce the engagement in self-care.

When meeting developmental requisites, individuals respond by taking charge and being responsible for their own self-care.

When meeting developmental requisites, elders find it easier to engage in self-care if they have a positive attitude toward aging, plus they value health and achieving goals.

When meeting developmental requisites, self-care is enhanced by knowledge, an awareness of self, and the ability to identify health needs.

When meeting developmental requisites, individuals with a negative attitude to aging or who felt helpless in the face of aging; or were hampered by a lack of knowledge and found it difficult to care for themselves relinquished control and relied on others for care.
Figure 4: Relation of Synthesized Findings, Categories and Findings for Developmental Self-Care Requisites (continued)

<table>
<thead>
<tr>
<th>Synthesized Findings</th>
<th>Categories</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive experience of self-care: When meeting developmental requisites, self-care activities are facilitated when individuals give priority to establishing balance in their lives; remain connected with family, friends and community and for some individuals, to allow time to gain mental and spiritual peace</td>
<td>When meeting developmental requisites, self-care involves maintaining a balance between health and illness, and between work and play</td>
<td>4 findings</td>
</tr>
<tr>
<td></td>
<td>When meeting developmental requisites, self-care activities are facilitated by remaining connected to family, friends and communities</td>
<td>2 findings</td>
</tr>
<tr>
<td></td>
<td>When meeting developmental requisites, for some individuals mental and spiritual practices are important components of self-care</td>
<td>5 findings</td>
</tr>
</tbody>
</table>
Health deviation self-care requisites

Changes in self-care activities to regulate the effects of deviation from normal structure or function (Figures 5-7). This analysis was based on 42 studies\textsuperscript{12,13,15,23-28,30-62} which generated 198 findings; 12 categories and three synthesized findings (Appendix K). Three synthesized findings emerged:

- Interacting with health care professionals
- Accepting the disability or disease as part of life
- Embarking on self-care and overcoming challenges

Interacting with health care professionals

Health care professionals empowered individuals by acknowledging their knowledge, and recognizing their efforts when engaging in self-care behaviours. Likewise, health care professionals could also disempower individuals by doubting their knowledge and questioning the reliability of their self-care behaviours. For example, one study on adults and elders reported several instances in which the participants were disappointed that their experiences were discounted and that nurses appeared to rely only on physical measurements such as HbA1c or INR to determine the effectiveness of the self-care behaviours. As one participant commented:

I tell her (diabetes educator) about how tired I am, how I just don't have the energy I used to and she says that I am obviously doing well because my A1c (glycosylated haemoglobin) is so good. I am arguing that the new insulin is not
for me because I feel terrible and she is saying it's fine because the numbers say it is.  

Health care professionals could also disempower informal caregivers. A study on informal caregivers of family members with mental illness indicated that sometimes health care professionals ignored or devalued their contributions about their family member. This was despite the intimate involvement and length of time the family caregivers spent providing the support needed by their relatives to develop self-care practices.

My main concern for carers is getting a response quicker, for people to listen to you ... you know the person better than anybody else. They think that because they are the professional that they can judge better... but you are seeing that everyday. I think as a carer you know what they are like when they are normal and you know what they are like when they are ill.  

A couple of studies discussed how individuals wanted to be involved in making choices about their care. A study on adults and elders with chronic obstructive pulmonary disease (COPD) described how most of their participants preferred to take on the responsibility of adjusting their medications as their condition fluctuated. These participants were comfortable working in collaboration with their doctors in managing their illness. “When I saw Dr. X he gave me a range [referring to medication dosage] that I could fiddle [with] myself and then after that I was more comfortable . . . doing that.  

Another study on Native women described their participants’ desire to choose their own treatment modalities (conventional or alternate), or to combine
traditional and conventional approaches when engaging in self-care. “I was in nursing school so I have a background there. I’ve always been interested in medicines and now holistic healing as well. Mostly herbal . . . aroma therapies also work.” 15,p.417

**Accepting the disability or disease as part of life**

In their study on individuals with chronic illness, Baker and Stern described what they termed ‘finding meaning in the disease’ as follows: “Informants who became self-care agents no longer sought a cure, scapegoated, or gave up, but perceived chronicity positively. They found symbolic meaning in chronic illness by assenting to it on the one hand, and by reframing its meaning in their life on the other hand.” 34,p.30 Hence, individuals who were able to reconstruct the implications of their illness or disability in a positive way saw themselves as the focus of their lives, not the disease/disability. This enabled them to engage in self-care. Finding this symbolic meaning provided hope for the future, strengthened coping mechanisms, and enabled a positive sense-of-self. This allowed the individual to acknowledge the vulnerability that accompanied the disease/disability but still maintain a balance in their lives in which they were the focus, not the condition.

One woman with diabetes had become effective in managing the symptoms of the illness after years of rejecting the prescribed treatment regimen and poor blood-sugar control. She described diabetes as something that she would always have and said, “It’s not too bad really. I’m used to it now and I take it day by day. I have a good life.” 34,p.30
Adults with chronic illness who were not able to find symbolic meaning in their illness were not able to embrace self-care behaviours. Instead they searched for cures, blamed doctors for not fixing them or gave up on life. "You have to trust your doctors, but don't trust them to the point that you think they're going to fix you... prepare for the worst."  

Individuals who were able to create a positive perspective of their illness or disability were also able to accept emotions as an important component of self-care. These individuals recognized the need to acknowledge and express their feelings of hope and despair.

For some individuals spirituality and faith were integral aspects of their self-care that helped them find meaning beyond their illness/disability. For example, a study on African-American women with HIV reported that spirituality and religious practices were significant means of self-care that provided healing and strength to get through difficult times, and acceptance of themselves and their lives with HIV/AIDS. “Well, my mother always told me verses to read if I’m worried and depressed, and she played a big part in my Bible life, because I used to see her sit and read and read. And she told me, there’s nothing God can’t do for you... and we went to church together and prayed.”

Meaning could also be found in mothering. For these African-American women with HIV, mothering was inextricably linked to self-care and was a motivation for staying healthy and for continuing to live. All of the women talked about the importance of
taking care of themselves so that they might live to see their children graduate from high school.57

My baby is on her way to being undetectable (viral load) now. It was like God was grinning down on me. So that inspired me to keep giving her meds, and I thought okay, if she is almost testing undetectable, then her mom needs to be the same way. You know, that made me want to take care of myself a little bit more.57,p.54

In another study on low-income white women with HIV, investing meaning in self-care meant searching for what was important in life, and involved creative strategies for living while facing death. “I talked to my therapist about people she's been with when they died. That has helped me and talking to my nurse practitioner ... having a good relationship with her has helped because I know when my time comes she'll guide me through it.”51,p.67

Embarking on self-care and overcoming challenges

For some individuals with health deviations, acquiring knowledge about their condition and how to perform self-care was an important first step when embarking on self-care behaviours. For example, in a study on adolescents with asthma, participants noted that their asthma symptom recognition and knowledge acquisition was enhanced by exposure to multiple educators. "I went to asthma camp...and took some other courses with swimming...so I kinda know a lot about it. (13 yr male)"28,p.76 Another adolescent stated: “I learned the most about asthma from my mom. She’s knows everything — everything. My sister has it worse than I do (17-yr female).”28,p.77
Another study described how for elderly women with osteoarthritis, embarking on self-care meant holding on to their sense of wellbeing by seeking to know about arthritis and how to perform self-care and be self-caring. “So I think that I have had to learn to be self-confident and learned that I have to rely on myself.”³³,p.37

A study on Australian adults with diabetes portrayed how these participants sought discipline and disease control, and focused primarily on acquiring knowledge and looked for the best health professional to provide that information. "I found that I came here straight away and got under the DNE's [diabetes nurse educator] umbrella like and got education about how to read labels and that was more beneficial than any doctor at the time."⁴³,p.5

Discussing the challenges for children with health deviations, a couple of studies²³;³¹ mentioned how children did not want to be set apart from their peers and have to interrupt activities to perform self-care behaviours. One mother commented on her son:

So he knows what he’s supposed to do, but sometimes when you’re with other kids, it’s like, ‘I don’t want to say anything. I don’t want to have to leave just because I have to eat.’ I think when he’s with other kids it’s like, ‘Why do I have to be different from them? Why can’t I just go as long as they do, and not eat lunch?’³¹,p.368

Some children with diabetes were also embarrassed by the diabetes care routine - such as wearing an ID bracelet or carrying supplies,³¹ and a few adolescents with
asthma also reported being embarrassed at having to take medication and mentioned this as a reason for not adhering to their self-care regime.\textsuperscript{23}

Studies discussed the numerous challenges and constraints adults and elders encountered that hampered their self-care behaviours when meeting health deviation requisites. These included financial limitations; workplace constraints; co-morbid conditions; professionals who were disempowering; costs and time wasted to attend appointments; habitual lifestyle patterns; stigma of their condition; and a sense of helplessness. Individuals needed to mobilize many resources to overcome these challenges. For example, a study on Latinos with diabetes commented that many participants reported financial constraints that impeded their diabetes self-care. “I have [been] going for over a week without medications because of lack of money. . .I am hoping that the diabetes will stay well.”\textsuperscript{35,p.206}

In another study on adults with disabilities, participants reported the importance of maintaining a belief in one’s capacity to master challenges caused by the disability; to be independent and fight feelings of helplessness.

When you’re going through a tough period, you have to fight it. Reassure yourself that you can make it and it’ll be better. You should never give up, but force yourself to do the necessary things... Once you’re out of bed and started doing something it usually gets better. (Female, 64 years, pulmonary disease).\textsuperscript{55,p.357}
Figure 5: Relation of Synthesized Findings, Categories and Findings for Health Deviation Self-Care Requisites

**Synthesized Findings**

**Categories**

**Findings**

**Interacting with health care professionals:** When meeting health deviation requisites, engaging in self-care may be influenced by the health care professional’s attitude. Collaborative models of care plus acknowledging the individual’s or his/her family caregiver’s knowledge about the condition helped to empower some individuals to engage in self-care activities.

- When meeting health deviation requisites, individuals felt empowered when health care professionals acknowledged their knowledge and recognized their engagement in self-care behaviours. Individuals felt disempowered when health care professionals doubted their knowledge and questioned the reliability of their self-care behaviours.

- When meeting health deviation requisites, medication plays an important role in self-care behaviours. Individuals recognize the relationship between medication and their functional ability, but are wary of medication side effects. Some individuals want to take on the responsibility of adjusting their medication as their condition and functionality fluctuates. The ability to choose the type of treatment modality engaged in (conventional and/or traditional/alternate) reinforces self-care activities.

- When meeting health deviation requisites, a collaborative model of sharing the power and responsibility between health care professionals and individuals supports the engagement of self-care behaviours. However, not all individuals want to interact in this model.

- When meeting health deviation requisites family caregivers assisting their relatives to engage in self-care activities feel that health care professionals do not acknowledge their roles or value their input regarding care.

5 findings

23 findings

14 findings

1 finding
Figure 6: Relation of Synthesized Findings, Categories and Findings for Health Deviation Self-Care Requisites (continued)

<table>
<thead>
<tr>
<th>Synthesized Findings</th>
<th>Categories</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accepting the disability or disease as part of life: When meeting health deviation requisites, individuals engage in self-care when they are able to find symbolic meaning in the disability/disease or are able to reframe the implications positively; have a positive sense-of-self; acknowledge the emotional dimension of their condition; maintain a balance in their lives; and have the capacity to integrate spiritual support if so desired</td>
<td>When meeting health deviation requisites, the capacity to find symbolic meaning in the disability/disease or reconstruct the implications positively facilitates the individual’s engagement in self-care by providing hope for the future; strengthening coping mechanisms; enabling a positive sense-of-self; allowing the individual to acknowledge the vulnerability that accompanies the disability/disease but still maintain a balance in their lives in which the individual is seen as focus not the condition</td>
<td>33 findings</td>
</tr>
<tr>
<td></td>
<td>When meeting health deviation requisites, for some individuals, spirituality and faith are important components of self-care</td>
<td>6 findings</td>
</tr>
<tr>
<td></td>
<td>When meeting health deviation requisites, emotions are seen as an important component of self-care. Individuals recognize the need to acknowledge and express their feelings of hope and despair</td>
<td>11 findings</td>
</tr>
</tbody>
</table>
Figure 7: Relation of Synthesized Findings, Categories and Findings for Health Deviation Self-Care Requisites (continued)

<table>
<thead>
<tr>
<th>Synthesized Findings</th>
<th>Categories</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>When meeting health deviation requisites, the motivation to engage in self-care behaviours includes family and social roles, especially role of mothering (particularly to an ill child), support of others, role models with the same condition who lead effective lives, comparison with others who were worse off, valuing health, positive consequences of self-care behaviours and the desire to decrease the pain or discomfort caused by the condition or its treatment</td>
<td>25 findings</td>
<td></td>
</tr>
<tr>
<td>When meeting health deviation requisites, individuals encounter numerous challenges and constraints which hamper their self-care behaviours. These include financial limitations, workplace constraints, co-morbid conditions, health care professionals who are disempowering, costs and time wasted to attend appointments, habitual lifestyle patterns, stigma of their condition, and a sense of helplessness. Individuals need to mobilize many resources to overcome these challenges</td>
<td>35 findings</td>
<td></td>
</tr>
<tr>
<td>When meeting health deviation requisites, self-care was enhanced when individuals perceived they had control over themselves and control over their condition. The environment was seen as being beyond control but self-care behaviours were engaged in to minimize the effect of the environment</td>
<td>17 findings</td>
<td></td>
</tr>
<tr>
<td>When meeting health deviation requisites, for some individuals, knowledge of the condition was considered important prior to engaging in self-care</td>
<td>22 findings</td>
<td></td>
</tr>
<tr>
<td>When meeting health deviation requisites, family caregivers assist their relatives to establish a sense of self, personal identity and self-esteem. Family caregivers provide the support needed by their relatives to develop self-care practices</td>
<td>4 findings</td>
<td></td>
</tr>
</tbody>
</table>

**Embarking on self-care and overcoming challenges:** When meeting health deviation requisites, acquiring knowledge, perceiving oneself as being in control and receiving support from others motivates the performance of self-care. Numerous resources have to be mobilized to overcome challenges such as stigma, financial and workplace constraints, lifestyle habits and a sense of helplessness.

62
Meta-synthesis across Orem’s self-care requisites

To synthesize the evidence across all three self-care requisites, the synthesized findings were aggregated on the basis of similarity in meaning to generate meta-synthesized findings (level 4 findings). Four meta-synthesized findings emerged (Figures 8-11):

- Caring for self
- Mastery and balance
- Sustaining self-care
- Disengagement from self-care

**Caring for self**

Engaging in self-care was facilitated by a strong, positive awareness of self, accepting the disease or disability as part of life, and acknowledging emotional, mental, physical and spiritual needs, and taking responsibility for attending to those needs.

**Mastery and balance**

Self-care entailed mastering specific behaviours, and balancing the inner world of mind, body and emotions, with the external influences of parenting, and support from family, health care professionals and others.
**Sustaining self-care**

Perceiving oneself as being in control, acquiring knowledge and receiving support from others were important factors that facilitated the sustaining of self-care behaviours and assisted with overcoming challenges.

**Disengagement from self-care**

Individuals may abandon self-care when feeling helpless in the face of overwhelming symptoms and disability. Disengagement from self-care may not be a permanent process but could be temporary as individuals adapt to new experiences of disability or increasing levels of impairment.
Figure 8: Relation of Meta-Synthesized Findings to Synthesized Findings by Orem’s Self-Care Requisites

<table>
<thead>
<tr>
<th>Meta-Synthesized Findings</th>
<th>Synthesized Findings</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Caring for self:</strong></td>
<td><strong>Supporting the self:</strong> When meeting universal requisites, self-care activities require self-awareness; discernment of basic needs; taking responsibility for attending to those needs; and protecting oneself from harm</td>
<td>3 categories</td>
</tr>
<tr>
<td>Engaging in self-care is facilitated by a strong, positive awareness of self, accepting the disease or disability as part of life, and acknowledging emotional, mental, physical and spiritual needs, and taking responsibility for attending to those needs</td>
<td><strong>Continued engagement in self-care:</strong> When meeting developmental requisites, continued engagement in self-care is facilitated by actively taking responsibility for one’s care, a positive attitude and the reinforcement of a sense of balance and vitality after performing self-care activities</td>
<td>4 categories</td>
</tr>
<tr>
<td><strong>Accepting the disability or disease as part of life:</strong> When meeting health deviation requisites, individuals engage in self-care when they are able to find symbolic meaning in the disability/disease or are able to reframe the implications positively; have a positive sense-of-self; acknowledge the emotional dimension of their condition; maintain a balance in their lives; and have the capacity to integrate spiritual support if so desired</td>
<td>3 categories</td>
<td></td>
</tr>
</tbody>
</table>
Figure 9: Relation of Meta-Synthesized Findings to Synthesized Findings by Orem’s Self-Care Requisites (continued)

<table>
<thead>
<tr>
<th>Meta-Synthesized Findings</th>
<th>Synthesized Findings</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mastery and balance</strong>: Self-care entails mastering specific behaviours, and balancing the inner world of mind, body and emotions, with the external influences of parenting, and support from family, health care professionals and others</td>
<td><strong>Balancing inner and outer worlds</strong>: When meeting universal requisites, self-care activities entail balancing both the inner world of mind, body and emotions, and time spent sharing oneself with others</td>
<td>2 categories</td>
</tr>
<tr>
<td></td>
<td><strong>Positive experience of self-care</strong>: When meeting developmental requisites, self-care activities are facilitated when individuals give priority to establishing balance in their lives, remain connected with family, friends and community and allow time to gain mental and spiritual peace</td>
<td>3 categories</td>
</tr>
<tr>
<td></td>
<td><strong>Influence of outer and inner worlds</strong>: When meeting developmental requisites, acquisition and mastery of self-care behaviours may be influenced by level of maturity and capacity to execute the behaviour, or by external conditions such as mothering style and values or support from others</td>
<td>4 categories</td>
</tr>
<tr>
<td></td>
<td><strong>Interacting with health care professionals</strong>: When meeting health deviation requisites, engaging in self-care may be influenced by the health care professional’s attitude. Collaborative models of care plus acknowledging the individual’s or their family caregiver’s knowledge about the condition helped to empower some individuals to engage in self-care activities</td>
<td>4 categories</td>
</tr>
</tbody>
</table>
Figure 10: Relation of Meta-Synthesized Findings to Synthesized Findings by Orem’s Self-Care Requisites (continued)

<table>
<thead>
<tr>
<th>Meta-Synthesized Findings</th>
<th>Synthesized Findings</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sustaining self-care:</strong> Perceiving oneself as being in control, acquiring knowledge and receiving support from others are important factors that facilitate the sustaining of self-care behaviours and assist with overcoming challenges</td>
<td><strong>Embarking on self-care and overcoming challenges:</strong> When meeting health deviation requisites, acquiring knowledge, perceiving oneself as being in control and receiving support from others motivates the performance of self-care. Numerous resources have to be mobilized to overcome challenges such as stigma, financial and workplace constraints, lifestyle habits and a sense of helplessness</td>
<td>5 categories</td>
</tr>
<tr>
<td><strong>Disengagement from self-care:</strong> Individuals may abandon self-care when feeling helpless in the face of overwhelming symptoms and disability</td>
<td><strong>Abandoning self-care activities:</strong> When meeting developmental requisites, self-care activities may be abandoned when overwhelmed by symptoms and disabilities or when feeling helpless in the face of aging</td>
<td>1 category</td>
</tr>
</tbody>
</table>
Figure 11: Relation of Meta-Synthesis, Synthesized Findings, Categories and Findings

<table>
<thead>
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<th>Meta-Synthesized Findings</th>
<th>Synthesized Findings</th>
<th>Categories [# Findings]</th>
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<tbody>
<tr>
<td>Caring for self</td>
<td></td>
<td>Univ – awareness of self [7]</td>
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<tr>
<td></td>
<td></td>
<td>Univ – take responsibility [6]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Univ – self protection [8]</td>
</tr>
<tr>
<td>Balancing inner &amp; outer worlds</td>
<td></td>
<td>Univ – interact with others [3]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Univ – balance in life [4]</td>
</tr>
<tr>
<td>Influence of inner and outer worlds</td>
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<td>Dev – master behaviour [13]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Dev – support of adults [2]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Dev – control of care [8]</td>
</tr>
<tr>
<td>Continued engagement in self-care</td>
<td></td>
<td>Dev - +’ve reinforcement [6]</td>
</tr>
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<td></td>
<td></td>
<td>Dev – take charge of self [22]</td>
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<tr>
<td></td>
<td></td>
<td>Dev – positive attitude [4]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Dev – know health needs [16]</td>
</tr>
<tr>
<td>Abandoning self-care</td>
<td></td>
<td>Dev - neg attitude to aging [7]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Dev – connect fam/others [2]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Dev – spiritual practices [5]</td>
</tr>
<tr>
<td>Interacting with health care professionals</td>
<td></td>
<td>HD – manage medication [23]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>HD – collaborative model [14]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>HD – accept other carers [1]</td>
</tr>
<tr>
<td>Accepting the disability/disease as part of life</td>
<td></td>
<td>HD – meaning in illness [33]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>HD – importance of faith [6]</td>
</tr>
<tr>
<td>Embarking on self-care and overcoming challenges</td>
<td></td>
<td>HD – motivation [25]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>HD – challenges [35]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>HD – control over self [17]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>HD – know condition [22]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>HD – help of other carers [4]</td>
</tr>
</tbody>
</table>

Requisites: Univ = universal; Dev = development; HD = health deviation
Analysis across developmental groupings for diabetes mellitus

The most frequently reported health deviation was diabetes mellitus (DM) (14 studies\textsuperscript{24,25,31,32,34,35,41-44,46,47,53,62}). This analysis was performed to gain a developmental perspective on self-care by purposively selecting DM as a rich source of data through which to consider this perspective. Developmental categories were defined by the study authors. In the 50 studies, the following age categories included: Children 3-14 years; adolescents 11-21 years; adult 19-65 years and elders 65-92 years. It is noted that there is an overlap in these categories. At each developmental stage, different aspects of self-care emerged and were reflected by four themes:

- Identifying symptoms and learning self-care routines
- Mastering self-care behaviours
- Integrating self-care: busy lifestyles and other challenges
- Self-care as a life goal

Identifying symptoms and learning self-care routines

One of the first motivating factors for children learning DM self-care behaviours was to decrease the pain involved by the procedure. In a study of young children with diabetes, a mother reports: “She was only 5 and we started out doing them for her. But then she did it soon after she was diagnosed. She felt like if she did it herself, it wouldn’t hurt as much. Her fingers were really sore at first.”\textsuperscript{31,p.366} The child referred to in this
study may sound young to engage in self-care behaviours of this complexity, but Alderson and colleagues’ study on children ages 3-12 years with DM found that there was no relationship between age and ability to use needles: “The children’s ability and willingness to use needles were not age related. Jonny and Nicola were 4 years old when they did their own blood tests and injections. James, diagnosed when aged 7, could do his injections before his mother felt able to do them.”

Children were also motivated to engage in self-care for DM to be independent so that they could visit friends and spend time away from home and their parents. According to one study that compared the experience of girls and boys, mothers of most of the girls reported that their daughters easily learned the self-care behaviours in very limited time. However, many of the boys were not motivated to learn. This may have been due to the influence of mothers. “The mothers of the girls had higher expectations for self-care and were more willing to allow their daughters to assume complete responsibility for diabetes-related tasks than were the mothers of boys.”

Children learned to identify and treat episodes of hypoglycemia although these situations were more complicated to treat in the school environment. One mother commented: “It’s hard at school because he has to go to the office, test himself, get the juice box, see if you feel better. [He thinks:] ‘Should I have a starch, too, or is it close to lunch?’ It’s easier at home.”
Children reported learning about how to engage in self-care for DM from many sources. Some parents described teaching on an ‘as we go’ basis rather than through pre-planned sessions. “We teach her as we go—we don’t sit down and read books about diabetes or anything like that. Learning has been gradual. She has learned from her experiences.”

Children with DM felt that having a friend or celebrity that had diabetes, made them feel better about themselves particularly from others with the condition who became role models for them.

The developmental stage of the child was seen to influence the child's vigilance with DM self-care practices. Children were not consistently attentive and vigilant to diabetic self-care, possibly due to an inability to reason. One mother described trying to reason with her son. “What happens if you’re playing basketball and your brother is not there? You take your chain off and everyone else leaves? People wouldn’t know how to take care of you.”

Despite this compelling argument, he refused to wear his ID necklace while playing basketball.

**Mastering self-care behaviours**

In a study on adolescents with DM, mastery of their self-care regimens gave participants the independence and freedom they desired. For example, they perceived the benefits of self-care in terms of having confidence in their self-management abilities. “Probably peace of mind when I’m off by myself.”

The study that explore the experience of the parents of these adolescents found that parents recognized the
benefit of their adolescent’s abilities and maturity and how this confidence helped with the mastery of their self-care behaviours. "She's just really matured and she's responsible for herself...knows that her health depends on her taking care of herself."

**Integrating self-care: busy lifestyles and other challenges**

The key issue for adults with DM was integrating self-care behaviours into busy lifestyles. Several studies on adults with DM\(^{35,41-43}\) reported that participants had great difficulty changing their lifestyle habits, and the habits of their families. “. . .my wife, she gives little importance to my illness. I feel she helps with the needs of my disease very little. She cooks foods that I am not supposed to eat and if I do not eat them she says that she is not going to prepare food for me again.”\(^{35,p.205}\)

In the workplace, adults described situations which were awkward and unaccommodating and often they felt it best not to inform workplace colleagues of their condition. Other challenges faced by adults were financial constraints which prohibited the purchase of both medicine and appropriate foods; multi-morbidities which conflicted and complicated self-care regimes for DM; and health care professionals who refused to engage in collaborative care. Some individuals with schizophrenia and DM frequently lacked the basic necessities because of financial problems. “To tell you the truth, a lot of times, I don’t eat breakfast.
You gotta stretch it, you know. I’ll get back to eating breakfast when things get better, but right now I gotta pay my electric bill.”

Studies on individuals from different cultures mentioned that their participants had different responses to DM and were motivated to engage in self-care for different reasons. For Mexican adults with DM their goal was to master both control of the self and control of the disease, and they struggled to change cultural eating habits. “Old habits, way of life, of not having breakfast. . .to change habits is difficult.”

They assessed how well they were managing the disease by how they felt rather than by glucose levels. Australians with DM expressed a sense of loss due to the disease “it stopped me eating chocolate” and sought knowledge to improve their self-care behaviours. Turks and Arabs living in Australia on the other hand saw DM as a result of stress and their main goal was to remain calm. They sought reassurance and emotional comfort from health care professionals. “The doctor usually tells you everything you need to know.” While Swedes focused on mastering the management of the disease, Yugoslavians looked for creative ways to deviate from DM self-care regimes. Adults with both schizophrenia and diabetes applied their lessons with schizophrenia self-care to DM with regard to consistency of care and adherence to medications. They learnt that continuously engaging in consistent self-care provided a measure of freedom and they sought to replicate this with DM. “I’ve been stable mentally for 15 or 20 years.
so I had a good jump on the diabetes when it started happening. I could take the medicine and remember to take it, and watch my sugar, and it would be ok.”

Self-care as a life goal

Studies on elders with DM often described their motivation to perform self-care couched in aspects of life goals, and in functional rather than biomedical terms, for example the need to “remain independent,” and “being able to walk.” Elders desired to engage with health care professionals in collaborative care, however not all were successful at attaining this goal. In one study of elders with DM, participants stated that the way information was given by health care professionals often affected their willingness and ability to engage in decision making with the professional. For example, when health care professionals spoke in medical jargon they could not understand, they perceived it as accentuating the power differential between the professional and themselves. One elder discerned: “If he can't be bothered to talk so I can understand him, he doesn't really want me to make the decision with him.”

Other studies of elders with DM noted that elders also tended to make downward comparisons to others who were doing poorly in comparison to themselves. “He had to retire because of diabetes, his vision was going, his legs and feet were going, and I look at him and I could see what could happen, you know, for myself, if I don’t take care of myself. . .and it’s really difficult. . .” These comparisons with others could provide a sense of empowerment “I don’t let it (diabetes) press on my mind and keep
me from doin’ things … if you got diabetes, whatever complaints you have, don’t think about it … some people’s mind is worse than mine … and keep on going and you just take care of yourself.”

Like adults, elders were challenged by financial constraints and multiple-morbidities which complicated diabetes self-care regimes. “respiratory problems, leg problems, hypertension, and problems with stairs don’t let me walk.”

However, one study commented on how spirituality and faith played an important role for some elders and allowed them to feel supported over and above the care they received from health care professionals. “Patients often attributed positive behaviors to God’s assistance and talked about the strength and comfort they received from saying prayers and giving thanks for God’s guidance.”

Discussion

Orem’s theory of self-care provided a valuable framework for the analysis and synthesis of studies in this review. Orem’s categories of universal, developmental and health deviation requisites facilitated the reframing of the data in terms of these components, and helped extract some of the key issues involved in engaging in self-care behaviours. As the self-care requisites represent the purpose of performing self-care, analyzing the data according to these requisites provided insights into why individuals performed these behaviours and the obstacles they encountered. Use of Orem’s self-
care framework also provided the opportunity to examine the process of engaging in self-care behaviours through different developmental groupings.

When the purpose of self-care was to meet the universal, basic human needs, studies reported that self-care activities focused around being aware of self, identifying needs and engaging in self-care behaviours that would meet these needs, such as protecting oneself from harm.

When meeting developmental requisites, studies reported that self-care behaviours were influenced by developmental stage and level of maturity. Individuals with a positive attitude toward health were more inclined to engage in self-care behaviours, which in turn were reinforced by feelings of well being that occurred after the performance of care.

When meeting health deviation requisites, studies reported that an individual’s desire to engage in self-care behaviours could be enhanced by positive and supportive relationships with health care professionals. Individuals who were able to find symbolic meaning in their disease/disability, saw themselves as the focus of their lives, not the disease/disability, and consequently found engaging in self-care behaviours much easier than individuals who were not able to find such meaning. Individuals had many challenges to overcome, including financial resources, workplace constraints, co-morbidities, and lifestyle habits. Support from others and a connection to spiritual support if desired, were frequently mentioned as facilitators of self-care behaviours.
The analysis of the experience of self-care across developmental stages for the health deviation of diabetes revealed a gradual evolutionary process. Children focused on identifying symptoms and learning the self-care behaviours. As the child matured into adolescence the desire for freedom and independence became primary goals, and the self-care behaviours were mastered. For adults self-care was reinforced by a collaborative model of care with a health care professional that allowed individuals to become partners in their care. Individuals struggled to overcome challenges and learned to balance care of self and care of the illness. Across all developmental stages, support from others was important and assisted individuals to initiate and sustain self-care behaviours. For elders, self-care was already a part of their lives and they had a strong preference to interact with health care professionals in a collaborative model and be partners in their care. Individuals abandoned self-care in the face of overwhelming symptoms or disability, or when disempowered by professionals.

Family members caring for their relatives also found that health care professionals tended to ignore their knowledge. Although they had extensive knowledge about their relative’s condition and capacity for self-care, health care professionals seldom included them or asked for their input on treatment and recommendations for care.

It is interesting to note, that despite the multiple disease/disabilities represented by these studies, there appears to be a commonality in the experience of self-care. The
four overarching themes obtained from this analysis apply to all conditions and there are similar threads in the experience of engaging in self-care that run through the different groupings.

Conclusions

When analyzing the reported experience of individuals and families engaged in self-care, it is seen as a process involving being aware of self, acquiring knowledge and taking responsibility for meeting needs at whatever level they are presented. The performance of self-care behaviours can be influenced both positively and negatively by attitudes of others. Throughout life the purpose for performing self-care differs and individuals face challenges that interfere with their ability to master these self-care behaviours. Individuals who are able to reframe their experience of disease or disability in a positive way are more capable of adapting and maintaining their focus on caring for themselves. Individuals abandon self-care when overwhelmed by symptoms or disability and/or feel that they are not supported.

Self-care is a generic care concept that transcends medical or impairment groupings. One of the strengths of this synthesis is the ability to integrate multiple disease/disability groupings and the recognition of a commonality among conditions in the experience of self-care. The benefit of combining 50 studies provides a wealth of data from which to view these common threads.
As a next step in the clarification of the concept of self-care, a study of the meaning of the term from key perspectives would enrich our understanding of this concept.

**Implications for Practice**

It is valuable for health care professionals to understand the struggle that individuals experience when trying to engage in self-care. This knowledge may improve how support can be tailored to an individual or family’s need. Furthermore, professionals need to be cognizant of how important their support is, in terms of encouraging individuals to adopt and maintain self-care behaviours. Some individuals do desire to engage in collaborative care models with health care professionals and these individuals would benefit greatly by this support and guidance. Conversely, doubt and disbelief in the ability of individuals to engage in self-care diminishes their confidence and desire to perform these behaviours. Individuals may actually abandon self-care when not supported by health care professionals resulting in a heavier reliance on the health care system. Recognizing the significance of their contribution to helping individuals engage in and maintain self-care behaviours will encourage health care professionals to consistently deliver this support.
Implications for Research

This review integrated the experiences of self-care as reported by individuals and/or their families. Understanding how self-care is perceived contributes to the knowledge about factors that influence the adoption and maintenance of self-care behaviours. This review has provided insight into the process of engaging in self-care through the different developmental stages of life, as well as the adoption of self-care behaviours to meet different requisites. Two areas for further research are evident: 1) development and evaluation of reliable and valid self-care assessments in order that health care professionals can tailor support to need; and 2) evaluate the evidence on the effectiveness of supportive care interventions to assist individuals in engaging in self-care with attention to different disease/impairment groupings identified in this review.

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Conflicts of interest

None.
References


Chapter 3: Care of Self – Care by Other – Care of Other: The Meaning of Self-Care from Research, Practice, Policy and Industry Perspectives

Abstract

Background

Currently, no single definition of self-care is broadly accepted in the literature. Definitions vary as to (1) who engages in self-care behaviour; (2) what motivates self-care behaviours; and (3) the extent to which health care professionals are involved. Perspectives of self-care differ between health care professionals and the general public, and between health care professionals in different disciplines and different roles. As different professions view self-care within their own domain of practice, we are left with a multitude of explanations and descriptions. This variety of conceptualizations does impact and complicate research on self-care. As part of a larger enquiry focused on the clarification of this complex concept, this study provides a content analysis of documented definitions of self-care, and a summary of the evolution of the definition of self-care over time.

Objectives

To examine the diversity of definitions of self-care from the perspectives of research, practice, policy and industry, and to identify themes or trends in the evolution of the definition of self-care over time.
Search Strategy

The search strategy was designed in consultation with a library scientist to find both published and unpublished papers. A three-step search strategy was used to locate the literature. The databases searched included: CINAHL; Medline; EMBASE; PsycINFO; AMED; Cochrane Library; Scirus; and Mednar.

Data Collection and Analysis

The definition of self-care was extracted from each paper included in the study. Using an inductive process, a content analysis was performed identifying common terms and phrases from the definitions. The definitions were then divided into four decades, 70s, 80s, 90s, and 2000s and the evolution of the definition of self-care was examined.

Results and Conclusions

In this study we sought to clarify the concept of self-care by examining in detail the definition of self-care. Content analysis of 139 definitions identified seven components of the definition and a range of terms that were applicable to each component. Evolution of the definition over time revealed a more expansive definition by the end of the 2000s. Current and evolving definitions of self-care would benefit by being comprehensive and encompassing as many facets of the concept as possible.

Implications for Practice

Health care professionals assess, guide, instruct and support individuals as they initiate or engage in self-care. Using a comprehensive definition of self-care would
provide an anchor linking each discipline as they interact not only with the individual but also amongst themselves.

Implications for Research

The concept of self-care is a many layered one. Identifying the components in the definition of the term delineates the different areas for potential research in this area. When planning a research project, the definition of the key concept guides the research and shapes the approach to the investigation. For researchers in this area, this study illustrates the wealth and diversity of the definitions of self-care.

Keywords

Self-maintenance, self-treatment, personal care, lay care

Background

Self-care simply defined is "the care of oneself without medical, professional, or other assistance or oversight." However, self-care is anything but simple. “At one time or another, self-care has been described as a movement, concept, framework, model, theory, process, or phenomenon.” As a complex concept it includes both therapeutic care (medication administration; self monitoring and self treatment) and personal care (activities of daily living – dressing, bathing, eating, etc.). As "the care of oneself" it may be performed in response to illness, injury, long-standing chronic conditions, or disability, and for a myriad of different reasons such as recovery; maintenance of health,
prevention; or in the case of personal care - the preservation of self. Self-care can be self-instigated or follow a prescribed regime, and the process of care may be performed by individuals themselves or by a caregiver (professional, formal or informal). Perspectives on self-care differ between health care professionals and the general public, and between health care professionals in different disciplines and different roles. As different professions view self-care within the framework of their own perspectives we are left with a multitude of explanations and descriptions. This variety of conceptualizations does impact and complicate research on self-care.

[S]elf-care conceptualizations are amorphous and multifaceted, thus, determinants and outcomes differ according to the definitions employed. Because separate bodies of research literature have developed around various conceptualizations, making comparisons of findings is cumbersome. 

Levin⁴ who is considered by many to be the “father” of self-care,²;⁵ suggests that achieving a common definition "may be possible only at the cost of losing the precision required for significant analytic research."⁴,p.¹⁰ In order to investigate the range and diversity of self-care definitions, this study specifically focused on examining definition content from different perspectives documented in the literature. From this, the evolution of the definition of self-care over time could be summarized.
Objectives

To examine the diversity of definitions of self-care from the perspectives of research, practice, policy and industry, and to identify themes or trends in the evolution of the definition of self-care over time.

Study Questions

This study was guided by two questions:

1. How has the concept of self-care been defined from the perspectives of research, practice, policy and industry?
2. Were themes or trends in the evolution of the definition of self-care are evident over time?

Criteria for considering papers for this study

**Types of literature:** Opinion papers, discussion papers, theory/scholarship papers, reviews and reports that provided a definition of self-care from the perspective of research, different health care professionals, policy and industry. Papers and reports in which no intervention was introduced were included.

**Type of intervention or focus:** Papers that discussed the perceptions of individuals from a variety of research institutions, individuals who are health care professionals of any health discipline, political decision makers (Health Canada, the Department of Health in the United Kingdom, and the World Health Organization), or commercial stakeholders with an interest in self-care activities.
**Type of Outcome:** Outcome of interest was definition of self-care.

**Search Strategy to Locate the Definitional Data**

The search strategy was designed in consultation with a library scientist (PO) to find both published and unpublished papers (Appendix A). A single comprehensive search strategy served to locate the literature for the studies described in chapters 2, 3 and 4. A three-step search strategy was used to locate the literature. An initial limited search of MEDLINE and CINAHL was undertaken to locate a few ‘gold standard’ papers. The Medical Subject Headings (MeSH) and listed keywords used by these articles were harvested and a second search using all identified keywords and index terms was then undertaken across all included databases. Third, the reference lists of all identified reports and articles were searched for additional sources. The databases searched included: CINAHL; Medline; EMBASE; PsycINFO; AMED; Cochrane Library; Scirus; and Mednar.

Electronic database searching had an international scope and retrieved articles were limited to English language. The search for unpublished papers included: Dissertation Abstracts; Sociological Abstracts; and Conference Proceedings.

Electronic searching resulted in lists of articles with details of title, author, source, and sometimes abstract. All identified articles were assessed on the basis of the abstract (or full article if the abstract was not available), and full reports were retrieved.
for all papers that met the inclusion criteria for the study. When in doubt, the full article was retrieved.

Initial keywords included, but were not limited to: Self-care; self-care skills; self administration; self medication; self efficacy; personal care; lay care; self maintenance; self regulation; self treatment; health prevention; health behaviour.

Use of the term ‘self-care’ and associated keywords generates a large volume of citations. To address this issue and begin filtering for relevant sources, a variety of search strategies were generated with specific foci such as health; illness/disability; industry; and policy.

**Methods**

Two distinct methods were used to answer the study questions:

1. **Content analysis:** A content analysis was performed on the definition of self-care. Using a process of induction, the definition of self-care was deconstructed into seven components. Terms and phrases used in each definition were extracted and placed into a table according to the relevant component. The final set of words and phrases for each component were then collated to reduce redundancy, providing a final set of terms or phrases relevant to each component.

2. **Evolution over time:** Self-care definitions were organized into four decades 70s, 80s, 90s, and 2000s to identify themes or trends in the definitions over time. Allocation
to decade was done according to the publication date of the paper, or the publication date of the cited definition.

Where authors had referenced other definitions of self-care these were purposefully included and indicated in the citations. This illustrates the cross-pollination of ideas and the breakdown of the silos of different perspectives and/or merging of perceptions of self-care.

All citations and articles were reviewed by the lead author. In collaboration with the co-author panel, selected studies were checked to verify those accepted into the study and those excluded. Regular discussion with the co-authors clarified and reinforced the boundaries of the study and the focus of the analyses.

The definition of self-care was extracted from each paper included in the study. Definitions of self-care that were cited by individuals other than the author (secondary source) were also extracted along with their specific publication date.

Results

The initial search strategy located 9,560 citations of which 139 met the inclusion criteria (Appendix L). Fifty-eight papers were not discussion papers and were discarded. Six papers were excluded because they did not provide a definition of self-care. Seventy-five papers comprised the final set included in this study (Appendices M & N).
Description of the papers

Seventy-five papers were included in this study (Appendix O). Papers ranged in publication date from 1976-2009. Nine countries (determined by the location of the lead author) were included (number of papers in brackets); USA (42); Canada (9); Denmark (8); United Kingdom (7); Australia (2); Netherlands (2); Switzerland (2); and one each from New Zealand and Thailand; and 1 other (encyclopediapedia).

There was a range of publications including (number of papers in brackets): discussion papers (28); reviews (17); book chapters (11); reports (10); conference proceedings (6); concept analysis (1); encyclopedia (1); and a monograph.

The Content Analysis of Self-Care Definitions

One hundred and thirty-nine definitions of self-care were retrieved and formed the basis for the content analysis. Using an inductive process, seven distinct components of the self-care definition were identified and the terms or phrases reflecting these components were aggregated. These components were aspects related to: a) health; b) illness or disability; c) general outcomes; d) the performer of self-care; e) the action of self-care; f) health care professionals; and g) the health care system.

a) Aspects related to health: Sixty-seven definitions included terms related to health. Twenty-six definitions mentioned prevention; 23 mentioned maintaining health or
maintaining life and 20 mentioned health promotion. Only three definitions referred
to risk or risk avoidance. Terms or phrases that addressed health were grouped into
four themes (Table 2).

**Table 2: Aspects Related to Health**

<table>
<thead>
<tr>
<th>General Health Promotion</th>
<th>Maintaining Health</th>
<th>Risks</th>
<th>Prevention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health promotion; Promote optimum health</td>
<td>Meet everyday health needs; Meet social and psychological needs</td>
<td>Risk factor avoidance; Risk reduction; Avoid unnecessary risks</td>
<td>Prevention; Prevent accidents; Prevent disease</td>
</tr>
<tr>
<td>Develop potential for health or health potential; Achieve maximum health</td>
<td>Encourage healthy choices; Performance of health related behaviours</td>
<td></td>
<td>Use of preventive services</td>
</tr>
<tr>
<td>Enhance health; Enhance functional ability</td>
<td>Healthy functioning; To get and stay physically and mentally fit</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Preserve health</td>
<td>Maintain health/maintain life</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Personal well being; To regulate one’s functioning in the interests of life, integrated functioning and well-being</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Address universal needs, goals and health issues in order to acquire well-being and independence</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

b) **Aspects related to illness or disability:*** Seventy-one definitions made reference to illness or disability. Nineteen definitions mentioned treating illness or symptoms and 9 definitions mentioned detecting illness. Terms or phrases that addressed the aspect of illness or disability were grouped into three themes (Table 3):
Table 3: Aspects Related to Illness or Disability

<table>
<thead>
<tr>
<th>Detect illness</th>
<th>Treat or Manage/Cope with Illness</th>
<th>Improve Health /Limit Illness / Prevent Consequences</th>
</tr>
</thead>
<tbody>
<tr>
<td>Detect disease</td>
<td>Disease management</td>
<td>Prevent the consequences of disease and disability</td>
</tr>
<tr>
<td></td>
<td>Treatment; Self-treatment;</td>
<td>Improve health; Restore health; Limit illness;</td>
</tr>
<tr>
<td></td>
<td>Rehabilitate from both acute and</td>
<td>Alleviate illness; Curative or rehabilitative action</td>
</tr>
<tr>
<td></td>
<td>chronic illness</td>
<td>to enhance health</td>
</tr>
<tr>
<td></td>
<td>‘Reactive’ or ‘response’ self-care to respond to symptoms of illness</td>
<td>Cope with symptoms; Cope with disease</td>
</tr>
</tbody>
</table>

Table 4: Aspects Related to General Outcomes

<table>
<thead>
<tr>
<th>General Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>A continuum of caring for the self, organized by the perceptions, decisions and options available to each individual</td>
</tr>
<tr>
<td>Build and enhance the capacities of individuals to do for themselves what people have always done, even though in the last century, some of these functions have been delegated to specialized occupations.</td>
</tr>
<tr>
<td>Allow people with disabilities to be participants in their daily lives.</td>
</tr>
<tr>
<td>Linked less to learning facts about specific health issues and more to learning how to set goals and organize resources and action strategies.</td>
</tr>
<tr>
<td>Continuous adaptability to the circumstances of their lives and refers to a mindset facilitating connectedness to contexts, personal growth and integration of self in daily life.</td>
</tr>
</tbody>
</table>

d) Aspects related to the performer of self-care: Fifty-three definitions specified who performed the self-care activities. Some definitions were specific and stated self-care was performed by “someone who is facing a health problem” or “people
with disabilities.” Self-care was also considered “a characteristic attribute of whole populations.” The most frequent term was individual (25 iterations) but ‘lay person,’ ‘family,’ ‘neighbour,’ ‘consumer’ and ‘community’ were all commonly used. Further, self-care included care by others, ”’self care’ as it has grown up in America included care by others in some instances, e.g. where self care is a reflection of deprofessionalised care.”

e) Aspects related to the action of self-care: Fifty-seven definitions mentioned terms related to the action of self-care. The notions of ‘taking action;’ ‘taking responsibility,’ ‘taking charge’ or ‘being responsible for one’s care’ were frequently encountered. Besides the well-known concepts of symptom monitoring and evaluation, some definitions introduced the idea of evaluating health care services.

It is also interesting to note that two definitions referred to self-care as an ‘unorganized’ or ‘non-organized’ process (Table 5).

Table 5: Aspects Related to the Action of Self-Care

<table>
<thead>
<tr>
<th>Action – General</th>
<th>Action – Related to Illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reflect a self-determined decision-making process (^1\text{2.p.}24)</td>
<td>Take responsibility for a major portion of their care (^1\text{3.p.}23)</td>
</tr>
<tr>
<td>Processes that permit people and families to take initiative, to take responsibility, and to function effectively (^1\text{4.p.}487)</td>
<td>Decision-making process which involves self-observation, symptom perception and labeling, judgment of severity, and choice and assessment of treatment options (^4\text{p.}11)</td>
</tr>
<tr>
<td>Process of taking responsibility; responsibly taking charge; the power to take responsibility;</td>
<td>Continuous substrate of behaviour (custom, lifestyle) and discrete or episodic actions (self-diagnosis, self-treatment) (^4\text{p.}11)</td>
</tr>
<tr>
<td>Set of activities in which one engages throughout life on a daily basis (^1\text{5.p.}39)</td>
<td>A process by which individuals examine themselves, monitor their families and in some cases treat themselves (^1\text{6.p.}35)</td>
</tr>
<tr>
<td>Immediate and continuing behavioural reactions;</td>
<td>Responsibility for one’s own decisions and care</td>
</tr>
<tr>
<td>Action – General</td>
<td>Action – Related to Illness</td>
</tr>
<tr>
<td>---------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>coping strategies; steps taken to preserve and maintain</td>
<td>along with a corresponding right of say in that care</td>
</tr>
<tr>
<td>It also includes the decision to do nothing</td>
<td>Ability to choose, understand, and evaluate professional health care services</td>
</tr>
<tr>
<td>Self-care is &quot;voluntary, self-limited, non-organized, universal, varying complex</td>
<td>What we do at home and at work ... includes how we decide to seek professional care, and what we do in the adhering to or deviating from the treatment regimes provided by our expert advisors</td>
</tr>
<tr>
<td>of behaviours ... involving both continuous and episodic actions ... and a</td>
<td></td>
</tr>
<tr>
<td>decision –making process</td>
<td></td>
</tr>
<tr>
<td>A deliberate action; actions directed toward self or environment</td>
<td>Active, it is participation rather than passive receiving</td>
</tr>
<tr>
<td>Unorganized health activities and health related decision making</td>
<td>Includes decisions to do nothing, self-determined actions to promote health or treat illness, and decisions to seek advice in lay, professional and alternative care networks, as well as evaluation of and decisions regarding action based on that advice</td>
</tr>
</tbody>
</table>

f) **Aspects related to health care professionals**: Thirty-nine definitions mentioned aspects related to health care professionals. There was no overall consensus on the involvement of health care professionals and definitions referred to this interaction as either: directed by health care professionals; without the involvement of health care professionals; or in collaboration with health care professionals (Table 6).

**Table 6: Aspects Related to Health Care Professionals**

<table>
<thead>
<tr>
<th>Health Care Professionals</th>
<th>Directed by Health Care Professionals</th>
<th>Without the Involvement of Health Care Professionals</th>
<th>In Collaboration with Health Care Professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Giving care to oneself that ideally should be given by health care professionals</td>
<td>That self-care does not involve a health professional and the individual independently attains and preserves their desired level of health</td>
<td>Self-care includes behaviours which both supplement and substitute for professional health care procedures, - or reverse - professional health care procedures include those which supplant or substitute for self-care behaviour</td>
<td></td>
</tr>
</tbody>
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<p>| | |</p>
<table>
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<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Directed by Health Care Professionals</td>
<td>Without the Involvement of Health Care Professionals</td>
</tr>
<tr>
<td>--------------------------------------</td>
<td>-----------------------------------------------------</td>
</tr>
<tr>
<td>Compliance to a professionally prescribed medication regimen (^{25,p.32})</td>
<td>Without dependence on, or control by, professionals (^{18,p.276})</td>
</tr>
<tr>
<td>Under the directives of health care professionals (^{17,p.117})</td>
<td>Without formal medical supervision (^{17,p.117})</td>
</tr>
<tr>
<td>The most favourable health outcomes may ensue when patient preferences are congruent with the self-care attitudes of the health care providers (^{27,p.1129})</td>
<td>It includes minimal reliance on appropriate therapists, involves few dependent behaviours, and lead to little neglect of one’s usual duties (^{28,p.218})</td>
</tr>
<tr>
<td>Self-care is not an alternative model for providing health care; it merely provides a different focus to traditional staff-patient interactions (^{27,p.1128})</td>
<td>That self-care does not involve a health professional and the individual independently attains and preserves their desired level of health (^{24,p.1145})</td>
</tr>
<tr>
<td>Self-care is no panacea; it is merely a direction in which medical practice is now moving. Like any approach or treatment, an overzealous or ill-advised involvement may create rather than solve problems (^{27,p.1129})</td>
<td>Instead of professional care (^{31,p.108})</td>
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</table>

**g) Aspects related to the health care system:** Eight definitions made reference to the health care system. Two statements emerged: i) The Individual functions effectively
as the primary health resource in the health care system;\textsuperscript{4,p.11} and ii) Self-care takes place outside the established medical system, distinguishing it from primary care, or first level entry with medical care system.\textsuperscript{2,p.4}

Besides the seven aspects identified by the content analysis, two further aspects relating to self-care were mentioned in the definitions that bear further elucidation here: i) representative perspective on self-care, and ii) the concept of ‘care by other.’

**Representative perspectives on self-care:** Twenty-nine definitions provided specific references to historic perceptions of self-care. It is interesting to note that one definition draws the distinction between primary and secondary self-care – a distinction that is not picked up in the literature as this concept does not appear in any other definition, past or present. These statements do provide a good illustration of how, in some circles, self-care was viewed as a ‘low quality’ and ‘ineffectual’ behaviour (Table 7).

**Table 7: Representative Perspectives on Self-Care**

<table>
<thead>
<tr>
<th>Perspectives on Self-Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lay interventions are dangerous, scientifically unsubstantiated, and associated with superstitious and parochial mentalities; self-care in health is a folk practice, culture-bound and “indigenous,” riddled with absurd and ineffectual remedies, rampantly empirical, contributing on occasion to unnecessary delays in seeking professional care and often implicated in the failure of laypersons to follow prescribed medical regiments. Self-care, so viewed, is considered a vestigial or at best a residual health function in the wake of the growth of “modern medicine” and is to be avoided and deplored.\textsuperscript{4,p.9} (1979)</td>
</tr>
<tr>
<td>In the medical profession’s approach, a distinction is made between professional care and nonprofessional care. The very word nonprofessional seems to imply that something is missing, a certain property – professionality. The designation carries the connotation of marginality, amateurism, a risk of low quality.\textsuperscript{34,p.16} (1981)</td>
</tr>
<tr>
<td>Self-care is not a poor and amateuristic placebo for professional service delivery. It stands on its own right as an essential and basic level of human caring.\textsuperscript{34,p.27} (1981)</td>
</tr>
<tr>
<td>Self-care is neither contemporary nor reactionary. It is the basic health behavior in all societies past and present. \textsuperscript{34,p.27} (1981)</td>
</tr>
</tbody>
</table>
### Perspectives on Self-Care

<table>
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<tbody>
<tr>
<td>The promotion by governments of lay people’s responsibility for their own health represents a ‘victim-blaming’ approach with party political and economic motives. 31,p.109 (1985)</td>
</tr>
<tr>
<td>In primary self-care, actions are based on the individual's knowledge and experience, whereas in secondary self-care, actions are based on information obtained in consultation with laypersons and professionals. 36,p.2 (1997)</td>
</tr>
<tr>
<td>The individual is the most important decision maker in terms of both medical self-care and health self-care because only the individual can attach a value to the benefits or risks of the actions under consideration. 37,p.370 (1994)</td>
</tr>
<tr>
<td>Self-care is much more than dressing, bathing and eating. It is a collection of carefully balanced tactics and strategies. 8,p.128 (1998)</td>
</tr>
</tbody>
</table>

### Care by other

One aspect that emerges from this content analysis that requires further clarification is the concept of ‘care by other’. The term is mentioned by Williamson in 1977 and he states: “Clearly, the person providing care can be the patient himself or someone else. ‘Self care’ as it has grown up in America included care by others in some instances, e.g. where self care is a reflection of deprofessionalised care.” 11,p.188 The term is not actually defined by Williamson or anyone else who uses it subsequently. However, for example, in a situation in which a woman has a disability and requires assistance to perform self-care (such as the activities of daily living) which she is able to guide and direct according to her preference or capability – then she is performing self-care regarded as ‘care by other’. This is illustrated by Meyer and colleagues 38 in their qualitative study titled: ‘They’re taking the place of my hands’: perspectives of people using personal care. Many of the participants in this study described how they assumed the role of being in control of their care in order to receive the specific assistance that
they needed. One participant who wanted to direct and participate in the care he was receiving and not receive care that did not meet his preferences, explained his approach:

It was difficult at first to be strong in your own home because the carers always feel that it’s their job—they know how to do it—why should I be telling them all the time. So I explain to them that I’m part of the scene, that they’re taking the place of my hands. Once they get the message that it’s not a personal criticism of them—this is just the way that I like things done. I have to explain that I’m actually taking part in the proceedings [through giving directions]. (Interview with participant, Rastas) 38,p.599

In a situation where the individual is providing care for another person, for example, when a mother is caring for her sick child with over-the-counter drugs, with, or without consultation with a health care professional, this an example of ‘care of other’, and in this instance, with regard to health care (Table 8).

**Table 8: Comparison of Care of Self, Care by Other and Care of Other**

<table>
<thead>
<tr>
<th></th>
<th>Care of Self</th>
<th>Care by Other</th>
<th>Care of Other</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Focus</strong></td>
<td>Care performed on one’s own behalf</td>
<td>Care performed with support or assistance from others</td>
<td>Care of others at a family or community level</td>
</tr>
<tr>
<td><strong>Degree of independence</strong></td>
<td>Independent - total care by self</td>
<td>Partial independence – partial assistance by others (may be varying degrees of independence)</td>
<td>May be responding to varying levels of independence and providing corresponding levels of assistance</td>
</tr>
</tbody>
</table>
| **Activity**         | - Activities of daily living (e.g., eating, bathing, and grooming)  
- Therapeutic self-care (e.g., medication) | - The individual guides or directs the assistance with activities of daily living (e.g., directed) | - Supporting activities of daily living (e.g., cuing for eating with an elder, assisted bathing of child) |
<table>
<thead>
<tr>
<th></th>
<th>Care of Self</th>
<th>Care by Other</th>
<th>Care of Other</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>administration and monitoring)</td>
<td>assistance with eating, bathing and grooming)</td>
<td>- therapeutic self-care (e.g., care of health issues such as coughs, colds; or ongoing such as cystic fibrosis; at community level, (emotional) care provided by grief support group)</td>
</tr>
</tbody>
</table>

The following clarification by the World Health Organization\(^{25}\) of self-care at various population levels is helpful to our understanding of these different distinctions:

**Individual level**: Exercising to maintain physical fitness and good mental health. It also includes eating well, self medicating, practicing good hygiene and avoiding health hazards such as smoking, as well as safe behaviour for injury prevention. Self-care has a role in early detection for disability prevention and could also mean compliance to a professionally prescribed medication regimen.

**Family level**: Self-care is supporting a family member who needs help. Children, elderly and the chronic patients need the family support as part of their self-care.

**Community level**: Self help groups support self-care at the community level by creating an enabling environment. Experience sharing in self-care and care for vulnerable family members, as well as improving required skills to support self-care are important examples.

Even at **secondary and tertiary levels**, care effectiveness operates through the individual, who assimilates the influence and determines the care. Self-care is taking care of minor ailments, long-term conditions, or one’s own health after discharge from secondary and tertiary health care.\(^{25,p.31}\)
Evolution of the Definition of Self-Care over Time

Self-care definitions were analyzed over time through four decades 70s, 80s, 90s, and 2000s according to the publication date of the paper, or the publication date of the cited definition. There were 8 papers in the 70s; 24 papers in the 80s; 21 papers in the 90s; and 22 papers in the 2000s.

**1970-1979:** Eight papers provided 23 definitions in this decade. At the beginning of this time period, definitions were brief and focused primarily on self-care related to health or illness. Of the 23 definitions, eight referred to promoting health and well-being, seven referred to detecting or treating illness, and four referred to both. One of the earliest definitions (1976) by Levin\(^{39}\) introduced the concept of health promotion and described the role of the individual within the health care system, defining self-care as: “A process whereby a layperson functions on his/her own behalf in health promotion and prevention and in disease detection and treatment at the level of the primary health resource in the health care system.”\(^{39,p.206}\)

In 1977 Williamson\(^{11}\) addressed the possibility that the individual may not be able to perform all the self-care activities on their own behalf. He suggested that self-care could be performed by the individual themselves, or by another person. He introduces this notion of ‘care by others,’ stating, “‘[s]elf care’ as it has grown up in America included care by others in some instances, e.g. where self care is a reflection of deprofessionalised care.”\(^{11,p.188}\)
Following that trend, in 1979 Levin opened the definition to include “one's own health; the health of one's family or group; and the health of one's community.” He further defined self-care as “a characteristic attribute of whole populations.”

Later that year, Levin proposed the concept of universality and described self-care as a non-organized and self-limited set of behaviours. “Self-care is a voluntary, self-limited, non-organized, universal, varying complex of behaviours evolved through a mixture of socializing and cognitive experiences.”

Also in 1979, Norris laid out quite clearly the view of self-care in relation to health. Norris defined self-care as “processes that permit people and families to take initiative, to take responsibility, and to function effectively in developing their own potential for health.” When coping with illness, however, self-care had to take on other activities, notably the decision making process: “Self-care can also be viewed as a decision-making process which involves self-observation, symptom perception and labeling, judgment of severity, and choice and assessment of treatment options.”

During this decade the discussion emerged as to which behaviour is primary – professional care or self-care and Levin addressed this question in his statement: “In relation to professional intervention in health, self-care includes behaviours which both supplement and substitute for professional health care procedures - or reverse - professional health care procedures include those which supplant or substitute for self-
care behaviour. This decade also lays the foundation for the three aspects of self-care: care of self – care by other – care of other.

1980-1989: Twenty-four papers provided 56 definitions in this decade. Twenty-six definitions referred to self-care promoting or enhancing health or well-being, 24 referred to the treatment of illness or restoration of health, and 14 referred to both. Beginning in 1980 and addressing the very practical issues of illness, Kemper (also cited in Gantz) defined medical self-care as care that “stresses how to recognize common problems, what to do when they occur, and when to seek appropriate help.” At the same time, Green (also cited in Gantz) provided a definition that explained precisely what to do in the event of illness, but with a strong emphasis on independence. Green defined self-care as “any activity undertaken by an individual, who considers himself to be ill, for the purpose of getting well. It includes minimal reliance on appropriate therapists, involves few dependent behaviours, and leads to little neglect of one’s usual duties.”

A year later, Dean included both health and illness in her definition, and anchored the concept of self-care as ongoing health behaviour. “Self-care in its various forms, preventive, curative and rehabilitative, is neither contemporary nor reactionary. It is the basic health behavior in all societies past and present.” This was verified by Verschure who defined self-care as “an essential and basic level of human caring.”

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Also in 1981, Verschure addressed the issue of self-care as ‘care performed by the person for themselves’ in contrast with ‘care by others.’ He strongly supported the ‘care-of-self’ perspective and heralded this direct route as a unique method of health care delivery:

Selfcare is care delivery people apply to their own needs; it always consists of activities people carry out. These activities are, or should be, executed in such a way that their various needs are satisfied. We assume that the matter of meeting human needs is first of all a personal activity and therefore anchored in the individual. In selfcare, then, the provider and the recipient of care are one and the same person. The chain of activities between provider and recipient is the shortest one possible.

This fact cannot be overemphasized. It is an exquisite event when compared to any others in care delivery, and most of its features cannot be replicated. The potential for valid data, the fit between need and response, the immediacy of response, the efficiency and lower costs, the ability to set priorities, and the satisfaction received from both activities and response – all create a prototype of care. \(^{34,p.17}\)

One of the definitions by Levin\(^{42}\) echoed this direct care-of-self, stating that self-care was performed by the person “in promoting their own health, preventing their own disease, limiting their own illness, and restoring their own health.”\(^{42,p.181}\) Despite this support, no one adhered as adamantly to the care-of-the-self in this singular manner as Verschure proposed. Rather the definition continued to be more inclusive. For example, King reinforced the earlier definition that taking care of one’s family was also a part of self-care: “Self-care is a process by which individuals examine themselves, monitor their families and in some cases treat themselves.”\(^{16,p.35}\)
With reference to the interaction with health care professionals, most of the definitions suggested that self-care was performed in collaboration with health care professionals. Only two (Levin\textsuperscript{42} and Hickey\textsuperscript{43}) explicitly state that self-care activities were “undertaken without professional assistance”\textsuperscript{42,p.181} or “as a medical care alternative,”\textsuperscript{43,p.1363} a sentiment supported by DeFriese\textsuperscript{7} (also cited in Gantz\textsuperscript{2}) who stated “the self-care movement seeks to build and enhance the capacities of individuals to do for themselves what people have always done, even though in the last century, some of these functions have been delegated to specialized occupations.”\textsuperscript{7,p.46} In 1983, with a focus on self-care and chronic illness, Grieco\textsuperscript{27} voiced some of the concerns about self-care that were held by the health care professionals (particularly medicine) at that time. Seeing self-care as a potentially harmful activity, Grieco and Kopel stated: “Self-care is no panacea; it is merely a direction in which medical practice is now moving. Like any approach or treatment, an overzealous or ill-advised involvement may create rather than solve problems.”\textsuperscript{27,p.1129}

In 1985 however, the attention was turned to the role of the environment on the performance of self-care and both Orem\textsuperscript{44} (also cited in Raven\textsuperscript{40}) and Spradley\textsuperscript{45} (also cited in Gantz\textsuperscript{2}) referred to this element in their definitions. Orem defined self-care as “the production of actions directed to self or the environment in order to regulate one's functioning in the interests of life, integrated functioning and well-being.”\textsuperscript{44,p.31} From a rehabilitation perspective Spradley was more specific with regard to the adaptation of
the environment to assist the individual’s performance of self-care. From this perspective self-care means “restoring or adapting environments so individuals can perform activities of daily living.”\(^{45,p.46}\)

One year later, Vickery\(^{13}\) extended the definition of self-care into a realm not mentioned before, or since. He suggested that self-care embraced those activities performed by lay persons in times of emergencies in which the person acts for the benefit of others:

Self-care goes far beyond minor illness, however. It includes those actions taken by the layman with respect to major emergencies; cardiopulmonary resuscitation (CPR) and the Heimlich manoeuvre are the best known examples.\(^{13,p.23}\)

Also in 1986 Dean\(^{22}\) (also cited in Health Canada\(^{46}\)) proposed her comprehensive definition of self-care (which included almost everything except the suggestion from Vickery):

Self-care involves the range of activities individuals undertake to enhance health, prevent disease, evaluate symptoms and restore health. These activities are undertaken by lay people on their own behalf, either separately or in participation with professionals. Self-care includes decisions to do nothing, self-determined actions to promote health or treat illness, and decisions to seek advice in lay, professional and alternative care networks, as well as evaluation of and decisions regarding action based on that advice.\(^{22,p.62}\)

Later in that year, Dean added another dimension missing from her previous definition as she described self-care or ‘lay-care’ as she referred to it, as a social phenomenon: “Lay-care thus is a social phenomenon. It is shaped by social conditions
and influences, and it in turn can assume forms of behaviour which influence the social situation."\textsuperscript{18,p.276}

At this time, Dean also quotes Van Harberden and Lafaille (original is in Dutch) who defined self-treatment as including “both self-medication, home remedies and ‘self-therapy’ or the therapeutic methods used by individuals to care for psycho-social and mental health problems.”\textsuperscript{18,p.276}

Finally in 1989, Van Agthoven and Plomp\textsuperscript{47} (also cited in Dean\textsuperscript{17}) added, “important to the concept of self-care is individual will and motivation; acknowledging responsibility for one’s own life and the decisions one makes.”\textsuperscript{47,p.245}

At the end of this decade self-care was seen to involve social support, and could be directed at the environment, or performed in emergency situations to help others. Notably, the definition by Van Harberden and Lafaille is the first to include mental health problems as those conditions addressed by self-care. The influence of previous writers is now evident in these definitions and the prolific writings of both Levin and Dean are manifest by their many thoughts on this topic, and the numerous citations of their work by others.

**1990-1999:** Twenty-one papers provided 31 definitions in this decade. Twenty of these definitions referred to promoting health or well-being, 18 referred to treating illness, disease management or responding to symptoms and 14 referred to both. In 1990, Hartweg\textsuperscript{15} (also cited in Sidani\textsuperscript{26}) recognized the continuity of self-care, and reinforced
Dean’s earlier concept of ‘ongoing care.’ Hartweg stated that self-care is: “The set of activities in which one engages throughout life on a daily basis.”

The following year, the World Health Organization (WHO) suggested this working definition: “Self-care in health is behaviour where individuals, families, neighborhoods and communities undertake promotive, preventive, curative and rehabilitative action to enhance their health.” However, the tendency to address self-care for health and self-care for illness as separate issues, evident in both the 70s and 80s, was reiterated by Vickery and Iverson in 1994 (also cited in Health Canada) and they distinguished between “medical self-care (actions concerning medical problems) and health self-care (actions aimed at maintaining and improving health.)” Vickery and Iverson further emphasized the importance of the individual’s role in the performance of self-care. “The individual is the most important decision maker in terms of both medical self-care and health self-care because only the individual can attach a value to the benefits or risks of the actions under consideration.”

In 1995 Dean supported this focus on the role of the individual and provided a comprehensive definition with a strong emphasis on the responsibility of the individual to either act, or take no action, on their own behalf. Dean also recognized that self-care was influenced by the perceptions of the individual and the options available to them.

Self care is a term representing the range of health related decision-making and care undertaken by individuals on their own behalf. Inherent in the concept is the recognition that whatever factors and processes may determine behavior, and whether or not self-care is effective and interfaces appropriately with
professional care, it is the individual person that acts (or does not act) to preserve health or respond to symptoms. We are referring then to a continuum of caring for the self, organized by the perceptions, decisions and options available to each individual.\textsuperscript{6,p.36}

In 1998 several definitions were reported that indicated an increased complexity in the perception of self-care. The World Health Organization\textsuperscript{48} (also cited in Webber\textsuperscript{32}) expanded on its own definition and ‘unpacked’ what Dean referred to as ‘options available to each individual’ by including aspects such as environmental factors and socioeconomic factors.

Self care is what people do for themselves to establish and maintain health, prevent and deal with illness. It is a broad concept encompassing hygiene (general and personal), nutrition (type and quality of food eaten), lifestyle (sporting activities, leisure etc), environmental factors (living conditions, social habits etc.), socioeconomic factors (income level, cultural beliefs etc.) and self-medication.\textsuperscript{48,p.2-3}

Health Canada\textsuperscript{49} noted the evolution of its own perspective on self-care since the eighties, and stated that engaging in self-care could also be considered a ‘determinant of health.’

Self-care, broadly defined as the decisions and actions individuals take in the interest of their own health. In the eighties, it was identified as a key mechanism for health promotion and prevention. Self-care can also be considered as an important determinant of health, concerned with the development and use of personal health practices and coping skills.\textsuperscript{49,preface}

Soller\textsuperscript{50} in turn, added a variety of aspects including ‘diagnosis of emergent signs, symptoms and conditions’ the use of ‘alternate therapies’ and other treatment modalities as well as lifestyle changes.
Self-care means responsibly taking charge of personal well-being by undertaking self-recognition/diagnosis of emergent signs, symptoms, and conditions; seeking professional diagnosis and consultation; using conventional and alternative therapies such as prescription and over-the-counter (OTC) drugs, medical foods, devices, and dietary supplements; and instituting appropriate lifestyle changes such as a balanced diet and exercise.\textsuperscript{50,p.134}

Approaching the definition from a rehabilitation perspective, McColl\textsuperscript{8} saw the value of performing of self-care for individuals with disabilities. “Self-care is much more than dressing, bathing and eating. It is a collection of carefully balanced tactics and strategies that allow people with disabilities to be participants in their daily lives.”\textsuperscript{8,p.128}

This decade saw the emergence of a more complex definition of self-care. In particular, there was a focus on the responsibility of the individual to take action (or to take no action) on their own behalf. Notably, there was also the inclusion of environmental and socioeconomic factors which influenced the individual’s ability to engage in self-care.

2000-2009: Twenty-two papers provided 29 definitions in this decade. Eighteen of these definitions referred to promoting health or well-being, 17 referred to treating illness, disease management or responding to symptoms, and 12 referred to both. In 2000 Mullett\textsuperscript{33} (also cited in the UK Department of Health\textsuperscript{51}) provided an interesting perspective on the role of the health care professional in her definition which stated that self-care is: “A more inclusive concept based on the ideology of supporting patients in making their own wise decisions rather than offering an alternative decision maker”\textsuperscript{33,p.9} Perceiving the health care professional in this supportive role was
reiterated by Webber: “In other words, self care presents an important opportunity for the healthcare professional in a supporting role, guiding and advising the self care manager.”

In 2005 the United Kingdom Department of Health proposed the following comprehensive definition of self-care in which it introduced several new concepts. It definitively included the role of carers and the care of others, and mentioned the meeting of social and psychological needs.

Self care is a part of daily living. It is the care taken by individuals towards their own health and well being, and in their role as carers includes the care extended to their children, family, friends and others, whether in their homes, neighbourhoods, local communities, or elsewhere. Self care includes the actions individuals and carers take for themselves, their children, their families and others to stay fit and maintain good physical and mental health; meet social and psychological needs; prevent illness or accidents; care for minor ailments and long-term conditions; and maintain health and wellbeing after an acute illness or discharge from hospital.

This definition also explicitly places the role of self-care as part of the continuity of care from hospital to home, and is indicative of health policy changes where individuals/families are now more explicitly expected to assume self-care.

In 2007 Hoy and colleagues defined self-care as “rooted in a perception of health as functionality, responsibility, integrity and growth” According to Hoy et al., self-care is “linked less to learning facts about specific health issues and more to learning how to set goals and organize resources and action strategies” Focusing on the perspectives of elders, Hoy et al., defined self-care as being either ‘a health capability’ or
‘a process for health,’ and introduced three new concepts: personal potential; independence and adaptability.

As a health capability, self-care was defined as an action capability whereby the elderly maintain, promote or enhance their functional ability, limit illness, and/or prevent dysfunction and disability in daily life. It refers to their personal potential to address universal needs, goals and health issues in order to acquire well-being and independence.\textsuperscript{9,p.458}

As a process for health, self-care was defined as an individual health development process related to illness and well-being. It demonstrates the elders’ continuous adaptability to the circumstances of their lives and refers to a mindset facilitating connectedness to contexts, personal growth and integration of self in daily life. \textsuperscript{9,p.458}

Finally in 2009, the World Health Organization\textsuperscript{25} provided a definition of self-care from a rehabilitation perspective which reiterated Hoy et al.’s concept of independence and introduced the idea of emotional needs previously seen in the United Kingdom Department of Health’s definition.

Self-care in rehabilitative measures is compliance to a professionally prescribed medication regimen. In the context of disability rehabilitation, self-care includes all measures aimed at prevention of complications, improving recovery rate, reducing disability and enhancing independence. Self-care for management of chronic conditions includes medical management, role management and emotional management. \textsuperscript{25,p.32}

New aspects to emerge in this decade were the supportive role of health care professionals, the integral role of carers, the need to meet social and psychological or emotional needs, and the ideas of personal potential; independence and adaptability.
Discussion

In this study we addressed two aspects relating to the definition of self-care: the content and the evolution of the definition over time. The content analysis revealed seven components of the definition and provided the scope or breadth covered by definitions of self-care. Summarizing this analysis we see that individuals or lay persons perform self-care by taking responsibility for their own care or for care of another. When engaging in activities to address health issues, behaviours relating to promotion, lifestyle, risk and prevention are foremost. When engaging in activities to address illness or disability, detecting, treating or managing, and coping with symptoms were commonly undertaken. Self-care may be performed independently, in collaboration with, or guided and directed by health care professionals. Ultimately, self-care enables the individual to assume responsibility for their own decisions and care, which may entail taking action, or taking no action.

Examination of the evolution of the definition of self-care over time indicated that the definition is becoming more expansive and all encompassing, and includes several key notions. By the 2000s the definition’s reference to health care professionals now includes the option of collaborative care and the supportive role of health care professionals, the care by others and of others is definitive, and notions of adaptation to illness or disability, and achieving one’s personal potential and independence are part of
the process. Self-care is described as including social support and addressing psychological and emotional needs as well as dealing with health, illness or disability.

It is interesting to note that the first specific mention of mental illness is in 1986 and then again in 2005 by the Department of Health and in 2009 by WHO. One might assume that the majority of definitions which simply referred to ‘illness’ included mental health under this concept or conclude that mental health has largely been ignored by these definitions.

To integrate the concepts elucidated by these two analyses and generate an operational definition of self-care it would be beneficial to view self-care as a continuum of care. On the one end one would have self-care activities that are performed to meet everyday basic needs, to maintain health and life and to promote health and prevent disease. These activities could be performed by individuals, families, communities, on their behalf or to assist another. These activities may or may not be performed in collaboration with health care professionals (Table 9).

At some place along the continuum an individual may experience injury, illness or disability that would require an alteration or increase in their self-care activities. At this time the individual may cope with the situation on their own, or may elect or need to engage in either temporary or ongoing assistance from professional (formal or informal) care services. Individuals may avail themselves of the option to engage in
traditional or alternative health care services, and to associate with professionals in either traditional or collaborative care modes. They may also elect to do nothing.

As one approaches the end of the continuum, the individual’s direct involvement in self-care activities will decrease. For example, if the individual becomes impaired and no longer able to enter or exit a bath tub safely on their own, they may require assistance to perform the self-care activity of bathing. To the extent that the individual is able to direct or guide the bathing activity, they are considered involved in their self-care. The self-care continuum would end at the point just before the individual moves into a situation of total dependence in which they are not able to participate in their self-care behaviours in any way (e.g., unconscious or catatonic).

**Operational definition of self-care**

Self-care involves a range of care activities deliberately engaged throughout life to promote physical, mental and emotional health, maintain life and prevent disease. Self-care is performed by the individual on their own behalf, for their families, or communities, and includes care by others. In the event of injury, disability or disease, the individual continues to engage in self-care, either on their own or in collaboration with health care professionals. Self-care includes social support and the meeting of social and psychological needs. Self-care provides the continuity of care between interactions with the health care system, enabling individuals to manage their disease or disability and maintain well-being.
Limitations of the study

Seventy-five papers and 139 definitions provided a wide range of perspectives on the topic. There is still the possibility that some relevant articles were not located despite comprehensive and explicit electronic and hand search strategies. As well, the search was limited to English.

Conclusions

Following a two stage analysis of the meaning of self-care where the content of documented definitions (n=139) and trends over time (1970-2010) were examined, several conclusions can be drawn.

A comprehensive definition of self-care needs to include as many aspects as possible from the seven aspects identified, to address the range of facets that this concept spans. These aspects relate to health; illness and disability; general outcomes; the performer of self-care; the action of self-care; the relation to health care professionals and the relation to the health care system.

The evolution of the definition of self-care has progressed from a simple reference to health and illness in 1970s to an expansive definition by the end of 2000s. Important concepts that have been included are: self-care is deliberate care performed throughout life; by individuals to themselves and to others; to promote health or improve both general health as well as mental health, and cope with illness or disability; and in collaboration with health care professionals or performed separately. Self-care
also includes social support and provides the continuity of care necessary to maintain well-being.
### Table 9: Self-Care Continuum

<table>
<thead>
<tr>
<th>Activities</th>
<th>Beginning of the Continuum</th>
<th>Middle of the Continuum</th>
<th>End of the Continuum</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Engaging in an exercise routine to promote health; treatment of minor ailments, e.g., mother treating her child with a cold and cough with over-the-counter medication</td>
<td>An increase or adaptation of self-care activities to include more complex or chronic conditions or impairments, or to recover from illness or injury, e.g., treating asthma with inhalers and following a management plan; recovering from total knee replacement surgery; living with spina bifida</td>
<td>Directing or guiding the assistance with self-care activities, e.g., living with hemiplegia following stroke and directing assisted bathing and grooming routines</td>
</tr>
<tr>
<td>Relation to health care professionals (HCP)</td>
<td>Generally independent of HCPs</td>
<td>In collaboration with or directed/guided by HCP</td>
<td>In collaboration with or directed/guided by HCP</td>
</tr>
<tr>
<td>Example of some decision points</td>
<td>• How do I maintain my health? • How do I deal with minor ailments? • What community resources are available to support self-care? • What preventative actions can I take to prevent illness and injury? • How do I gauge changes (positive or negative) in health status? • If there is a change in health status, at what point do I contact HCP?</td>
<td>• How do I sustain my health? • How do I promote recovery? • What resources are available to assist me in coping with this situation (alternate therapies; self-help groups; community resources)? • How do I gauge changes (positive or negative) in health status? • If my health deteriorates, at what point do I contact HCP? • How can the environment be adapted to allow me to continue to function effectively?</td>
<td>• Which support person will provide help that best suits my needs? • How do I deal with changes in ability if decompensation occurs? • How do I gauge changes (positive or negative) in health status? • How can the environment be adapted to allow me to continue to function effectively? • At what point will I relinquish control for total care (if this is a conscious decision)?</td>
</tr>
</tbody>
</table>
The use of a comprehensive, all encompassing definition of self-care could create a valuable foundation for the understanding and use of this complex concept in practice, policy and research. As a next step in the clarification of the concept of self-care, the delineation of the attributes and facets of self-care through a formal concept analysis would enhance our knowledge of this concept.

**Implication for Practice**

Health care professionals assess, guide, instruct and support individuals as they initiate or engage in self-care. Using a comprehensive definition of self-care that encompasses all components would provide an anchor linking each discipline as they interact not only with the individual but also amongst themselves. As the numbers of people who need assistance engaging in and maintaining self-care increases, and as we move toward more interprofessional health care delivery, a strong and comprehensive definition of self-care will benefit both professionals and care recipients alike.

**Implication for Research**

The concept of self-care is a many-layered one. Identifying the components in the definition of the term delineates the different areas for potential research in this area. When planning a research project, the definition of the key concept guides the research and shapes the approach to the investigation. For researchers in this area, this study illustrates the wealth and diversity of the definitions of self-care and highlights the
need for further concept clarification. One area for future research would be the clarification of the components of self-care in an interprofessional approach.

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Conflicts of interest

None.
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Chapter 4: Self-Care: A Concept Analysis

In the next stage of the enquiry on self-care the focus shifts to further understanding self-care through a concept analysis study. A concept analysis is performed to examine the structure and function of a particular concept, and serves to clarify that concept’s attributes and uses.¹ This concept analysis serves to delineate the attributes of self-care and increase our understanding of this notion.

Self-care is a core concept relevant to multiple health care disciplines, such as nursing, rehabilitation, medicine, psychology, sociology and social work. Self-care is also a key element from both political and industry perspectives. However, as different professions view self-care within the framework of their own perspectives we are left with numerous definitions, explanations and descriptions of this concept. The importance of self-care as an integral part of promotive, preventive, curative and rehabilitative care⁴ necessitates that we examine this concept and endeavour to define it as explicitly and inclusively as possible.

Criteria for considering literature for this study

The scope of literature used in this concept analysis was drawn from qualitative, quantitative and discussion or opinion papers that focused on the concept of self-care. Papers were accepted regardless of the presence or absence of an intervention. Types
of outcomes were the experience of self-care, the definition of self-care or factors associated with the engagement of self-care.

The literature was located by performing a rigorous search and retrieval from research databases. A single comprehensive search strategy served to locate the literature for the studies described in chapters 2, 3 and 4 (Appendix A). The systematic search strategy aimed to find both published and unpublished studies. An initial scoping search of MEDLINE and CINAHL was undertaken to analyze the text words contained in the title and abstract, and of the index terms used to describe the article. A second search using all identified keywords and index terms was then undertaken across all included databases. Finally, the reference lists of all identified reports and articles were searched for additional studies. The databases searched were CINAHL; Medline; EMBASE; PsycINFO; AMED; Cochrane Library; Scirus; and Mednar.

Electronic database searching had an international scope and retrieved articles were limited to English language. The search for unpublished studies included: Dissertation Abstracts; Sociological Abstracts; and Conference Proceedings. The search strategy located 9,560 citations. From this set, 141 papers formed the basis of this analysis. These papers were representative of three distinct knowledge bases: 1) qualitative studies that focused on individuals’ and families’ experience of self-care (50 studies); 2) quantitative studies focused on self-care research (16 studies); and 3) discussion papers, opinion papers, reports and reviews that discussed the concept of self-care from the perspective of research, practice, policy and industry (75 papers).
Concept Analysis Method

This concept analysis follows the methodology proposed by Walker and Avant,\textsuperscript{1} which has been used to illuminate other complex concepts such as palliative care (e.g., Foster’s\textsuperscript{2} \textit{Pediatric palliative care revisited: a vision to add life}). Walker and Avant modified Wilson’s\textsuperscript{3} original concept analysis procedure and reduced the steps from 11 to eight.\textsuperscript{1} These steps guide the process of elucidation as follows: 1) select a concept; 2) determine the aims or purposes of the analysis; 3) identify all uses of the concept; 4) determine the defining attributes; 5) identify a model case; 6) identify borderline, related, contrary, invented and illegitimate cases; 7) identify antecedents and consequences; 8) define empirical referents. The data I have used to support this analysis is provided by published research.

Step 1: Select a concept

\textit{Walker and Avant}\textsuperscript{1,p.66} describe this step as selecting a concept that is significant or reflects a topic or area of great interest – a topic that you would like to examine in its various contexts, boundaries and relevance to your own work.

The concept of self-care is multi-faceted, and commonly regarded as an activity performed to promote or sustain health, treat illness or injury, or cope with disability. Self-care includes both therapeutic self-care (medication administration, self-monitoring and self-treatment) and personal care (activities of daily living such as bathing, eating and dressing). Self-care can be performed by the individual on his/her own behalf, or on
behalf of his/her family or others. Self-care may be perceived as the most direct care available in which the person delivering the care and the recipient of care are one and the same person, or it can include care administered or guided by others. Self-care may be performed following a medical regime or be self-initiated, and may be performed with or without consultation with a health care professional.

The following examples illustrate a few varieties of self-care activities: 1) a person who goes for daily walks to keep fit and attends community gatherings on a regular basis is performing self-care (care of self); 2) a mother caring for her sick child with over-the-counter drugs, with, or without consultation with a health care professional, is an example of ‘care of other’ or the care of family, in this instance with regard to health care; 3) a person with disabilities who is assisted with certain aspects of his/her activities of daily living such as bathing or dressing, is performing self-care (or care by other) even though he/she may require the assistance of another person to complete the task.

In Canada, self-care is perceived as one of the pillars of health care reform and enabling individuals and families to engage in their own preventive and rehabilitative care is seen as an important contribution toward the overall health care system. As the incidence of chronic disease increases, the capacity of individuals to take responsibility for a portion of their care reduces the burden on the health care system. From the perspective of the Nonprescription Drug Manufacturer Association of Canada (NDMAC), self-care has generated a $4.7 billion dollar industry, which in turn, is able to
generate a greater variety of products to assist individuals and families in their
dficiency of self-care.

Considering the multiple perspectives of individuals, health care professionals,
policy and industry, it is important to clarify the concept of self-care.

**Step 2: Determine the aims of the analysis**

_This step answers the question: “why am I doing this analysis?”_

Self-care has been selected as the topic for this concept analysis because the
many facets of the term contribute to a variety of different views on its scope and
applicability. Because these differences exist amongst health care professionals who
must communicate both amongst themselves and with the individuals and families who
are performing these care activities, it is important to explicate this complex concept.
Therefore, the aim of this concept analysis is to identify the various components that
delineate and clarify the concept of self-care.

**Step 3: Identify uses of the concept**

_“Using dictionaries, thesauruses, colleagues, and available literature, identify as many
uses of the concept as you can find.”_  

The research literature indicates that the concept of self-care is used in two
distinct ways: 1) self-care as it relates to a health care behaviour; and 2) self-care as it
refers to a child’s care of themselves at home alone in the absence of a parent (called
‘latch-key children’ in Canada). This second usage is described in articles emanating from the United States and is defined as: “A self-care child is one between the ages of approximately 6 and 13 who spends time at home alone or with a younger sibling on a periodic basis.”\textsuperscript{12,p.294} This concept analysis will not include the use of self-care in this context, but will examine self-care as it relates to health care behaviours. It is important to note that the literature on self-care is heavily weighted to the topic of self-care as it relates to disease/disability management. There is notably less coverage on other facets of self-care such as personal care and self-care as it relates to health promotion and prevention.

Self-care has been variously described as “a movement, concept, framework, model, theory, process or phenomenon”\textsuperscript{13,p.2} This multiplicity regarding the scope of self-care is evident in the variety of definitions that described self-care during the years 1975 to the mid 2000s\textsuperscript{14}. The Encyclopedia of Public Health (2002) defined self-care as follows: “Self-care involves activities to enhance health, prevent disease, evaluate symptoms, and restore health - either with or without participation by professionals.”\textsuperscript{15,p.1} To analyze the content of the definition it is helpful to view the definition as addressing several different components: 1) enhancing health and preventing disease; 2) treating illness or restoring health; and 3) having a potential interaction with health care professionals. Two other components have been identified from other definitions: Who performs the self-care activity, defined as, “a process by which individuals examine themselves, monitor their families and in some cases treat
themselves,” and the action performed during the process of self-care, generally referred to as “a self-determined decision-making process.”

Self-care has been seen as both a long-standing and ongoing process. As defined by Dean, “self-care in its various forms, preventive, curative and rehabilitative, is neither contemporary nor reactionary. It is the basic health behavior in all societies past and present.” Fundamentally, self-care is “the capacities of individuals to do for themselves what people have always done.” However, ‘what people have always done’ has not always been perceived as positive. Self-care practices have also been seen as:

dangerous, scientifically unsubstantiated, and associated with superstitious and parochial mentalities. In effect, this view holds that self-care in health is a folk practice, culture-bound and “indigenous,” riddled with absurd and ineffectual remedies, rampantly empirical, contributing on occasion to unnecessary delays in seeking professional care and often implicated in the failure of laypersons to follow prescribed medical regimens. Self-care, so viewed, is considered a vestigial or at best a residual health function in the wake of the growth of “modern medicine” and is to be avoided and deplored.

In 1986 Dean defined self-care as a social phenomenon: “Lay-care thus is a social phenomenon. It is shaped by social conditions and influences, and it in turn can assume forms of behaviour which influence the social situation.” This notion was reiterated by the World Health Organization in 2009: “Self-care is health-related decision-making and care undertaken by individuals, family and communities and ... the decision-making process depends on local socio-cultural aspects.” Alternatively, Hoy
and colleagues suggested that “from a lay perspective, ... self-care is understood as a general private activity.”

It is helpful at this point to examine the use of self-care within the various components, namely: health; illness or disability; the individual who performs self-care; the action of self-care; and the interaction with the health care professionals and the health care system.

**Health**

“Self-care is rooted in a perception of health as functionality, responsibility, integrity and growth.” Self-care was seen as something more than an activity to be engaged in to address illness and disability; “it is also about taking care of yourself by living a healthy lifestyle.” In her definition of self-care, Orem introduced the idea that self-care provided the conditions that promote functionality and development. Self-care was seen as “continuous performance of sets of related actions by older children and adults that supply the materials and bring about the conditions that are regulatory of their own functioning and development.”

In their discussion of self-care and the elderly, Hoy and colleagues also addressed the idea of functional ability and defined self-care as a health capability, a process for health, or a health resource. In these definitions Hoy et al. introduced the notions of personal potential to address self-care needs, the goal of acquiring independence, and the continuous adaptability to circumstances that is required to remain integrated in daily life.
As a health capability, self-care was defined as an action capability whereby the elderly maintain, promote or enhance their functional ability, limit illness, and/or prevent dysfunction and disability in daily life. It refers to their personal potential to address universal needs, goals and health issues in order to acquire well-being and independence.\textsuperscript{22,p.458}

As a process for health, self-care was defined as an individual health development process related to illness and well-being. It demonstrates the elders’ continuous adaptability to the circumstances of their lives and refers to a mindset facilitating connectedness to contexts, personal growth and integration of self in daily life.\textsuperscript{22,p.458}

Self-care as a health resource is defined as a person-oriented framework, ... emphasizing self-care as a health-promoting approach ... and comprising both a general and specific ability to act and respond to health issues in order to maintain and improve health and well-being.\textsuperscript{22,p.463}

When definitions of self-care addressed the component of health, it could refer to “one's own health; the health of one's family or group; and the health of one's community."\textsuperscript{20,p.12} However, few definitions of self-care referred exclusively to the health component. Wilkinson,\textsuperscript{24} for example, described in detail some of the elements that needed to be considered for self-care in health. “Self-care could be understood as people being responsible for their own health and well-being through staying fit and healthy, physically, mentally and where desired, spiritually. This includes taking action to prevent illness and accidents, the appropriate use of medicines and treatment of minor ailments.” \textsuperscript{24,p.1145}
Illness and disability

Historically, self-care for illness was seen “more like training for family ‘first-aid’ in the event of illness or accident. It was care ‘until the doctor comes!’” More recently, and from the perspective of the medical profession, self-care was regarded as a process “to transfer responsibility for certain levels of care (i.e. assessment, monitoring, treatment, compliance) to patients.” Woods explained what the responsibility for certain levels of care entailed and defined self-care as:

A person’s attempts to promote optimal health, prevent illness, detect symptoms at an early date, and manage chronic illness. Self-care may also include processes of self-monitoring and assessment; symptom perception and labeling; evaluation of severity; and evaluation and selection of treatment alternatives, such as self-help, lay helping resources, or formal health services.

Soller, who presented the perspective of the Nonprescription Drug Manufacturers Association, introduced the consumption of drugs, dietary supplements and medical foods to be taken in response to illness, and defined self-care as meaning,

responsibly taking charge of personal well-being by undertaking self-recognition/diagnosis of emergent signs, symptoms, and conditions; seeking professional diagnosis and consultation; using conventional and alternative therapies such as prescription and over-the-counter (OTC) drugs, medical foods, devices, and dietary supplements; and instituting appropriate lifestyle changes such as a balanced diet and exercise.

In the following comprehensive definition, Dean reinforced the responsibility of the individual for his/her own care in illness by introducing the decision to do nothing,
the ability to seek advice in alternate care networks, and the evaluation of advice obtained in consultation.

Self-care in illness is the range of individual behaviour involved in symptom recognition and evaluation, and in decisions regarding symptom responses, including decisions to do nothing about symptoms, to treat the symptoms by self-determined actions or to seek advice regarding treatment. Self-care thus includes consultation in the lay, professional and alternative care networks as well as evaluation of and decisions regarding action based on the advice obtained in consultation.\textsuperscript{21,p.276}

From a broader perspective, Hoy and colleagues used self-care to refer to “an ability to care for oneself regardless of the health condition and it reflects the extent to which elders are able to care for themselves. Self-care is linked less to learning facts about specific health issues and more to learning how to set goals and organize resources and action strategies.”\textsuperscript{22,p.463} Providing an unique definition, Vickery too suggested that “self-care goes far beyond minor illness, however. It includes those actions taken by the layman with respect to major emergencies; cardiopulmonary resuscitation (CPR) and the Heimlich maneuver are the best known examples.”\textsuperscript{28,p.23}

Approaching self-care from the bigger political picture, Health Canada proposed that “self-care can also be considered as an important determinant of health, concerned with the development and use of personal health practices and coping skills.”\textsuperscript{29,preface}

When applied specifically to disability and rehabilitation, self-care has been defined as “much more than dressing, bathing and eating. It is a collection of carefully balanced tactics and strategies that allow people with disabilities to be participants in
Furthermore, the World Health Organization defined self-care in rehabilitative measures as regarding:

...compliance to a professionally prescribed medication regimen. In the context of disability rehabilitation, self-care includes all measures aimed at prevention of complications, improving recovery rate, reducing disability and enhancing independence. Self-care for management of chronic conditions includes medical management, role management and emotional management.

**Who performs self-care activities?**

Self-care activities are performed by individuals, families, lay persons, and consumers. Levin described self-care as being:

Those activities individuals undertake in promoting their own health, preventing their own disease, limiting their own illness, and restoring their own health. These activities are undertaken without professional assistance, although individuals are informed by technical knowledge and skills derived from the pool of both professional and lay experience.

In 1981, Verschure declared that self-care was an unique prototype of care. “In selfcare, then, the provider and the recipient of care the one and the same person. The chain of activities between provider and recipient is the shortest one possible.”

However, rather than follow this lead, definitions of self-care became more inclusive and care by others was commonly reported, as mentioned by Williamson: “‘Self care’ as it has grown up in America included care by others in some instances, e.g. where self care is a reflection of deprofessionalised care.”

Dean consistently recognized “the central role individuals play in their own care,” a sentiment reiterated by Cicutto, who noted, “the terms self-care or self-
management denote any self-initiated, self-directed action of engaging in activities of daily living and other activities to preserve physical, emotional and social wellness. This term emphasizes the patient’s role as primary in his/her health care.\(^{32,p.168}\)

In this detailed definition, Dean credited the individual with the power to act, to preserve his/her own health or respond to symptoms.

Self care is a term representing the range of health related decision-making and care undertaken by individuals on their own behalf. Inherent in the concept is the recognition that whatever factors and processes may determine behavior, and whether or not self-care is effective and interfaces appropriately with professional care, it is the individual person that acts (or does not act) to preserve health or respond to symptoms. We are referring then to a continuum of caring for the self, organized by the perceptions, decisions and options available to each individual.\(^{33,p.36}\)

In 2005, the Department of Health in the United Kingdom proposed this working definition of self-care which gave several details of the role of carers:

Self care is a part of daily living. It is the care taken by individuals towards their own health and well being, and in their role as carers includes the care extended to their children, family, friends and others, whether in their homes, neighbourhoods, local communities, or elsewhere. Self care includes the actions individuals and carers take for themselves, their children, their families and others to stay fit and maintain good physical and mental health; meet social and psychological needs; prevent illness or accidents; care for minor ailments and long-term conditions; and maintain health and wellbeing after an acute illness or discharge from hospital.\(^{34,p.5}\)

**The action of self-care**

Self-care was consistently reported as being an active process, a time to take charge, and take responsibility\(^ {28}\) for one’s own care. Dean stated: “Self-care is active, it
is participation rather than passive receiving of care or directives given by professionals."\(^{31,p.118}\) When dealing with illness or disability, self-care was viewed as “a decision-making process which involves self-observation, symptom perception and labeling, judgment of severity, and choice and assessment of treatment options.”\(^ {20,p.11}\)

**Interaction with health care professionals**

“A general theme found in the medical, sociological, and nursing literature is that self-care is giving care to oneself that ideally should be given by health care professionals.”\(^ {35,p.61}\) Most definitions of self-care described the process as being performed under the direct care of health care professionals, totally independent of health care professionals or in collaboration with their care. Webber proposed that working in collaboration provides the opportunity for health care professionals to guide and support individuals’ self-care practices. “Self care may be exercised alone (e.g. treating a mild headache) or in collaboration with professional care. In other words, self care presents an important opportunity for the healthcare professional in a supporting role, guiding and advising the self care manager.”\(^ {36,p.67}\)

However, not everyone perceived this move toward self-care as a positive event. In 1983 Grieco stated: “Self-care is no panacea; it is merely a direction in which medical practice is now moving. Like any approach or treatment, an overzealous or ill-advised involvement may create rather than solve problems.”\(^ {37,p.1129}\)
Interaction with health care system

Levin proposed that self-care was "a process whereby a layperson can function effectively on his own behalf in health promotion and prevention and in disease detection and treatment at the level of the primary health resource in the health care system."\(^{38, p.206}\)

Step 4: Determine defining attributes of the concept

Defining the attributes is the heart of concept analysis. "The effort is to try to show the cluster of attributes that are the most frequently associated with the concept and that allow the analyst the broadest insight into the concept."\(^{1, p.68}\)

Self-care is a complex concept and has many defining attributes (Table 10).\(^{39}\)

Elements of self-care\(^{7}\)

Self-care is regarded fundamentally as either therapeutic care (medication administration; self monitoring and self treatment) or personal care (activities of daily living – dressing, bathing, eating, etc.). Therapeutic care is used with reference to activities performed in response to illness, injury or impairment that require ongoing monitoring and treatment. The term self-management is often used either synonymously with self-care, or to represent the management process that occurs with therapeutic care.

Personal care refers to the care performed as part of the activities of daily living (ADLs) and comprises four elements, namely: physical care, emotional care, intellectual
care and spiritual care. Physical self-care refers to the daily actions such as toileting, dressing, eating, etc. Emotional self-care refers to the methods of coping with emotional experiences, such as strategies to deal with an emotionally stressful situation (e.g., loss or separation). “Intellectual self-care refers to those activities one undertakes in an effort to stimulate one’s brain, to advance one’s learning, or to test one’s intellectual capacities.” Spiritual self-care refers to desire to seek and find meaning and inspiration from a connection with the spiritual domain.

Physical self-care has been divided further to accentuate intimate self-care which specifically refers to bathing and showering, washing intimate parts of the body, i.e., genitalia and menstrual care.

*Context of care*

Self-care is performed in the context of health, disease, disability, recovery and prevention.

*Performance of care*

The performance of self-care can be considered as care of self, care of other, or care by other. The care by other can be either formal care or informal care, which can provide either partial assistance or total assistance. Self-care can be performed for the preservation of self (i.e., activities of daily living). Self-care may be performed to either start a behaviour, or stop a behaviour.
Timeline of care

The requirement to perform self-care may be a one-time affair, a limited time frame, a long time frame or a lifetime.

Requirements in order to perform self-care

The performance of self-care may require the acquisition of new skills or knowledge, or may be within the pre-existing repertoire of individual.

Behaviour range

Self-care may entail the performance of a simple behaviour (one behaviour), or may entail the performance of complex behaviours (set of behaviours), such as a treatment regimen that may evolve over time. Self-care behaviours may be performed in private without social support, or in public with many people and open to social support.

Self-care with regard to illness or disability

Self-care with regard to illness or disability entails self observation, identification of the symptom or condition, judgment of severity, self-treatment or self-medication, monitoring, evaluation, and ongoing self-monitoring and/or self-treatment. Self-care may be performed in response to a specific disease or in response to a generic condition or disability.

Initiation of self-care activities

Self-care can be initiated by the individual where no condition is present, by the individual in response to a condition, or by the prompting of a health care professional.
**Motivation**

The individual may be motivated to perform self-care or may require constant encouragement and external support.

**Self neglect**

Self neglect is not an attribute of self-care, however, it best describes the antithesis of self-care. Self-neglect may be passive, for example, in the choice to remain inactive and not to perform behaviours to promote health; or active, such as self-abuse (self-mutilation) or actively engaging in activities that threaten health and well-being such as smoking.

**Step 5: Identify a model case**

“A model case is an example of the use of the concept that demonstrates all the defining attributes of the concept.”

Mr. Brown looks at his watch. It is 08:00 a.m. He stands up and walks into the kitchen. He takes his glucose monitoring meter and insulin syringe out of the cupboard and retrieves his insulin from the fridge. He loads the lancet, pricks his finger and places the test-strip into the glucose monitoring meter. He notes the blood sugar level in his daily log book and draws up the required morning dose of insulin which he injects into the right side of his abdomen. He sets about preparing his breakfast that will be ready to eat in thirty minutes. After he finishes his breakfast, he puts on his coat and hat,
carefully remembering to put an orange into his pocket for his mid-morning snack, and sets out for his daily walk in the woods.

In this example, we see a performance of self-care according to a carefully planned regime. Although no health care professional is mentioned, most diabetic care is performed in collaboration with health care professionals, with the bulk of the care being the responsibility of the individual. It is common for insulin dosages to be set by the health care professional with instructions on adjusting the dosage according to blood sugar levels. Mr. Brown is not only following the monitoring and medication administration aspects of self-care, he is also making sure he eats within the required timeframe of his insulin and that he has a daily exercise routine. He is also vigilant about having mid-morning snack to maintain the constancy of his blood sugar levels. This is an example of a dedicated self-care regime of an individual with diabetes.

Step 6: Identify borderline, related, contrary, invented and illegitimate cases

A borderline case

A borderline case contains “most of the defining attributes of the concept being examined but not all of them.”

Lying on her back, Joyce stares at the ceiling. It is almost a month since her accident and the full extent of her injuries have yet to sink in. The sound of the monitors and machines in the room confuse and scare her. All she knows is that she is not able to
move her arms or legs. The implications of this for her future are beyond her grasp. The pain in her head is pounding, throbbing almost in rhythm with the beeps from the monitors. She recalls the doctor saying, all she has to do is move her head to the right and the nurse will come into her room. Slowly, and with much effort, she shifts her head, so that her right cheek presses against the call bell lying on top of her pillow. Immediately the light goes on outside her room and the nurse walks in, saying “Hello Joyce, how can I help you?”

This case exemplifies a borderline scenario because Joyce is not able to perform the self-care activity of attending to her pain and taking an analgesic on her own. However, she is able to summon another person, the nurse, who would provide the analgesic.

A related case

A related case is an instance of the concept that is related to the concept being studied but does not contain all the defining attributes. A related case is similar and in some way connected to the main concept.¹, p.71

Joe was struggling to adapt to life in his wheelchair. The loss of his legs was an immeasurable blow and now he had to learn to negotiate his world in a chair. He could not anticipate problems or barriers and frequently ended up in awkward or potentially dangerous situations. He began to despair ever getting his life back on track. The occupational therapist at the rehabilitation centre suggested that he join the amputee
self-help group which held its meetings in a community centre near where he lived. The occupational therapist assured Joe that by joining the self-help group he would meet people who were in the same situation as him and they would have ideas and suggestions on how to adapt to the challenges of his new life. Sharing with these people, Joe would learn from their experiences and be able to share some of his own feelings as he dealt with the changes in his life.

This is a related case because self-help groups are often considered as being similar to or in the same category as self-care activities. Self-help groups have been defined as “groups in which solutions to problems of individuals are sought through mutual aid provided in groups of persons experiencing the same condition.”21,p.276 Self-help has a strong emphasis on mutual support whereas self-care is commonly performed by the individual on his/her own behalf or for others. However, they are related concepts, both being aspects of health care. “Self-care and self-help are parts of a matrix in the health care process whereby lay persons can actively function for themselves and/or others to 1) prevent, detect, or treat disease and 2) promote health so as to supplement or substitute for other resources.”13,p.8 Furthermore, seeking support is, in itself a form of self-care.

A contrary case

“Contrary cases are clear examples of ‘not the concept.’”1,p.71
The asthma attack had come on fast and suddenly Gwen was struggling to breathe. She remembered the last time she had had an asthma attack; after which the doctor at the emergency department had given her a peak flow meter and created a self-management care plan with her. She took out the peak flow meter and put the care plan on the table in front of her. She blew into her meter and wrote down the score. It was 200. The doctor had recommended she come to the emergency department if the level was below 250, and had written this in her care plan. Gwen stared at his writing, hoping she just misread the figure. She re-measured her peak flow, and it was definitely 200. She hated going to the hospital. She never quite understood all the things they were doing and that made her nervous. Then there was the scary thought of calling the ambulance. She was getting anxious just thinking about it. She paced round her kitchen, what was she to do? Should she go to the dreaded hospital and, even worse, should she call the ambulance? But then there was her breathing ... or rather by now, extreme difficulty in breathing. I know, she mused; I will just have a cigarette and think about it for a few minutes. She sat down at her kitchen table and lit a cigarette.

This is a contrary case of self-care. Although Gwen has a self-management care plan which guides and directs her self-care behaviour in the case of an asthma attack, she is anxious about going to hospital and chooses instead to smoke a cigarette while she contemplates her next move. Smoking a cigarette during an asthma attack could be considered the antithesis of healthy self-care in this situation.
An invented case

“Invented cases are cases that contain ideas outside our own experience. ... Often to get a true picture of the critical defining attributes, you must take the concept out of its ordinary context and put it into an invented one.”

Brian was delighted. The weekend was finally here and he could drive to his cottage and spend the weekend sailing on the lake. He packed his gear into his vehicle, grabbed some snacks and set off for the two hour journey to his cottage. Half-an-hour later a loud metallic voice broke his reflections. “Turn left, 500 meters ahead. Then stop at the garage 100 meters ahead. Urgent – engine needs oil! Do not ignore this instruction – urgent engine needs oil!” Reluctantly Brian heeded the instruction, took the exit 500 meters ahead and drove to the garage.

This is an invented case of a vehicle engaging in self-care by recognizing low engine oil levels and instructing the driver to make a detour to get the oil.

An illegitimate case

An illegitimate case is “an example of the concept term used improperly or out of context.”

“I hear Mrs. Dent’s husband is doing really well,” Daisy told her neighbour. “Really? He must be one of those strong ones, who recover quickly,” replied Lauren. “Oh, yes,” said Daisy, “I believe he is eating and bathing already.” “Gosh, he will be ready to come home in no time,” replied Lauren. Back in the intensive care unit, the
nurse goes about her care of the unconscious patient. She monitors the rate of the parenteral nutrition and checks the urine output. After taking his vitals, the nurse performs eye care, and begins to bathe Mr. Dent.

This is an illegitimate case of self-care or an improper use of the term (as inferred by eating and bathing) because although Mr. Dent’s body may be receiving nutrients, it would be incorrect to say that he was eating. Furthermore, in his unconscious state, Mr. Dent is not able to perform his own self-care (such as bathing and care of his eyes). He is also not able to direct or guide the care that is provided to him by another person.

**Step 7: Identify antecedents and consequences of self-care**

**Antecedents of self-care**

*The antecedents and consequence shed light “on the social contexts in which the concept is generally used. ... Antecedents are those events or incidents that must occur prior to the occurrence of the concept.”*¹,p.73

Because the spectrum of self-care is so broad, there is an extensive range of antecedents and consequences. The items discussed emerged from the literature contributing to this concept analysis. It is recognized that this is not an exhaustive representation of these aspects (Table 10).
Using an inductive approach, statements referring to antecedents were aggregated into four categories based on factors related to: individuals; environment; health care system; and the socio-political domain.

**Antecedents related to the individual**

“Self-care theory operates on the assumption that each human has a need to care for himself or herself.”\(^{41}\),p.385 Moreover, there is an assumption that people have an innate ability to care for themselves, desire to promote or maintain their own health and will choose to perform behaviours to meet this end.\(^{16,42}\) Therefore, ideal of ‘valuing of self’ means that self-care “includes efforts to minimize threats to self-nurturance, self-improvement and personal growth along with the ability to carry out activities of daily living”\(^{43}\),p.565

**The performance of self-care activities**

According to Orem, in order to perform self-care, behaviours “must be learned, deliberately and continuously performed, and kept in accord with stable or changing internal and external conditions.”\(^{44}\),p.33 However, the predisposition to engage in self-care activities depends on psychological factors (self-concept, self-esteem, self-discipline, personality traits, perceived self-competence and motivation);\(^{45}\) cognitive skills (learning skills, memory, problem-solving skills, organizational skills, and knowledge);\(^{45,46}\) and is also dependent on physical factors (dexterity, psychomotor skills, activity or functional capacity, and disability or injury).\(^{45}\)
Other factors such as age or maturity, gender, education, socioeconomic status, living arrangements, whether the aspects of health care are under the individual’s control or not, and the availability of family and/or other informal supports play an important role in determining the engagement in self-care activities. The spiritual aspects of health care behaviours may be important for some individuals as incentive and encouragement to engage in self-care activities.

The role of the individual’s perception

The performance of self-care is influenced by the individual’s perception of the following factors: his/her capacity to perform the behaviours; the efficacy of the action/behaviour to be carried out; the interpretation of the condition as a health problem; his/her health status; the importance of health to him/her; his/her control over his/her health; his/her definition of health; belief in illness etiology; the benefits to be gained by performing self-care; and barriers to the performance of self-care.

Antecedents related to the environment

The environment was seen as a strong influence on an individual’s and his/her family’s engagement in self-care activities. The Ottawa Charter states: “To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment.” This statement portrays the environment in a rather negative light as
something to be coped with or changed. However, the environment can be a positive influence without alteration. Comments in the literature address both social and physical environments.

**Social environments**

Safe and friendly social environments are important, and serve not only as support but to counteract the stigma of certain conditions that are commonly encountered.\(^{51}\) The social environment created by the family is the influencing role model for their children’s behaviour, especially food habit, smoking, drinking, hygiene behaviours, and decision-making for health-seeking behaviour.\(^4\)

Adults spend the majority of their time in work environments and these can enable or inhibit the engagement in self-care activities. In their reports of their experience of self-care, many individuals described their work environments as stressful and constrained, lacking access to appropriate food choices, imposing unrealistic time constraints, or promoting stigma regarding the performance of certain self-care behaviours.\(^{52-54}\)

At a broader level, the influence of the community is more pervasive.

[Community facilitates holistic self-care with social and moral support and social network such as lay referral system, physical and psychological care and self-help groups. Community can also have a negative effect on self-care such as social stigmatization, when social discrimination and devalued patients react with delay in self-care, delay in seeking care, noncompliance with medical appointment and early termination of long-term treatment.\(^4, p.11\)
Physical environments

The physical environment can either promote or be a barrier to the engagement of self-care activities. For example, Thorne states: “An increasingly toxic nanomaterial environment may well be implicated in the proliferation of newer chronic conditions, such as fibromyalgia, as well as increased prevalence rates for well-established conditions, such as asthma.” On the positive side, many individuals report being inspired to initiate or engage in self-care behaviours when communing with nature in peaceful environments.

For individuals with disabilities, the physical environment can present a formidable barrier both in the home and community (schools, workplaces, etc.) and adaptations of the environment are necessary to enable the performance of self-care activities. Assistive devices are frequently employed to help individuals and their families negotiate environmental barriers.

Antecedents related to the health care system

The ability to engage in self-care activities depends on the knowledge of and access to formal services. Furthermore, attitudes or beliefs specific to medical care, such as “a low faith in or skepticism regarding medical treatment may be related to a tendency toward self-treatment in contrast to seeking medical services for symptoms.”

To support the initiation of self-care behaviours necessitates a change of role for health care professionals to that of a supporting role, guiding and advising individuals,
and being facilitators and partners in care. However, frequently doctors are challenged within the time-constrained consultation to create an environment “in which the patient feels comfortable in expressing his or her treatment wishes and, consequently, incorporating them into the treatment.”

**Antecedents related to the socio-political domain**

The support of the government is essential to plan and implement self-care on a large scale. The World Health Organization recommends that “government’s policy and commitment are a prerequisite for promotion of self-care as an integral part of Primary Health Care on the national scale.” The engagement in self-care activities also depends on socio-cultural factors such as cultural practices and beliefs, health values and beliefs, social support, availability of resources, and the prevailing economic policy. The World Health Organization portrays the role of the environment in a broad context:

The environmental effects on self-care practice are migration, urbanization and politics. Migration, particularly urbanization, is another determinant since migrants are marginalized population for health-care due to the language barrier, and the people’s illegal status prevents them from access to health information and services. Politics is a determinant and plays a role in the selection of the type of health-care system (traditional, modern, and mixed), distribution of health resources, equity and access to self-care by income.

**Consequences of self-care**

Consequences are “those events or incidents that occur as a result of the occurrence of the concept – in other words, outcomes of the concept.”
Positive consequences of engaging in self-care activities include: the achievement of desired outcomes, increased sense of satisfaction, increased sense of responsibility, control, independence, and autonomy (Table 1).\textsuperscript{45} An adolescent with diabetes remarked that for him, the benefit of performing self-care was "just feeling that you can take care of it yourself."\textsuperscript{59,p.169} Performing self-care was also seen to increase functional balance and integrity,\textsuperscript{22} enhance recovery from surgery or illness, enhance coping with or adjustment to illness, and decrease the burden of chronic illness.\textsuperscript{45} "Performance of self-care activities allows for optimal timing of monitoring and therapy,"\textsuperscript{28,p.24} which may contribute to the decrease in the risk for complications, health services utilization, rates of readmission and health care costs, seen amongst individuals who perform self-care activities.\textsuperscript{45}

Performing self-care may also improve a sense of well-being, functioning, and quality of life.\textsuperscript{45} A woman commented on how her self-care activities left her feeling healthier than before:

I walk to my garden every weekend. It’s about a 10-minute walk. I spend around half a day loosening the soil, planting trees, and watering flowers. My body and clothes are soaked with sweat. I don’t feel tired but rather feel relaxed and become more active. I lose weight as well. I look younger and healthier than before.\textsuperscript{56,p.902}

Engaging in self-care may maintain or improve physical, mental, social and spiritual well-being.\textsuperscript{22} A middle age Thai woman reported that despite her busy schedule, her few minutes of self-care enable her to feel good and able to go on with her day.
I go to work by bus in the early morning. I go back home in the afternoon to take care of my paralyzed husband. I cook for him and my children. After I wash dishes, I take my husband to bed. I spend a few minutes after I’m free from my housework doing Buddhist meditation or sometimes I listen to Buddha’s teaching. In this way, I feel good in the morning and ready to go to work.  

Engaging in self-care behaviours may enhance self-esteem and provide a sense of transcendence of self. An individual reported her experience of practicing yoga: “I feel my mind is clear. That lets me feel fresh during my day. I feel that after I practice deep breathing, my blood circulation keeps going well and my anxiety disappears. It’s really good. I will keep doing it [yoga].”  

The benefit of performing self-care may also be seen as enhanced self-confidence and mastery in daily life. A middle aged Thai woman described her enjoyment in performing self-care: “I think self-care is more than self-centered things. I do it because of my desire. I do it for myself. I do it for my own enjoyment. I do it for my personal growth. There is no one forcing me to do it; I swear. It’s my trial to test the effectiveness of self-care. If I feel good, I will do it forever.”  

Self-care is about feelings of togetherness with family, friends and colleagues. Giving social support as well as receiving it, has been reported as a means of health maintenance and self-care and enhancing physical, mental and social well-being. “We had a picnic together, the whole family. It is the best therapy for a person.”  

Self-care also pertains to prevention and Health Canada’s definition of self-care “as an important determinant of health, concerned with the development and use of
personal health practices and coping skills reinforces this aspect. Thus consequences of self-care in this regard manifests in the prevention of disease and disability and the increase in well-being.

Increasing individuals’ performance of self-care activities also has significant economic implications for the health care system. In its report on Self-Care in the Context of Primary Health Care, the World Health Organization concludes: “Finally, self-care will ease the burden of the overstretched health systems, reduce cost and increase its effectiveness, all of which facilitate efforts in achieving universal coverage.”

The negative consequences of engaging in self-care activities would occur when the individual recognizes that they are no longer able to engage in the self-care behaviours that they were accustomed to. For example, an individual that suddenly loses his sight may experience both frustration and helplessness, when realizing that he cannot perform his usual activities of daily living or instrumental activities of daily living. As he learns to negotiate these activities without sight, his successes may encourage him continue engaging in self-care. Alternatively, he may feel overwhelmed by the impairment and elect to abandon self-care activities either temporarily or permanently.

“When I lost my sight I went into a deep depression and was about to take my life... Why me, I asked myself? I couldn’t read, watch TV, drive, nothing. But gradually more important things came into focus. I have a family, I can talk and listen and have much more time to spend with them. I couldn’t ruin this. It’s true that life is much more restricted now, but the things I can’t do isn’t that important any longer.” (Male, 44 years, visually disabled).
Step 8: Define empirical referents

This step answers the question: “If we are to measure this concept or determine its existence in the real world, how do we do so? Empirical referents are classes or categories of actual phenomena that by their existence or presence demonstrate the occurrence of the concept itself.”

Self-care encompasses a large spectrum of behaviours and multiple methods are used to assess such aspects as the performance of self-care, self-care agency (or capacity), the frequency of self-care activities, barriers and facilitators to self-care, correlates of self-care activities, and economic implication of self-care activities (Table 10). Common methods of assessment include surveys using a variety of closed and open questions and/or Likert scales, participant diaries, interviews and focus groups.

Given the expansive constellation of behaviours considered under the rubric of self-care, when measuring self-care outcomes, it is common for researchers to develop their own instruments in order to assess the particular aspects of self-care that they are investigating. For example, Green\(^61\) describes a scale developed by Krantz in 1980 to assess to following aspects of self-care: “a) beliefs in the efficacy and benefits of self-care; b) frequency of information-seeking and questioning of physicians and nurses; c) beliefs about the benefits or disadvantages of making one's own medical decisions; d) attitudes towards use of a physician versus oneself as a health-care provider; e) frequency of self-diagnosis.”\(^61,p.330\) As another example, in 1983 Knust\(^62\) developed an assessment tool based on the concepts of self-care theory and investigated the aspects of functional, developmental, and health risk behaviours. Longitudinal studies are most
valuable in self-care research and a commonly cited example of such a study is the *National Survey of Self-Care and Aging* (Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill, 1996)\(^6\) which surveyed 3,485 community dwelling adults 65 years and older.\(^5\)

In their chapter on self-care outcomes from an occupational therapy perspective, Bradley and Vrkljan\(^5\) discuss the measures used to capture self-care outcomes from 57 studies. They note that nearly one quarter of the studies used modified or home-made versions of existing measures.

The determination of outcome measures is dependent on the perspective and discipline of the researcher. For example, Bradley and Vrkljan list the three outcomes most commonly addressed by the occupational therapy self-care interventions in the 57 studies as:\(^5,p.115\)

1. Activities of daily living (ADL) retraining – including direct retraining of activities such as bathing, toileting, feeding and dressing.
2. Interventions targeting instrumental activities of daily living (IADL) such as retraining for occupations such as driving, shopping, home management, and cooking.
3. Provision of and training in cognitive compensation strategies such as memory training and energy conservation.
By contrast, Sidani\textsuperscript{45} investigated outcome measures of self-care in nursing and located 32 instruments. The most frequently measured self-care outcomes in nursing from this study were:\textsuperscript{45,p.88-98}

1. Self-care action performed to meet universal needs
2. Self-care action performed to meet developmental needs
3. Health promotion
4. Performance of ADLs
5. Self-care in response to illness (chronic or acute)

Taking a more expansive view and including an important aspect such as health service utilization, a recent systematic review on the evaluations of self-care/self-management outcomes in health care determined six main outcome measures from 19 studies, including: self-efficacy; health behaviour/attitude; health status; health service utilization; quality of life; and psychological indicators.\textsuperscript{66}

Sidani\textsuperscript{45} discusses three issues related to the measure of self-care outcomes: the content of self-care instruments, the operationalization of self-care and the method of assessing self-care. In terms of the content, global measures capture domains and self-care behaviours that are relevant across populations and across practice settings. Alternatively, specific measures are adapted to particular individual groups or disease/impairment groupings. Hence both are usually valuable when conducting a comprehensive assessment of self-care. However, the majority of investigations tend to
rely on specific measures to address only their population of interest. The development of global measures is more challenging, and requires clarifying domains and behaviours expected of different populations across the continuum of care.\textsuperscript{45}

Depending on how the researcher operationalizes self-care, measurement of the concept can entail the assessment of self-care behaviours plus the capacity to perform those behaviours – or the self-care agency. These are distinct yet interrelated concepts and ideally measuring both would be optimal but may increase the response burden when assessing frail or ill populations.\textsuperscript{45}

The method of assessing self-care is preferably done by self-report. However, when the individual is not capable of self-report (e.g., young children or cognitively impaired individuals), the issue becomes who is the best person to assess either the self-care agency or the performance of the self-care behaviour itself. Traditionally, either significant others, caregivers or health care professionals have performed these assessments. However, this may introduce an element of unreliability.\textsuperscript{45} To enable a comparison of the effectiveness of interventions, both Sidani and Bradley et al., recommend the increased use of standardized instruments and/or the creation of more generic measures for the measurement of self-care in general.

**Limitations of the concept analysis study**

Limitations of this study relate to the evidence base used to support the analysis. Publications were limited to those written in English and the inclusion of other languages may have contributed additional sources of attributes or models. The concept
analysis was conducted by one researcher, thus limiting the interpretation of the analysis. The inclusion of several authors with a range of clinical and research expertise would strengthen the analysis.
## Table 10: Key Elements of the Concept Analysis of Self-Care

<table>
<thead>
<tr>
<th>Attributes</th>
<th>Antecedents</th>
<th>Consequences</th>
<th>Empirical Referents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elements</td>
<td>Individual</td>
<td>Increase in sense of responsibility, control, independence, autonomy</td>
<td>Pervasive problem of multiple outcomes and multiple methods of assessment</td>
</tr>
<tr>
<td>Context</td>
<td>Need to care for self and other, ability to learn self-care behaviours (psychological factors, cognitive skills, physical and functional factors), developmental status, socio-economic status</td>
<td>Increase in well-being and functionality</td>
<td>Outcomes depend on perspective of self-care and discipline of researcher</td>
</tr>
<tr>
<td>Performance</td>
<td>Individual’s perception of factors related to the definition of health, assessment of the condition and performance of care</td>
<td>Increased sense of mastery and self-confidence, sense of accomplishment</td>
<td>Rehabilitation OT e.g.: ADL – retraining, IADL – retraining, cognitive compensation strategies – memory training, energy conservation</td>
</tr>
<tr>
<td>Timeline</td>
<td>Environment – Social</td>
<td>Prevention of disease and disability</td>
<td>Nursing e.g.: Meeting universal or developmental needs, health promotion, ADL performance</td>
</tr>
<tr>
<td>Requirements</td>
<td>Positive: support – social and moral, counteracting stigma parental modeling of behaviours and attitudes, networking</td>
<td>Reduction of economic burden on health care system</td>
<td>Self-efficacy</td>
</tr>
<tr>
<td>Self-care with regard to illness and disability</td>
<td>Negative influences: discrimination, stressful and constrained, limitations barriers to performance of self-care</td>
<td>Negative – frustration and helpless if self-care activities cannot be performed</td>
<td>Health behaviour/attitude</td>
</tr>
<tr>
<td>Behaviour range</td>
<td>Environment – physical</td>
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<td>Initiation of activities</td>
<td>Positive: peaceful and nurturing, enabling</td>
<td></td>
<td>Health status</td>
</tr>
<tr>
<td>Motivation</td>
<td>Negative: toxic and unhealthy, barriers to performance of self-care</td>
<td></td>
<td>Quality of life</td>
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<tr>
<td>Attributes</td>
<td>Antecedents</td>
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<tr>
<td>Health care system</td>
<td>Knowledge of services, access to services, attitude regarding health care – individual and HCP, changes in HCP role, time constraints</td>
<td>Psychological indicators</td>
<td></td>
</tr>
<tr>
<td>Socio-political domain</td>
<td>Importance of government support, socio-cultural factors, availability of resources, economic policy, migration, urbanization, policy</td>
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</table>

HCP=health care professional; ADL = activities of daily living; IADL – instrumental activities of daily living
Conclusion

Through the concept analysis the attributes and uses of the concept of self-care were delineated. Within the context of health care, self-care addressed issues related to promoting and preserving health, and treating, managing and coping with illness, injury or disability. The action of self-care was commonly defined as taking charge or taking responsibility for one’s care and could be performed independently or in collaboration with a health care professional. Self-care included care performed by the individual or care provided by others. Self-care had at least nine different attributes and multiple antecedents that would preempt the individuals’ engagement in self-care activities. The majority of consequences following the performance of self-care were positive, such as improved sense of well-being, enhanced functionality, independence, enhanced coping and adjustment to illness, and a decrease in service utilization. The complexity and range of self-care activities results in a variety of assessment methods.

Notably, besides references by Levin\textsuperscript{20} to historic views of self-care as a dangerous activity, the literature did not present the potential negative aspects of self-care. With a growing emphasis on engaging in self-care for individuals with chronic or longstanding conditions or disabilities, this aspect may have been neglected. However it bears mention that the potential for adverse events to occur in the process of self-care does exist, for example, with the misuse of monitoring technologies.

This chapter concludes the first phase of the enquiry – to clarify the concept of self-care. Before proceeding to the study of the effectiveness of self-care interventions,
a summary of the findings from these three studies would elucidate the contribution to knowledge thus far.
References


Chapter 5: Self-Care Concept Clarification: Direction for Enquiry

Self-care and its meaning has been examined from various perspectives in three integrative studies. This chapter serves to summarize these perspectives. The understanding about self-care has been gained from: Chapter 2 – the experience of self-care: a systematic review in which I synthesized the findings portraying the experience of self-care as reported by individuals and families; chapter 3 – Care of self – care by other – care of other: the meaning of self-care from research, practice, policy and industry perspectives in which I examined the definition of self-care from various perspectives; and chapter 4 – self-care: a concept analysis in which I analyzed the concept of self-care following the methodology proposed by Walker and Avant.1

Summary of Studies

The experience of self-care: a systematic review2 (Chapter 2).

In this study I performed a systematic review of qualitative evidence. The integration of the findings from various studies reflected the essence of self-care as it is manifest in daily life, and provided a glimpse into the richness of the experience of self-care from individuals of different ages within the contexts of health, illness and disability. Fifty qualitative studies comprised the data set for this study which was analyzed according to Orem's Theory of Self-Care.3 The experiences of self-care reported by individuals and families were categorized into one of three self-care
requisites - universal, developmental and health deviation. The overarching synthesis of the qualitative studies resulted in four synthesized findings:

**Caring for self** - Engaging in self-care was facilitated by a strong, positive awareness of self, and an ability to acknowledge emotional, mental, physical and spiritual needs, and taking responsibility for attending to those needs. Positive experiences of being and feeling healthy reinforced the engagement in self-care activities. Some individuals were able to find symbolic meaning in chronic illness and reframed the experience within the context of their lives (e.g., reconstructing the implications in a positive way). This reframing enabled them to engage in self-care activities. Epitomizing this focus, (quote from chapter 2), Native women perceived being healthy as feeling the balance between the physical, mental and spiritual realms of their lives.

And that’s part of health, being healthy. Is knowing your own body. Knowing yourself well enough to know when something’s out, when something’s wrong, something’s out of balance. Something’s not right. So really being in touch with yourself and with your body. And with your mind and with your spirit world.\(^{4, p.421}\)

**Mastery and balance** - Self-care entailed mastering specific behaviours, and balancing the inner world of mind, body and emotions, with the external influences of parenting, and support from family, health care professionals and others. For example, (quote from chapter 2), as adolescents with asthma mastered their self-care activities, their parents were less involved and respected their competence. “Usually my mom doesn’t get involved with it unless it’s really serious, like when I have to go to the hospital. Usually she lets me handle it because she knows I know how to.”\(^{5, p.602}\)
**Sustaining self-care** - Perceiving oneself as being in control, acquiring knowledge and receiving support from others were important factors that facilitated the sustaining of self-care behaviours and assisted with overcoming challenges. For example, (quote from chapter 2), individuals with colorectal cancer directed their self-care activities to attain both physical and mental stability.

(Self-care is] the immediate things like taking care of my body and making sure that I do everything I possibly can with hygiene, diet, all these things to keep me as fit as possible…it’s got a wider aspect, it’s about your mental state as well I think and trying to be as normal as possible and trying to just be you…it’s a whole big thing, it’s not just the physical…it’s the mental side of it as well and just trying to keep going and be the person I always was.^[6, p. 472]

**Disengagement from self-care** - Individuals may abandon self-care when feeling helpless in the face of overwhelming symptoms and disability. For example, (quote from chapter 2), Finnish primary care patients felt helpless when confronting aspects in their own lives such as aging, loss of physical and mental vigor, poverty, unemployment, loneliness and alienation: “Every day I feel helpless. I am only 53 years of age and I feel that there are still lots of things that would be nice to do, but I have to leave a lot undone. I simply cannot do any more.”^[7, p. 738]

**Care of self – care by other – care of other: the meaning of self-care from research, practice, policy and industry perspectives^[8 (Chapter 3).**

In this study I explored the concept of self-care from a variety of perspectives. Seventy-five studies and 139 definitions of self-care were the data set for this study.
Using an inductive approach, seven components of the self-care definition were identified, and are listed as specific aspects relating to: 1) health; 2) illness or disability; 3) general outcomes of self-care; 4) the performer of self-care; 5) the action of self-care; 6) health care professionals; and 7) the health care system. These components help to itemize the elements that need to be present and the aspects that need to be considered in order to generate a thorough and all-embracing definition of self-care.

In this study (chapter 3) I also examined the definition of self-care over four decades 70s, 80s, 90s and 2000s to identify trends or themes over time. Initially in the middle 70s to early 80s definitions of self-care were rather narrow and addressed simply health promotion or illness and disability, with or without the assistance of a health care professional. Since then, definitions have expanded, including care by others, cultural and socio-economic contexts, the influence of the environment, and the meeting of psychological and emotional needs. An example, (quote from chapter 3), of one of the most comprehensive and relatively recent definitions of self-care was proposed by the United Kingdom’s Department of Health (2005) which defined self-care as:

Self care is a part of daily living. It is the care taken by individuals towards their own health and well being, and in their role as carers includes the care extended to their children, family, friends and others, whether in their homes, neighbourhoods, local communities, or elsewhere. Self care includes the actions individuals and carers take for themselves, their children, their families and others to stay fit and maintain good physical and mental health; meet social and psychological needs; prevent illness or accidents; care for minor ailments and long-term conditions; and maintain health and wellbeing after an acute illness or discharge from hospital.9,p.5
This definition states upfront that self-care is not an unusual occurrence, or one connected only to illness or disability – it is part of daily living. It also emphasizes the care of self, as well as care extended to others, and includes the meeting of social and psychological needs. However, it does not mention the interaction with health care professionals, and more importantly, the nature of this relationship (directed or guided by, independent of, or in collaboration with).

Self-care: a concept analysis (Chapter 4).

In this study I analyzed the concept of self-care using the methodology proposed by Walker and Avant, which guides the process through eight steps: 1) select a concept; 2) determine the aims or purposes of the analysis; 3) identify all uses of the concept; 4) determine the defining attributes; 5) identify a model case; 6) identify borderline, related, contrary, invented and illegitimate cases; 7) identify antecedents and consequences; and 8) define empirical referents.

Data for this analysis came from 141 papers: 50 qualitative studies, 16 quantitative studies and 75 discussion and opinion papers focused on self-care. Nine attributes of the self-care concept were identified, including: 1) elements of self-care; 2) context of care; 3) performance of care; 4) timeline of care; 5) requirements in order to perform self-care; 6) behaviour range; 7) self-care with regard to illness and disability; 8) initiation of self-care activities and 9) motivation.
When describing the antecedents of self-care, the highlight was the contribution that the individual’s perception makes to the performance of self-care. The individual’s perception of the efficacy of the self-care behaviour, seriousness of symptoms, their own health status, the importance of health to them and also their definition of health, to name a few, were reported to determine the performance of self-care activities.\textsuperscript{10,11}

Consequences of self-care, such as increased responsibility, control, independence, and autonomy as well as enhanced coping with or adjustment to illness, were described as strong rewards that may assist the individual to sustain their engagement in self-care activities.

\section*{Self-Care Conceptualization – the Self-Care Concept Schema}

How does each study contribute to our knowledge about self-care? The purpose of a concept analysis (chapter 4) is to examine the structure and function of a concept and provide information about the foundation of the concept under investigation.\textsuperscript{1} The nine attributes delineated by the concept analysis convey the foundational aspects of self-care. For example, these attributes - context of care (health, disease, disability, recovery and prevention); performance of self-care (considered as care of self, care of other, or care by other); requirements in order to perform self-care (requires the acquisition of new skills or knowledge, or may be within the repertoire of individual), are the building blocks of our conceptualization of self-care. The antecedents (aspects
necessary for the performance of self-care) and consequences (results of the performance of self-care) further help to delineate the parameters of the concept.

The content analysis of the definition of self-care (chapter 3) outlined the components of the self-care definition. These seven components provide the boundary of the concept of self-care by indicating the restrictions or limits within which the concept is contained. For example, the definition quoted above from the United Kingdom’s Department of Health indicates that self-care is performed by individuals for their own health and well-being, as well as in their role as carers whereby care is extended to include others. This places a perimeter around the concept of self-care (albeit a rather broad one) to include care of self, care by other and care of other.

The synthesis of qualitative evidence (chapter 2) provides the essence of the experience of self-care. This study conveys what self-care means to each individual in the context of their daily lives. For some individuals self-care may be a focus on health promotion and prevention activities. For others, it may be a challenge to master the care for one or more diseases or impairments. And for others still, self-care may have to be abandoned in the face of overwhelming symptoms or disability.

The interaction of three constructs of structure, boundary and essence can be illustrated by an adaptation of the Queen’s Research to Practice Framework (QRPF). The QRPF is a generic framework used to organize key elements of the evidence to practice process. In its original form, the framework comprises a triangle which contains an inner circle. The triangle presents three constructs: concept of focus, context of
interest and current knowledge. These constructs are the foundation of the framework, and give reference to the inner circle which represents the cycle of the systematic review process: question, synthesis and application.

The QRPF was selected to illustrate the constructs arising from the three studies because it is able to graphically demonstrate the linkage between these elements. Adapted for the integration of these three studies, and referred to as a Self-Care Concept Schema, the schema comprises a triangle, circle and four-pointed figure (Figure 12). Symbolically, the triangle represents the conceptual analysis which provides the structure and foundation of the concept of self-care. This ‘structural triangle’ contains within it a circle which symbolically represents the definitional boundaries that contain (encircle) the concept of self-care. Within the centre of this circle is the essence, a four-pointed figure which symbolically represents the experience of self-care as reported by individuals and their families.

Summary

The knowledge we have gained from the studies on the experience of self-care as reported by individuals and families (chapter 2); the meaning of self-care from different perspectives (chapter 3); and the conceptual analysis of self-care (chapter 4) is symbolically portrayed by the Self-Care Concept Schema. The framework graphically links these aspects and illustrates their interrelatedness. The concept analysis provides the foundation and structure to anchor the self-care definitions which in turn provides
the parameters of the self-care process within which to view the experience of self-care as it is outplayed in individuals’ lives.

However, implicit in this framework is a process of transfer, a translation of the evidence into practice. In order to accomplish this, the next step is to examine and assess the current knowledge in the practice domain. What do we already know that health care professionals can do to assist and support self-care?

The initial studies on the self-care concept now provide the basis for exploring the range and type of interventions that health care professionals could use in supporting self-care. Evidence on intervention strategies designed to initiate or enhance individuals’ engagement in self-care activities will be described and evaluated in chapter 7.
Figure 12: Self-Care Concept Schema

Concept of Focus: Self-Care

Context of Interest: Health Care Behaviour

Current Knowledge: Research Literature

Legend:
- Green triangle: Structure
- Blue circle: Boundary
- Purple star: Essence
References


Ref Type: Unpublished Work
This chapter is a description of the development of the methods used in the enquiry. In conducting this enquiry two substantive methodological challenges were encountered that require some background and explanation: 1) locating complex concepts in the research literature, and 2) integrating evidence from systematic reviews across Cochrane Collaboration Review Groups. Experts in synthesis methods, library science and computer/information science were consulted to discuss current methodologies, issues and my proposed solutions. To maintain transparency with the method I kept a log of all steps and decisions throughout the process which tracked the barriers and problems. The method evolved after much ‘trial and error’ and the contribution of numerous experts.

In addition to debriefing regularly with supervisors I attended two advanced programs focused on knowledge translation 1) Canadian Institutes of Health Research (CIHR) workshop (Integrated Knowledge Translation: What are its Active Ingredients?, March 2009); 2) CIHR-OHRI Knowledge Synthesis and Mentorship Program (University of Ottawa, 2009). The latter program entailed three one-week modules over 9 months. These sessions corroborated current issues in the evolving methodologies of synthesis and provided the opportunity for consultation with international experts to deliberate the challenges of this enquiry, including:
• Dr David Moher, Senior Scientist, Clinical Epidemiology, Ottawa Hospital Research Institute; Director, University of Ottawa Evidence-based Practice Centre;

• Dr. Jeremy Grimshaw, Professor, Department of Medicine, University of Ottawa; Director, the Canadian Cochrane Centre; Canadian Research Chair in Health Knowledge Transfer and Uptake;

• Dr. Peter Tugwell, Professor of Medicine, and Epidemiology & Community Medicine, University of Ottawa; and

• Dr. David Gough, Director Social Science Research Unit; Professor of Evidence-informed Policy and Practice, London, England.

Conversations with these individuals provided valuable insight and advice on methodological issues in this self-care enquiry.

Another crucial element was from library scientists in the design of the methodology related to searching for complex concepts. Numerous sessions were held with Patricia Oakley MLS, Head, National Research Council Information Centre Institute for Information Technology, New Brunswick and Amanda Ross-White, MLS, Health Sciences Librarian, Clinical Outreach and Nursing, Bracken Health Sciences Library, Queen's University. Knowledge about the creation of an ontology, a new technology to construct relational databases, was aided by Dr. Craig Kuziemsky, Assistant Professor, Telfer School of Management University of Ottawa. Dr David Lamb, Associate Professor
Queen’s University School of Computing provided information about the innovative technology of Semantic Web applications.

**Methodology to Locate Complex Concepts in the Research Literature**

**The problem**

Complex concepts pose a challenge to traditional search strategies. Not only do these concepts comprise many facets, they often represent constructs that are substantially more than simply a combination of those facets. Currently searching the large bibliographic databases such as MEDLINE and CINAHL is accomplished using a combination of subject heading terms and keywords. The National Library of Medicine defines its Medical Subject Heading (MeSH) terms as:

MeSH is the National Library of Medicine’s controlled vocabulary thesaurus. It consists of sets of terms naming descriptors in a hierarchical structure that permits searching at various levels of specificity.

MeSH descriptors are arranged in both an alphabetic and a hierarchical structure. At the most general level of the hierarchical structure are very broad headings such as "Anatomy" or "Mental Disorders." More specific headings are found at more narrow levels of the eleven-level hierarchy, such as "Ankle" and "Conduct Disorder." There are 25,186 descriptors in 2009 MeSH. There are also over 160,000 entry terms that assist in finding the most appropriate MeSH Heading, for example, "Vitamin C" is an entry term to "Ascorbic Acid." In addition to these headings, there are more than 180,000 headings called Supplementary Concept Records (formerly Supplementary Chemical Records) within a separate thesaurus.

By combining subject heading terms and keywords and creating complex search strategies, the vast reservoirs of literature are searched to locate the relevant articles.
Searching involves a delicate balance between sensitivity and specificity. Sensitivity refers to the number of relevant articles that are located by the search strategy and specificity refers to the focus of the search strategy in order to locate only those relevant articles. If the search strategy is too focused the chance of missing relevant articles is high. However, broadening the focus of the strategy increases the return of numerous articles that are off topic. Finding the right balance between the sensitivity and specificity of a search strategy is always a challenge, and in conducting systematic reviews the tendency is to broaden the search strategy to locate as many relevant articles as possible.

The problem of searching for complex concepts manifests in three areas of the search process: 1) how the articles are indexed, 2) capturing all the facets of the complex concept in the search strategy, and 3) the volume of citations returned. The National Library of Medicine\(^2\) has a rigorous process of indexing which they describe as follows:

Indexers analyze each article by reviewing the complete text and interacting with a series of formatted screens displayed on their computer monitors. The first screen displays most of the bibliographic data for the article, and the second screen displays the abstract. A program designed to prevent misspellings and typographical errors from appearing in MEDLINE compares textwords in the title and abstract with a dictionary file. Any words not in the dictionary are highlighted for action by the indexer, who must either correct the misspelling or override the warning.

The final two screens allow the indexer to add the appropriate subject headings, qualifiers, check tags, and publication types to the article record. Subject headings, qualifiers, and check tags are selected from NLM's controlled vocabulary, Medical Subject Headings, also known as MeSH\(^8\), and are validated
against the MeSH file for spelling and authorized main heading/qualifier combinations. The indexing system allows for online interaction with the MeSH file to display the annotation (indexing instructions), scope note (definition), and allowed qualifiers for any specific term. This feature enhances the indexers' ability to select rapidly the most appropriate terms for each journal article. Publication types are also assigned from a predefined list.

Many validations are built into this part of the indexing system. For example, if an indexer adds the check tag "PREGNANCY," the system automatically adds "FEMALE," then displays a message asking the indexer to add "HUMAN" or "ANIMAL." If the indexer adds the MeSH heading "DOG DISEASES" to an article, the program will automatically add the check tags "DOGS" and "ANIMAL." Use of the publication type "PRACTICE GUIDELINE" will prompt the indexer to enter the name of the sponsoring organization at the end of the guideline's title. Various warnings, reminders, and suggestions may be invoked by the program whenever specific headings or qualifiers are assigned. Warnings may be overridden by the indexer, but error messages, concerning misspelled MeSH headings or invalid qualifiers, may not. The system will not allow a record to be added to the database until all errors are corrected.

As a researcher, I rely upon the indexers to apply all the suitable subject heading terms to an article. However, sometimes interpretations differ and I am not able to locate the relevant articles using only subject heading terms. Furthermore, when searching the key bibliographic databases such as MEDLINE, CINAHL, PsycINFO and EMBASE, I am searching against only the article title and abstract, not the full text of the article. The indexer reads the full article and applies the subject heading terms accordingly. For all others searching the databases, the search is restricted to title and abstract.

The second problem posed by complex concepts is that indexing may be restricted to only a few of the concept’s facets. For example, the study of the meaning
of self-care (chapter 3), identified at least seven components for the concept of self-care, including: aspects related to health and health promotion; aspects related to illness and disability; aspects related to the outcomes of self-care; aspects related to who performs the self-care action; aspects related to the self-care action itself; aspects related to health care professionals; and aspects related to the health care system. However, the MeSH terms mapped to the concept of self-care are much more restricted, including only the therapeutic aspects of self-care (those aspects related to illness or disability), such as blood glucose self-monitoring, self-administration and self-medication. Table 11 indicates the terms mapped to self-care for each of five key research databases, CINAHL, MEDLINE, AMED, PsycINFO and EMBASE.

Table 11: MeSH Terms Mapped to the Term ‘Self-Care’

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<td>Self care skills</td>
<td>Self care</td>
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<td>● Blood glucose</td>
<td>● Blood glucose</td>
<td>● Self care</td>
<td>● Independent living</td>
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<td>self monitoring</td>
<td>self monitoring</td>
<td>Self care</td>
<td>management</td>
<td>Self treatment</td>
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<td>● hearing aid</td>
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To locate articles that address the other aspects of self-care such as personal care or the aspects related to the self-care action itself, multiple combinations of MeSH terms, keywords and keyword phrases are used. Although successful, this approach generates extensive and sometimes cumbersome search strategies.
The third problem, the volume of citations returned by searches, can be somewhat daunting. There are three options when searching MEDLINE just using the term ‘self-care:’ 1) self-care exploded (MeSH term which would include blood glucose self monitoring, self administration and self medication) – returns 30,290 citations; 2) self-care – (just the MeSH term) returns 17,467 citations; and 3) self-care as a keyword – returns 21,043 citations. To negotiate these huge volumes, I collaborated with a library scientist and generated a comprehensive search strategy of 134 lines in length and it managed to reduce the hit rate to an almost manageable 1999 citations. However, it took an inordinate amount of time to create this search strategy, and it located only 141 relevant articles.

**A Broad Perspective on Information Retrieval**

The essence of the search process is information retrieval, and the use of subject heading terms is a linear approach based on matching index terms with text in the article. If an article refers to diabetic self-care and describes aspects of glucose monitoring, the subject heading term ‘blood glucose monitoring’ will be applied to that article. If I enter the subject heading term ‘blood glucose monitoring’ in my search strategy, I will retrieve that article. However, if the article refers to the stigma experienced by individuals with diabetes when they have to perform self-care behaviours in public, but does not actually mention the phrase ‘blood glucose
monitoring’ the chances are, I will not locate it. Perhaps there is another way to approach the information retrieval problem.

The brain is the most complex database we have and we are constantly trying to find ways of entering information into that database and, even more importantly, how to get information out. Turning to the current research on memory which addresses this problem, there are keys that assist in the process of information retrieval (from a complex database like the brain). In 2008, Ranganath\textsuperscript{3} discussed two mechanisms for the retrieval of long term memory; creating either a relational or an item-specific link to the item will increase the chance of it being remembered later.

For example, in behavioral studies of memory for word lists, it has been shown that thinking about a word in terms of its surface features (e.g., the font that a word is printed in) typically results in poor memory, whereas elaborating on the item by using relational (e.g., making up a story to link the words) or item-specific (e.g., forming a distinctive mental image of the word’s referent) strategies will result in a richer memory trace that is more likely to be remembered later. Whereas relational strategies involve focusing on common elements across a set of items, item-specific strategies involve focusing on distinctive attributes of specific items that are being processed. In general, it is thought that relational encoding promotes memory for associations amongst items, whereas item-specific encoding enhances the distinctiveness of specific items.\textsuperscript{3,p.18}

I would like to suggest that the current method of searching using subject heading terms and keywords is analogous to what Ranganath refers to as ‘item-specific’ strategies. The focus is placed on one specific attribute of the concept either using subject heading terms or keywords, and attempt to locate articles (retrieve information) based on that attribute. However, creating a relational link to our search concept
requires a different approach all together, requiring at least three steps: 1) Brainstorm
the concept to come up with as many related terms as possible; 2) Note the specific link
each related term has to the core concept; and 3) House the related terms and their
detailed links in database so that this information is accessible. This is precisely the role
of an ontology.

New Methodologies – Ontologies and the Semantic Web

Ontologies are defined as “knowledge representation frameworks that describe
an area of knowledge by defining the common concepts of that domain and the
concepts’ properties and relationships.” In essence, an ontology is a relational
database, or simply “a document or file that formally defines the relations among
terms.” Specific software is used to generate these databases, and Protégé’s open-
source software Ontology Web Language (OWL) is widely accepted as the standard. When building an ontology, OWL facilitates the creation of the multiple properties and
relationships between the terms.

Most of the World Wide Web’s content has been designed for humans to read. However, there is much to be gained by the Semantic Web which uses content created
for computers to read. The Semantic Web brings structure to the meaningful content of
Web pages, creating an environment where browsers can roam from page to page and
carry out sophisticated tasks for users. “The Semantic Web is not a separate Web but
an extension of the current one, in which information is given well-defined meaning,
better enabling computers and people to work in cooperation.” However, in order
for the semantic web to function, “computers must have access to structured collections of information and sets of inference rules that they can use to conduct automated reasoning”\(^5\), p.37. Furthermore, the computer must have a way to discover common meanings for the terms across the various databases. This is where ontologies fit in. “Ontologies are a central building block of the Semantic Web. Ontologies define domain concepts and the relationships between them, and thus provide a domain language that is meaningful to both humans and machines.”\(^6\), p.1

Ontologies form the knowledge structures for Semantic Web applications. For example, if you create an ontology about automobiles and include terms such as car and vehicle, creating the relational links between these terms, then when you run a search using the word ‘automobile’, the Semantic Web application will return information about cars and vehicles as well. Likewise you could retrieve semantically related publications, even if they don’t contain the specific keyword used to locate them.\(^6\)

**A Potential Solution**

I would like to suggest that the use of ontologies and the Semantic Web are potential solutions to the problem of locating literature on complex concepts. The first step would be to build the ontology for that complex concept. Using the concept of self-care as an example, the ontology would begin with self-care as an incidence of health care behaviour. You would then list all the aspects that are considered an incidence of self-care such as, care of self, care by other and care of other. The ontology would cover the attributes, components, antecedents and consequences of self-care and all terms
would be linked reflecting their relationship to each other. The more comprehensive and accurate the ontology, the better chance the Semantic Web application has of locating relevant articles.

The second step would be the creation of the Semantic Web application that would use the self-care ontology as its knowledge base to search through the bibliographic databases. Because search engines already exist for these databases, the Semantic Web application would have to link to these existing search engines. The building of both ontologies and Semantic Web applications require specialized skills and are best performed by experts in this field.

**Vision for a Future Project**

There are a number of researchers developing Semantic web applications and methodologies, for example, Canada’s National Research Council Institute of Information Technology. An interesting collaboration would be with a research institute such as this one and the National Library of Medicine who develops bibliographic databases such as Pubmed and is responsible for MeSH headings. Coming in as a content expert on self-care I would propose the development of an ontology on self-care and a Semantic Web application to determine if this technology is able to go beyond the current linear method of searching and locate literature for complex concepts. If this methodology does work it would create a template for further development and research in this area. I envisage applying for funding to undertake this project.
The Cochrane Collaboration

The Cochrane Collaboration is an international not-for-profit and independent organization, dedicated to the production of systematic reviews about the effects of health care.⁷ Established in 1993, the Cochrane Collaboration comprises 52 different review groups, each of which performs systematic reviews focused on a particular chronic disease or impairment.⁷ Systematic reviews performed by these groups investigate a range of aspects including: the effects of interventions for prevention, treatment and rehabilitation; the measurement of disease or dysfunction; the creation of care protocols; the implementation of educational strategies; the interventions to reduce disease or dysfunction; and the evaluation of interventions.⁷ The intent of these reviews is to provide high-quality, independent evidence to inform health care decision-making.⁸ Cochrane Reviews are currently considered to represent the highest level of evidence available on which to base clinical treatment decisions.⁸:⁹

To integrate the evidence across review groups, i.e., across disease/impairment groupings, the integrative study performed in chapter 8 was conducted as a systematic review of systematic reviews, or an ‘overview of reviews,’ also called an umbrella review. Cochrane defines an overview of reviews as: “intended primarily to summarize multiple Cochrane Intervention reviews addressing the effects of two or more potential
interventions for a single condition or health problem. However, rather than addressing a single condition, the integrative study summarized the evidence across multiple disease or impairments. A specific methodology was developed in order to accomplish this task.

The Systematic Review Process

The integrative review was performed following the guidelines outlined by the Joanna Briggs Institute (JBI). The steps entailed: 1) Developing a rigorous proposal or protocol; 2) Stating the questions or hypothesis; 3) Identifying the criteria that will be used to select the literature; 4) Detailing a strategy that will be used to identify all relevant literature; 5) Establishing how the quality of primary studies will be assessed; 6) Detailing the extraction of data; and 7) Synthesis and summary. These steps were carried out in the same manner as for a systematic review, bearing in mind that the data were systematic reviews instead of individual trials.

Development of a protocol

The protocol was developed and submitted to JBI for peer review. The final version of the revised protocol (reg. # 373) was accepted on March 21, 2010.

The review question

The overall research question for the integrative study was:

What is the evidence on interventions to initiate or enhance individuals’ self-care activities across population groups in the Cochrane repository of systematic reviews?
Identifying inclusion criteria

The PICO template was used to help clarify the criteria for the review.

Population – individuals who were either recently diagnosed with, or are currently living with, a disease or impairment, and who engage, or have the potential to engage, in self-care activities (no age stipulation);

Intervention – strategies to initiate or enhance self-care activities;

Context – in the context of disease or impairment as focused on by the 52 review groups of the Cochrane Collaboration. Health care settings across the continuum of care, including acute, community or rehabilitation settings;

Outcomes – the successful engagement of the individual in self-care activities; the sustainment of self-care activities; health outcomes, health system outcomes.

The criteria for a review need to be specified with as much clarity as possible. In the case of the integrative study, the complexity of the systematic reviews confounded this process, and required greater attention to detail. The initial searches had revealed many different interventions that could be perceived as relating to the topic of self-care. The lead author collaborated with two authors from the review panel (MBH and RL) to ensure utmost clarity in the specification of these criteria. To increase the precision, both inclusion and exclusion criteria were specified.

The search strategy

The search strategy aimed to find all systematic reviews contained within the Cochrane Library that addressed interventions to initiate or enhance self-care. The
search strategy was generated in collaboration with a library scientist (PO). The Cochrane Library is available by three different interfaces: as a publication title, as the Cochrane Database of Systematic Reviews through the OVID interface, and as the Cochrane Database of Systematic Reviews directly through Wiley. All three of these interfaces were searched to ensure access to all published reviews.

**Method of the review**

The use of conceptual frameworks in the process of evidence synthesis help to inform the association of variables, structure and clarify the outcomes, identify knowledge gaps and indicate areas for future research. Consequently, three frameworks were used to assist in this complex integration of systematic reviews. The first framework was Orem’s Theory of Self Care which specifies the purpose of engaging in self-care in terms of three requisites. The requisite ‘health deviation’ addresses changes in structure and function. This framework was used to guide the inclusion criteria and systematic reviews were included if they addressed the health deviation self-care requisite.

The essential focus of the integrative study was one of knowledge translation and so the Knowledge to Action framework by Graham and colleagues was used to contextualize the interventions. Finally, it was useful to categorize the outcomes according to what was being measured, i.e., knowledge, the change in behaviour with the use of that knowledge, patient outcomes and system outcomes. This was
accomplished using the Knowledge Use and Impact framework by Graham and colleagues.\textsuperscript{14}

**Critical appraisal**

Assessment of methodological quality was performed using the JBI Critical Appraisal Checklist for Systematic Reviews. This checklist has 10 questions and a cut-off point of 7/10 was established. All reviews were appraised by two assessors, and demonstrated agreement for 95% of the assessments.

I included an analysis of how each review assessed the quality of their included trials. This was done because it became apparent that all systematic reviews were not using the same assessment instruments and I wanted to document these differences. It was also useful to note the level of methodological rigor for all the included trials across all reviews. When aggregated, this data provides a clear indication of the need for an increase in methodological rigor at all levels of research, particularly given that all included trials represent Randomized Controlled Trials (RCT) which are second only to systematic reviews in the hierarchy of methodological rigor.

**Data extraction**

Data was extracted from the systematic reviews using an adaptation of the standardized data extraction form, the JBI Data Extraction Form for Systematic Review of Experimental/Observational Studies. This adaptation took the form of a Microsoft Access database that was constructed to facilitate the extraction and analysis of the data.
The Access database

An Access database was constructed using the JBI extraction form as the initial template. Therefore important fields were retained, such as: author with full reference details; participants’ population group and type of studies which became type of trials included in the reviews, and outcomes. The creation of an Access database requires forethought and planning. Before creating the database it is important to know exactly what data will be extracted, how the data in each table will relate to each other and how the data will be analyzed. Once the database has been set up, it is usually piloted with a few records to ensure all relevant data is being captured. Invariably, even after preplanning, it was necessary to add a field or two because of unforeseen circumstances. For example, as I started extracting the data I noticed that some reviews reported results from single studies (this is usually due to heterogeneous data and results are presented individually or singly from each included trial). I created a ‘data synthesized’ field to keep track of this, which itemized whether the results were synthesized or not. As I progressed through the reviews and noted the frequency of single study results I realized that I needed to be more specific about capturing this data. I created a ‘single study result’ field on the results table and was therefore able to tally exactly how many single study results were extracted and then exclude them from my analysis.
The final Access database has 14 tables and holds 133 fields (Figure 13). Separate tables were created for author details, author full reference details, interventions, outcomes, results, strategy details, study details, study analysis, critical appraisal, risk of bias and conclusion. There are three look up tables for country, review group and disease/disability description. I like to extract as much detail as possible (within reason) because once it has been entered into the database it is available for multiple analyses.

As data extraction got underway, the systematic review date was the first hurdle. As can be seen from the example below, there are three dates quoted for each Cochrane review.

**Publication status and date:** Edited (no change to conclusions), published in Issue 1, 2009.

**Review content assessed as up-to-date:** 28 July 2006.


An information specialist with one of the Cochrane Review Groups was consulted and the citation date was the one recommended for use in this study.

Although there were specific fields for coding the disease/impairments and interventions, I found it helpful to also include these details in the outcome description as well as in the result description. So an outcome may be coded as: “Asthma - information only education – knowledge” (representing disease – intervention strategy
– outcome). A result description would be coded “asthma – education for asthma -
doctor visit - Educational intervention led to a greater likelihood of scheduled outpatient
follow-up appointment in two studies (RR 1.73; 95% CI 1.17 to 2.56) involving 198
participants” (representing disease – intervention strategy – outcome – and result). I
included this level of detail so that one could read either the outcome or the result
details and still retain a sense of the context. This level of detail was also helpful when
synthesizing the data.

Results

Three fields were created in the results table to tabulate the actual result as
either ‘favouring the intervention’, ‘favouring the control’, or ‘no difference’. A fourth
field indicated whether the result was significant, inconclusive, conflicting, or no
significant difference. As much detail as was possible was extracted with the results,
including the measure of significance if provided.

Synthesis

The synthesis step in an overview of reviews is actually a meta-synthesis of a
meta-synthesis. I am not sure if this makes it a ‘mega’-synthesis but what is clear, is that
there are many factors that complicate the process.

Thirteen reviews stated that their data was so heterogeneous that they could
not synthesize it and presented results singly from each included trial. Consequently,
these reviews were excluded from my analysis. From the set of 30 reviews that were
included in the analysis, a further 50 results were also excluded because they reflected outcome results reported by one trial. All review authors complained about the heterogeneity of their data and this remains an important issue for further research.

In the mega-synthesis process, it is the conclusion stated by the review authors that become your results. However, the conclusions from Cochrane reviews were often worded rather vaguely because there was no clear-cut indication of the effectiveness of the interventions. For example, the review by Renz et al., 15 (2007) titled: *Psychological interventions to improve adherence to oral hygiene instructions in adults with periodontal diseases*, concluded from their synthesis:

There is tentative evidence from low quality studies that psychological approaches to behaviour management can improve oral hygiene related behaviours. However, the overall quality of the included trials was low. Furthermore, the design of the interventions was weak and limited, ignoring key aspects of the theories. Thus, there is a need for greater methodological rigour in the design of trials in this area. 15,p.2

Phrases such as “no firm conclusions can be drawn at present about the effects”; “may lead to small, short-term improvements”; and “there is insufficient evidence.” were encountered. Many review authors echoed the conclusion by Gray et al., 16 (2009) in their review titled: *Interventions for improving adherence to ocular hypotensive therapy*: “However, due to inadequate methodological quality and heterogeneity of study design we are unable to advocate any particular interventions at this time.” 16,p.2

Consequently, I elected to establish the unit of analysis for this integrative study as the
review set i.e., effectiveness of the interventions as indicated by the meta-analysis results and reported as statistically significant. This meant I was able to tally significant results and report the success or failure of the intervention strategies based on these findings. To make sure I did not over-represent the significance of results, I tallied all the results reported by each review and calculated how many results were significant in relation to their entire result load. Therefore, I could report which intervention generated significant results that were more than 50% of the review’s total result load. The total number of results tallied for each review did not include the single study results since they had been excluded from the analysis.

A systematic review reports on the results from many trials. Consequently, one outcome result may be reported as significant - from three trials, and also be reported as finding no significant difference – from three other trials. In this instance where two conflicting results were reported, regardless of the number of trials ‘for’ or ‘against’ the intervention, I classified this as an inconclusive result.

**Conclusion**

The integration of systematic reviews is a rewarding process, although not without its challenges. The rewards include gaining a very much larger perspective on your concept of focus. In the integrative study using Cochrane systematic reviews, the reward was a more expansive view on the interventions to support self-care across
multiple disease/impairment groupings. This provided valuable new knowledge for practice.

When completing an overview of reviews it is important to be cognisant of the level at which you are conducting the synthesis because you have two levels of data. At the mega-synthesis level one is striving for a higher level of synthesis since this perspective provides information not readily apparent at the other levels.
Figure 13: Integrative Review Access Database
References


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Chapter 7: Intervention Strategies that Support Self-Care Activities:
an Integrative Study Across Disease/Impairment Groupings

Executive Summary

Background

The incidence of chronic disease and people with complex chronic medical needs is increasing worldwide. Self-care is an important element for these individuals and can pose challenges both to the recipients and providers of care. Health care professionals seeking evidence on how best to support self-care face challenges finding this research. As a care concept it is typically dealt with clinically and studied relative to specific conditions. The Cochrane Database of Systematic Reviews reports on research across 52 different disease/impairment groupings, with many reviews presenting inconclusive results. Although individual reviews may not offer as much evidence as hoped, it is possible that by synthesizing evidence from multiple reviews that further knowledge and direction about the supportive care professionals can provide for self-care can be found and made available to inform practice.

Objective

To explore and evaluate the evidence on self-care interventions through a cross-cutting, integrative study.

Inclusion criteria
Types of studies: All systematic reviews contained within the Cochrane Database of Systematic Reviews.

Types of participants: Participants who were either recently diagnosed with, or currently living with, a disease, disability or impairment. No age stipulation was applied.

Types of interventions: Interventions focused on initiating, supporting or enhancing self-care activities.

Types of outcomes: The successful engagement of the individual in self-care activities; the sustainment of self-care activities; health outcomes or health care service utilization.

Search strategies

The search strategy was designed to find all systematic reviews contained within the Cochrane Database of Systematic Reviews that addressed interventions to initiate or enhance self-care. The Cochrane Database of Systematic Reviews was searched directly through Wiley and through the OVID interface. Keywords and index terms were harvested from key reviews and a second round of searching was performed.

Methods of the review

Inclusion criteria: Inclusion criteria were guided by Orem’s Theory of Self-Care. Reviews were included that addressed health deviation self-care requisites which refer to changes in self-care activities to regulate the effects of deviation from normal structure or function.
**Interventions:** Interventions were examined within the context of knowledge translation, using the Knowledge-to-Action framework by Graham and colleagues. Interventions were grouped into one of two sections in the framework: a) the adaptation to a specific population, or b) the sustainment of knowledge use.

**Outcomes:** Outcomes were classified according to the Knowledge Use and Impact framework by Graham and colleagues. This framework categorizes outcomes in terms of what is being measured (knowledge; use of knowledge) as well as the impact of the use of that knowledge (patient/individual; provider or system outcomes).

**Assessment of methodological quality:** Methodological quality was assessed using the JBI Critical Appraisal Checklist for Systematic Reviews. A cut-off point of 7/10 was established.

**Data extraction:** Data were extracted from the systematic reviews using an adaptation of the standardized data extraction form, the JBI Data Extraction Form for Systematic Review of experimental/Observational Studies.

**Data synthesis:** Study results were synthesized and discussed in narrative form.

**Results**

Thirty reviews were included in the analysis spanning 16 different disease/impairment groupings and representing a total of 91,170 participants. The most commonly reported intervention strategies were educational sessions (26 reviews) and self-care management plans (11 reviews), and 27 reviews assessed multiple intervention strategies. Twenty-one reviews reported statistically significant results.
Conclusion

There is an emerging body of evidence for effective self-care. This study identified two strategies (educational sessions and self-care management plans) that could be used generically as supportive care by professionals as they assist individuals with self-care.

Implications for practice

The use of multiple strategies, including educational sessions and self-care management plans have been identified as options that may be effective to support adoption and sustainment of self-care activities.

Implications for research

This study highlighted the pervasive problem of heterogeneous data at the primary research level preventing the effective synthesis of current evidence. Further research to standardize the type of outcome measured and the method of measurement would advance our ability to determine ‘best practices’ with self-care. Cochrane systematic review authors reported their systematic review methodologies in varying degrees of detail. Also of note was the range of different methods to assess risk of bias.

Keywords

Self-care; self-care skills; self administration; self medication; personal care; lay care; self maintenance; self treatment.
Background

The incidence of chronic disease and numbers of people who live with complex chronic medical needs is increasing worldwide. In a report discussing the challenge of chronic conditions, the World Health Organization (WHO) claims the rapid rise in chronic health problems is “to the extent that chronic conditions now account for over half of the global disease burden.” Chronic disease is typically regarded as “a condition that has lasted or is expected to last a year or longer, limits what one can do, and may require ongoing care.” This ongoing care commonly takes the form of self-care and is a vital element for these individuals as they adapt to life with impairments. Impairment, from the Latin word *impejorare*, to make worse, has been defined as: “any disorder in structure or function resulting from anatomic, physiologic, or psychologic abnormalities that interfere with normal activities.”

The interference in normal activities is more pervasive in circumstances where individuals have multiple conditions. In these instances the performance of self-care may pose further challenges to both recipients and providers of care. For example, individuals with osteoarthritis have a high rate of comorbidity with chronic conditions such as hypertension, cardiovascular diseases, obesity, and respiratory diseases. Both the number of conditions and severity of them are associated with limitations in activities and increased pain for these individuals. Similarly, individuals with diabetes and comorbid common mental disorders such as depression, testify to lower medication adherence and greater difficulties managing their medical care. Integrating self-
management tasks for coexisting and often interacting diseases is complex,\(^9\) and may reduce an individual's and/or their family's ability to perform self-care activities.

As an example, individuals performing therapeutic self-care (self-care activities performed to address illness or impairment) typically assess and monitor their symptoms, perform treatments (e.g., medication administration) and evaluate the results. For individuals with multiple conditions this becomes more complex as they are frequently required to follow several potentially conflicting self-management recommendations.\(^2\) Statements such as: "hard to keep on top of needing different medications at different times"; "medication for one affects another health problem"; and "can't exercise for diabetes due to the breathing", illustrate some of the struggles individuals report when balancing self-care with multiple conditions.\(^6,p.19\) Management and treatments based on single disease conditions may be mutually incompatible, become ineffectual, or at worst, harmful\(^2\) when applied to individuals with co-morbid conditions.

For health care professionals, supporting self-care can be particularly difficult as well, "given that clinical guidelines are tailored to individual illnesses, and specialized care may involve multiple providers that need to work together to provide patient-centered, coordinated care."\(^10,p.373\) Health care professionals focus on developing strategies that inform, guide and support individuals as they adopt and sustain self-care activities. Unfortunately, research that would inform practice about self-care support is spread across many fields, and difficult to access. Elements of self-care (e.g., symptom
monitoring, adequate knowledge of disease/condition) are generic across populations. Yet typically, self-care is studied only within specific conditions. Self-care needs and concerns are relevant across populations, increasing in complexity for those individuals with chronic or co-morbid conditions. Thus a new approach to assessing self-care interventions is required.

Systematic reviews represent the highest level of evidence that is currently available.¹¹ However, with regard to the interventions which this study is focused on, the gold standard is a meta-analysis for the amalgamation of evidence following critical research of individual studies. According to Borenstein,¹² when analyzing a series of studies, performing a meta-analysis yields a more precise estimate of effect. “Meta-analysis provides a framework for evaluating the series of studies as a whole, rather than looking at each one in isolation.”¹²,p.xxiv The Cochrane Collaboration is an international body advancing the science of synthesis related to health care interventions. The Cochrane Database of Systematic Reviews currently contains over 4000 systematic reviews reporting on the evidence of research across many disease and impairment groupings. Many reviews present inconclusive results. This is in part due to the state of science (i.e., level and availability of evidence) in a field but also the variability of methodological rigor and heterogeneity of interventions and outcomes of the primary studies included in the reviews. Although individual reviews may not be able to offer as much evidence as hoped, it is possible that by synthesizing evidence from existing systematic reviews about self-care with various conditions that there may
be opportunity to amalgamate similar interventions and outcomes to further knowledge and direction about the support of self-care.

To address this objective all current evidence across multiple disease/impairment populations (e.g., stroke, heart disease, musculoskeletal conditions) was examined rather than focusing on a single condition or disease. This study integrated the evidence on interventions aimed at initiating, supporting or enhancing individuals’ engagement in self-care activities. This includes any behaviour performed by the individual on their own behalf or by another as assistance to address health, illness, injury or disability. When initiating a self-care activity, a behaviour that was not previously part of the individual’s repertoire is established. Strategies to support this initiation could include the provision of written material or computerized programs to assist individuals to adhere to a medication regime. When enhancing self-care activities, support is provided for already existing behaviours, with strategies such as the creation of an asthma self-care management plan to maintain asthma self-care activities.

The Cochrane Database of Systematic Reviews was used as the primary data source to integrate the evidence about strategies to initiate and support self-care. This database was specifically chosen because:

1) It is a repository of systematic reviews performed by 52 different Cochrane Collaboration Review Groups, each of which focuses on a different disease, impairment or condition (except for the Methods Group which focuses on synthesis methodology);
2) All Cochrane Review Groups conduct systematic reviews using similar methodology; and

3) Cochrane reviews have been shown to be of high quality.¹³

As an integrative study, this review was performed as an ‘overview of reviews.’ In the Cochrane handbook for the performance of systematic reviews Becker and Oxman¹⁴ defined an overview of reviews as being “intended primarily to summarize multiple Cochrane Intervention reviews addressing the effects of two or more potential interventions for a single condition or health problem.”¹⁴,chapter22,section22.1.2 The integration of evidence across conditions or health problems is an important enhancement of this process.

The definition of self-care adopted for this integrative study was provided by Health Canada in 1997 as “the decisions and actions taken by someone who is facing a health problem in order to cope with it and improve his or her health.”¹⁵,p.2 This definition was adopted because it focuses on self-care from the individual’s perspective and related to a health problem. The intent with this integrative study was to draw together interventions across disease/impairment groupings. Hence the focus was limited to management of diseases or impairments with the exclusion of health promotion and prevention.
Objectives

To explore and evaluate the evidence on self-care interventions through a cross-cutting, integrative study.

Review Questions

The overall research question for the integrative study was: What is the evidence on interventions to initiate or enhance individuals’ self-care activities across population groups in the Cochrane repository of systematic reviews?

The synthesis process was guided by the following specific questions:

1. What intervention strategies to initiate or enhance self-care have been described?
2. How have the outcomes of interventions to initiate or enhance individuals’ self-care activities been measured?

This integrative study also addressed the following questions:

1. What evidence has been provided by this cross-cutting investigation that is of value to rehabilitation practice?
2. Is there a conceptual map or framework to facilitate the comprehension of this evidence?
3. What gaps in this area of research were revealed?
Methods of the Review

Criteria for considering studies for this review

PICO

Population – individuals who were either recently diagnosed with, or are currently living with, a disease or impairment, and who engage, or have the potential to engage, in self-care activities (no age stipulation);

Intervention – strategies to initiate or enhance self-care activities;

Context – in the context of disease or impairment as focused on by the 52 review groups of the Cochrane Collaboration. Health care settings across the continuum of care, including acute, community or rehabilitation settings;

Outcomes – the successful engagement of the individual in self-care activities; the sustainment of self-care activities; health outcomes, health system outcomes.

Inclusion criteria

The lead author collaborated with two authors from the review panel (MBH and RL) to ensure clarity in the specification of these criteria.

The inclusion and exclusion criteria were guided by Orem’s theory of self-care\(^{16}\) which has three conceptual elements: self-care (engaging in action); self-care agency (capacity to perform those actions); and self-care requisites (requirements that guide actions in the care of the self).\(^{17}\)

The purpose of the self-care action is depicted by the self-care requisites\(^{18}\) and there are three types of requisites:\(^{19;20}\)
1. Universal self-care requisites – activities required by all people during all stages of life to maintain health, promote health and prevent disease.

2. Developmental self-care requisites – requirements that support and promote the process of human development and prevent conditions that would negatively affect the developmental process.

3. Health deviation self-care requisites – changes in self-care activities to regulate the effects of deviation from normal structure or function.

   Systematic reviews were included if they addressed the health deviation self-care requisites.

**Types of studies**

   In this integrative study, all systematic reviews contained within the Cochrane Database of Systematic Reviews were considered. No review groups were purposefully excluded. However, it was recognized that the Methodology Review Group would not have contributed reviews because its focus is on methodology and not health conditions.

**Types of participants**

   Reviews involving participants who were either recently diagnosed with, or currently living with, a disease, disability or impairment were included. No age stipulation was applied. These individuals were either engaged in self-care activities, or had the potential to engage in self-care activities. Individuals who had the potential to engage in a new self-care activity would be individuals who were recently diagnosed
with a condition such as asthma or diabetes mellitus. Individuals who currently engaged in self-care activities (but required ongoing support) would be individuals who performed self-care activities to manage an ongoing condition such as spina bifida. According to Orem’s self-care theory, these individuals would meet the health deviation self-care requisite, which describes the purpose of performing self-care as ‘addressing a deviation in structure or function.’

**Types of intervention(s)/phenomena of interest**

Systematic reviews that described interventions focused on initiating or enhancing self-care activities were considered. Systematic reviews were included if the interventions they studied met the following criteria:

- Interventions were targeted at individuals or families, not health care professionals.
- Participants received educational interventions focused on self-care or disease management.
- Participants were required to actively engage in a behaviour related to self-care, such as following a written action plan of self-treatment, or self-medication. Behaviours such as specific relaxation or biofeedback techniques commonly used with individuals who have asthma were also included.
Strategies that provided assistive devices or aids were included only if the devices were specifically to assist participants in the performance of self-care.

Interventions were included that investigated a variety of methods to deliver education on self-care, such as written plans, culturally sensitive educators or lay persons as educators.

Psychological interventions were included when they were used to increase adherence to treatment regimes but not if used only as treatment for a condition.

Exercise as a strategy was included if it was an option that the individual could select (as an act of choice) in order to manage their health. Exercise as treatment for a condition was excluded.

Strategies were included if they supported individual’s attempts to initiate a self-care behaviour or maintain a self-care behaviour, for example, special dosage packaging for ease of medication administration.

**Types of outcomes**

Outcomes of interest for this study included: the successful engagement of the individual in self-care activities; the sustainment of self-care activities; health outcomes or health care system utilization. To assess engagement or sustainment in self-care activities, the range of outcomes measured included (but were not limited to):
a) Cognitive and behavioural aspects such as: knowledge, adherence to self-care routines, self-management skills (including dietary habits and physical activity levels), the ability to engage in work and self-efficacy.

b) Clinical outcomes such as: glycated hemoglobin, fasting blood glucose levels, body weight, lipid profile and blood pressure.

c) Health outcomes such as: number of exacerbation days per month, number of symptom free days per month, pain levels, fatigue, dyspnea, and frequency of epileptic seizures.

d) Health care service utilization such as: number of emergency department visits, hospitalizations, visits to health care professionals and readmission rates.

Method of measurement included a range such as questionnaires, participant diaries, medical records, administrative logs, and interviews.

**Exclusion criteria**

Systematic reviews that were in the protocol stage, null reviews (i.e., number of included studies n=0) and reviews with only one included study (i.e., number of included studies n=1) were excluded. The focus of this integrative study was on the synthesis of evidence across disease/impairment groupings and was limited to individuals with health problems in which the self-care undertaken was performed with the support of health care professionals. Hence, aspects related to general health promotion and disease prevention were excluded.
Systematic reviews were excluded that involved interventions for the following purposes:

- To reduce or cope with an addictive behaviour such as smoking, drug abuse or alcohol abuse.
- To demonstrate the efficacy of the intervention itself rather than its use as a part of self-care.
- To cope with a specific medical treatments (e.g., physical exercise as a means of counteracting several of the side effects that cancer treatments induce).
- To initiate activities specifically intended to promote health or prevent diseases.

**Search Strategy**

The search strategy was designed to find all systematic reviews contained within the Cochrane Database of Systematic Reviews that addressed interventions to initiate or enhance self-care. Four methods were used to access this database:

1. A comprehensive search strategy (Appendix P) was run against the Medline database using the OVID interface. These results were then intersected (AND) with the Cochrane Database of Systematic Reviews as a publication title.
2. The same comprehensive search strategy was used to search the Cochrane Database of Systematic Reviews through the OVID interface.
3. The Cochrane Database of Systematic Reviews was searched directly (through Wiley). The comprehensive search strategy (mentioned above) contained 115 lines and it was not possible to enter this many lines into the search feature used by the Cochrane Library. Consequently several smaller search strategies were created using the index terms and keywords from the comprehensive search strategy.

4. When five ‘gold standard’ (i.e., meeting inclusion criteria and on topic) reviews were identified, the index terms and keywords were harvested from their listed search strategies and a second round of searching using all of these index terms and keywords was then undertaken.

Records were retrieved from the search resulting in the lists of reviews with details of title, author, and abstract. All identified reviews were assessed on the basis of the abstract by two reviewers, and full reports were retrieved for those that met the inclusion criteria. If a consensus could not be reached by reviewing the abstract, the full review was retrieved for further examination.

Initial MeSH terms and keywords included, but were not limited to: self-care; self-care skills; self administration; self medication; self-care intervention(s); self-care strategy(ies); self efficacy; personal care; lay care; self maintenance; self treatment.
Conceptualization of the interventions

Essentially, the variety of intervention strategies described by the Cochrane systematic reviews reflects the process of knowledge translation whereby health care professionals use different strategies to transfer knowledge as they inform, guide, support and assist individuals to engage in self-care. Hence, the interventions were examined within this context of knowledge translation. The Knowledge-to-Action framework by Graham and colleagues\textsuperscript{22} was used to guide the conceptualization of this process. Knowledge translation (KT) has been defined by the Canadian Institutes of Health Research (CIHR) as follows:

Knowledge translation (KT) is defined as a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system\textsuperscript{1} accessed May 17, 2010)

Although this definition generally speaks to the transfer of knowledge between researcher and user, it likewise applies to the transfer of knowledge between health care professional and individual or family. In this instance, the knowledge is transferred to strengthen the individual or family’s capacity to engage in self-care activities.

Graham and colleagues\textsuperscript{22} describe the process of the transfer of knowledge as the 'knowledge-to-action' (KTA) process, and they provide a map to guide the sequence of events (Figure 14). The knowledge-to-action process is divided into knowledge creation and action involving that knowledge and the map depicts these two parts as 1)
a central funnel entitled “knowledge creation” surrounded by, 2) the “action cycle”, comprising several steps. Knowledge creation and action utilizing that knowledge are not isolated events but interact dynamically. The knowledge funnel has three elements: knowledge inquiry; knowledge synthesis and knowledge tools or products, and the funnel represents the processes of tailoring and refining that knowledge in order to be applicable at the practical level. The first level, knowledge inquiry, represents the vast databases of primary studies that are integrated through the second level of synthesis to create tools such as guidelines that are found at the third level. In essence, this whole phase represents the transition from data into evidence.

Subsequently the action cycle includes the activities that lead to the implementation of knowledge. This includes:

- identifying the problem or selecting a focal aspect of the knowledge (e.g., guideline)
- adapting the knowledge to the local context
- assessing the barriers to knowledge use
- tailoring interventions
- monitoring how members use the knowledge
- evaluating the outcomes, and
- sustaining the knowledge use.
Classification of the outcomes

All of the systematic review outcomes were classified according to the framework - Measures of Knowledge Use and Impact - proposed by Graham and colleagues.\(^{23}\) They divide outcomes into two broad categories: “knowledge use” (use of the evidence) and its “impact” (what results from use of that knowledge). The framework further divides knowledge use into “conceptual use”, “instrumental use” and
“enablers of instrumental use”. Impact of knowledge use is divided into “patient impact”, “provider impact” and “system/organizational impact”.

Contextualized for this study, the elements of knowledge use are: a) conceptual use which refers to the changes in the individual’s knowledge, attitudes, or intentions; b) instrumental use which refers to the individual’s behavior based on that knowledge, for example, adherence to a medication regime; and c) enablers of instrumental use refers to the changes required to enable behaviour changes to occur such as acquiring of necessary equipment, or provision of reminders to enable adherence to a medication regime or management plan. The elements of the impact of knowledge use are: a) patient/individual impact reflecting the direct effects resulting from following the protocol or management plan, such as changes in the individual’s health status; b) provider impact reflecting the changes in quality or continuity of care provided by the health care professional; and c) system/organizational impact reflecting the impact on the health care system by hospitalization, re-admission, emergency room visitation or health care costs.

**Assessment of methodological quality**

Methodological quality was assessed using the JBI Critical Appraisal Checklist for Systematic Reviews (Appendix Q). This checklist has 10 questions and the cut-off point was set to 7/10 to include only those reviews which demonstrated a high level of methodological rigor. The cut-off point was set high (70%) because the data set
comprised Cochrane systematic reviews that undergo rigorous peer reviews prior to publication in order to maintain high methodological standards. This checklist addresses ten methodological issues that are pertinent when performing systematic reviews. Although there is no agreed upon cut-off point that indicates a substantive reduction in methodological rigor, it was decided that failing to address more than three of these issues represented sufficient deviation to warrant exclusion.

**Data extraction**

Data were extracted from the systematic reviews using an adaptation of the standardized data extraction form, the JBI Data Extraction Form for Systematic Review of Experimental/Observational Studies (Appendix R).

The extraction tool was adapted (Appendix S) to reflect details of the self-care intervention strategy, outcomes measured and results. If the Cochrane review included studies with multiple interventions, only those interventions that met the inclusion criteria of this study were extracted.

**Data synthesis**

Given the heterogeneity of the range of self-care intervention strategies, the results were synthesized and discussed in narrative form.
Review Results

Description of studies

The combined search strategies returned 2,686 records (Appendix T). At the abstract review stage, 2,590 records were discarded as either duplicates or off topic, and 53 were discarded as not meeting the inclusion criteria. No systematic reviews were excluded as a result of the methodological quality assessment. Thirteen reviews were excluded because they provided results from single studies and the final set comprised 30 systematic reviews (Appendices U and V).

Included reviews ranged in publication date from 2001 to 2010. According to the location of the lead author, 14 reviews originated in the United Kingdom, eight reviews in Australia, four reviews in the Netherlands, three reviews in Canada, and one review in the U.S.A. Twenty reviews included only randomized controlled trials (RCT), six reviews included both RCTs and clinical controlled trials (CCT), and four reviews included RCTs plus quasi randomized trials. The number of trials included in each review ranged from two to 50 and the total number of trials included across all reviews was 466. The trials included in the reviews were conducted from 1975 to 2008. Twelve reviews had less than ten included trials. Fifteen reviews focused on the adult population; five reviews both adults and children; seven reviews both adults and elders; two reviews children only; and one review children and adolescents. The total number of participants was 91,170.
Thirteen Cochrane review groups were represented (number of reviews in brackets): Airways group (12), Consumers and communication group (4), Metabolic and endocrine diseases group (4), and one review each from the Back group, Depression anxiety and neurosis group, Effective practice and organization of care group, Eyes and vision group, HIV/AIDS group, Hypertension group, Infectious diseases group, Musculoskeletal group, Oral health group and Wounds group.

Sixteen disease or impairment groupings were addressed (number of reviews in brackets): Asthma (10), Diabetes Mellitus (6), chronic obstructive pulmonary disease (COPD) (3), general chronic conditions (2), and one review each for eating disorders, ocular hypertension, general medical disorders, HIV/AIDS, hypertension, increased blood cholesterol, low back pain, malaria, mental health conditions, obstructive sleep apnea, periodontal disease, and rheumatoid arthritis. (One review included the conditions asthma, diabetes mellitus and COPD, which were added to the appropriate groups). (See details of included studies Appendix W).

All reviews were appraised by two assessors, and demonstrated agreement for 95% of the assessments. No reviews scored below the cut-off point and thus none were excluded. Twenty-four reviews scored 10/10, two reviews scored 9/10, and four reviews scored 8/10.
Number of interventions, outcomes and results

Thirty systematic reviews described 30 interventions which were assessed by 248 outcomes, which in turn lead to 243 results (effect of the interventions at the trial level) being reported (Table 12). The unit of analysis for this integrative study was the review set i.e., effectiveness of the interventions as indicated by the meta-analysis results and reported as statistically significant. This was calculated by a range of methods such as Odds Ratios, Risk Difference, Relative Risk, and Mean Difference. The clinical importance or significance of the results was not consistently reported, thus references to ‘significance’ in this integrative study refer to statistical significance.

Table 12: Included Systematic Reviews by Intervention Focus (n=30)

<table>
<thead>
<tr>
<th>Author/Year/ # of Included Trials</th>
<th>Disease/ Impairment</th>
<th>Intervention Focus</th>
<th>Intervention Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gray 2009 Trials: 8</td>
<td>Glaucoma, Ocular hypertension</td>
<td>Improving adherence to ocular hypotensive therapy</td>
<td>Educational sessions, follow-up telephone support, prompts and reminder cards</td>
</tr>
<tr>
<td>Rueda 2006 Trials: 19</td>
<td>HIV/AIDS</td>
<td>Increase adherence to antiretroviral therapy medication regimes</td>
<td>Educational sessions, cognitive or behavioural principles, counselling session, management plan, psychological intervention</td>
</tr>
<tr>
<td>Schroeder 2004 Trials: 38</td>
<td>Hypertension</td>
<td>Adherence to blood pressure lowering medication</td>
<td>Counselling session, educational material, educational sessions, follow-up telephone support, media - video, prompts and reminder cards, simplified dosing, visit with nurse or doctor</td>
</tr>
<tr>
<td>Orton 2005 Trials: 5</td>
<td>Malaria</td>
<td>Adherence to treatment in people with uncomplicated malaria.</td>
<td>Functional aids or instruments, prompts and reminder cards, unit dose drug packaging</td>
</tr>
<tr>
<td>Author/Year/ # of Included Trials</td>
<td>Disease/ Impairment</td>
<td>Intervention Focus</td>
<td>Intervention Strategies</td>
</tr>
<tr>
<td>----------------------------------</td>
<td>---------------------</td>
<td>--------------------</td>
<td>-------------------------</td>
</tr>
<tr>
<td>Heneghan 2006 Trials: 8</td>
<td>Medical disorder</td>
<td>Adherence to medication regimes</td>
<td>Functional aids or instruments, prompts and reminder cards</td>
</tr>
<tr>
<td>Smith 2009 Trials: 17</td>
<td>Obstructive sleep apnea</td>
<td>Adherence to use of CPAP machines</td>
<td>Counselling session, educational material, educational sessions, follow-up telephone support, regular medical review</td>
</tr>
<tr>
<td>Renz 2007 Trials: 4</td>
<td>Periodontal disease</td>
<td>Adherence to oral hygiene instructions</td>
<td>Checklists, cognitive or behavioural principles, educational sessions</td>
</tr>
<tr>
<td>Gibson 2002 Trials: 12</td>
<td>Asthma</td>
<td>Limited (information only) education</td>
<td>Computer program, educational material, educational sessions, media – video</td>
</tr>
<tr>
<td>Bailey 2009 Trials: 4</td>
<td>Asthma</td>
<td>Culturally appropriate education - asthma minority child and adult</td>
<td>Educational material, educational sessions, management plan</td>
</tr>
<tr>
<td>Powell 2002 Trials: 15</td>
<td>Asthma</td>
<td>Asthma self-management education</td>
<td>Educational material, educational sessions, management plan, regular medical review</td>
</tr>
<tr>
<td>Boyd 2009 Trials: 38</td>
<td>Asthma</td>
<td>Asthma education following exacerbation</td>
<td>Educational material, educational sessions, management plan, telephone hotline</td>
</tr>
<tr>
<td>Tapp 2007 Trials: 12</td>
<td>Asthma</td>
<td>Educational interventions following acute asthma exacerbation</td>
<td>Educational material, educational sessions, management plan, telephone hotline</td>
</tr>
<tr>
<td>Wolf 2002 Trials: 32</td>
<td>Asthma</td>
<td>Asthma self-management education for children with asthma</td>
<td>Educational sessions, management plan</td>
</tr>
<tr>
<td>Gibson 2002 Trials: 36</td>
<td>Asthma</td>
<td>Self-management education with regular practitioner review</td>
<td>Educational sessions, management plan, regular medical review</td>
</tr>
<tr>
<td>Murray 2005 Trials: 24</td>
<td>Chronic conditions</td>
<td>Education using interactive computer programs</td>
<td>Computer program, decision aids, educational material, educational sessions</td>
</tr>
<tr>
<td>Author/Year/# of Included Trials</td>
<td>Disease/Impairment</td>
<td>Intervention Focus</td>
<td>Intervention Strategies</td>
</tr>
<tr>
<td>----------------------------------</td>
<td>--------------------</td>
<td>--------------------</td>
<td>-------------------------</td>
</tr>
<tr>
<td>Foster 2007 Trials: 17</td>
<td>Chronic conditions</td>
<td>Lay-led self-management education</td>
<td>Educational material, educational sessions, media – video</td>
</tr>
<tr>
<td>Effing 2007 Trials: 14</td>
<td>COPD</td>
<td>Self-management education for COPD</td>
<td>Educational material, educational sessions, management plan</td>
</tr>
<tr>
<td>Hawthorne 2008 Trials: 11</td>
<td>Diabetes Mellitus</td>
<td>Culturally appropriate education - DM</td>
<td>Educational material, educational sessions, media – video</td>
</tr>
<tr>
<td>Valk 2001 Trials: 9</td>
<td>Diabetes Mellitus</td>
<td>Patient education for foot ulcers in DM</td>
<td>Educational material, educational sessions, media - video, supervision</td>
</tr>
<tr>
<td>Deakin 2005 Trials: 11</td>
<td>Diabetes Mellitus</td>
<td>Group based patient centered education - diabetes</td>
<td>Educational sessions</td>
</tr>
<tr>
<td>Duke 2006 Trials: 9</td>
<td>Diabetes Mellitus</td>
<td>Individual face-to-face patient educational sessions - DM</td>
<td>Educational sessions</td>
</tr>
<tr>
<td>Perkins 2006 Trials: 15</td>
<td>Eating disorders</td>
<td>Self-help (guided or pure) compared to other strategies in eating disorders</td>
<td>Counselling session, educational material, educational sessions, self-help resources</td>
</tr>
<tr>
<td>Engers 2008 Trials: 24</td>
<td>Low back pain</td>
<td>Individual patient education for LBP</td>
<td>Cognitive or behavioural principles, educational material, educational sessions, exercise, media – video</td>
</tr>
<tr>
<td>Riemsma 2003 Trials: 50</td>
<td>Rheumatoid arthritis</td>
<td>Patient education for rheumatoid arthritis</td>
<td>Cognitive or behavioural principles, counselling session, educational material, educational sessions</td>
</tr>
<tr>
<td>Bhogal 2006 Trials: 4</td>
<td>Asthma</td>
<td>Effect of written action plans - child and adolescent with asthma</td>
<td>Management plan, visit with nurse or doctor</td>
</tr>
<tr>
<td>Toelle 2004 Trials: 7</td>
<td>Asthma</td>
<td>Individualized asthma management plan to increase management</td>
<td>Educational material, educational sessions, management plan, prompts and reminder cards</td>
</tr>
<tr>
<td>Turnock 2005 Trials: 3</td>
<td>COPD</td>
<td>Management plans for COPD</td>
<td>Action plan (guideline), educational material, educational sessions, management plan</td>
</tr>
<tr>
<td>Author/Year/ # of Included Trials</td>
<td>Disease/ Impairment</td>
<td>Intervention Focus</td>
<td>Intervention Strategies</td>
</tr>
<tr>
<td>----------------------------------</td>
<td>--------------------------------</td>
<td>--------------------------------------------------------</td>
<td>-------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Welschen 2005 Trials: 6</td>
<td>Diabetes Mellitus</td>
<td>Self monitoring of blood glucose</td>
<td>Educational material, educational sessions, self-monitoring blood glucose</td>
</tr>
<tr>
<td>Duncan 2010 Trials: 2</td>
<td>Mental health condition</td>
<td>Shared decision making for mental health</td>
<td>Decision aids</td>
</tr>
<tr>
<td>Thompson 2003 Trials: 12</td>
<td>Increased blood cholesterol</td>
<td>Effects of dietary advice in reducing blood cholesterol</td>
<td>Educational material, educational sessions, exercise</td>
</tr>
</tbody>
</table>

**Interventions**

There were three broad types of interventions with different foci: 1) to provide education and information (13 interventions); 2) to increase adherence to an existing regime (7 interventions); and 3) to assist and guide self-management (10 interventions). Within these groups there was a variety of approaches. Using the group of educational interventions as an example, there was culturally appropriate education; group based patient-centered education; limited (information only) education focus; and individual face-to-face patient education. Each of these interventions used a range of implementation strategies.

**Strategies to deliver the interventions**

The intervention strategies varied widely with respect to complexity, intention, intensity, frequency, duration, setting, delivery and follow-up. For example, some strategies that addressed asthma included components such as: education about
environmental asthma triggers; parental intervention to reduce tobacco smoke exposure; self-care management plans, peak flow meters and education regarding triggers and physiology of asthma; access to a helpline; and provision of allergen impermeable mattresses (Boyd 2009\textsuperscript{24}). Culturally appropriate strategies included components such as an educator fluent in each participant’s own dialect; and the provision of educational material in the individual’s own dialect (Bailey 2009\textsuperscript{25}).

Management plans (also called clinical management plans, self-management plans or written action plans) consist of a written set of instructions given to individuals for the management of chronic symptoms as well as for the prevention and management of exacerbations. A management plan acts as a communication tool between the health care professional and the individual. It functions as a reminder of the treatment plan, including instructions for step-up and step down therapy in response to deterioration and improvement.\textsuperscript{26} Some management plans were specifically formatted to target different audiences such as children. For example, Bhogal (2006)\textsuperscript{26} described three management plans targeted at children that associated the self-care steps taken before seeking medical attention with the streetlight colour approach (green-yellow-red). Because management plans refer to the self-care actions performed by individuals with respect to their conditions, in this study they are referred to as ‘self-care management plans’.

The majority of reviews (27) reported the use of multiple intervention strategies and the most common strategies were educational sessions (26 reviews) and self-care
management plans (11 reviews). From the set of 21 reviews reporting significant results, 19 reviews reported the use of multiple strategies, 18 reviews reported on the use of educational sessions and eight reviews reported the use of self-care management plans (Table 13).

**Table 13: Intervention Details**

<table>
<thead>
<tr>
<th>Interventions</th>
<th>Number of Reviews (n=30)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Multiple strategies</td>
<td>27</td>
</tr>
<tr>
<td>Single strategies</td>
<td>3</td>
</tr>
<tr>
<td>Educational sessions</td>
<td>26 *</td>
</tr>
<tr>
<td>Self-care management plans</td>
<td>11 *</td>
</tr>
<tr>
<td>Reviews reporting significant results</td>
<td>21 reviews</td>
</tr>
<tr>
<td>Multiple strategies</td>
<td>19</td>
</tr>
<tr>
<td>Educational strategies</td>
<td>18 *</td>
</tr>
<tr>
<td>Self-care management plans</td>
<td>8 *</td>
</tr>
</tbody>
</table>

* - not mutually exclusive

**Conceptualization of the interventions**

Conceptually, the focus of this integrative study is the process of knowledge translation. In this instance, the knowledge is being transferred by health care professionals to individuals and families to assist, support and guide them as they engaged in self-care activities. The Knowledge-to-Action framework by Graham and colleagues\(^{22}\) was used to guide the examination of the interventions within this context.
As previously described, the Knowledge-to-Action framework depicts two areas of action, the inner funnel and the outer circle. The systematic reviews that form the data for this integrative study reflect the middle section of the funnel – the synthesis of evidence. However, the range and variety of interventions they report exemplify the outer circle and the activities that lead to the implementation of knowledge. There are two stages in this action cycle that are addressed by these interventions: the ‘tailoring of intervention strategies to local use’ and the ‘sustainment of knowledge.’

The condition of asthma was the most frequently addressed condition (10 reviews). Using this condition as an example, we see a range of interventions that indicated the process of adaptation or tailoring to the local setting or specific population group. The following intervention foci indicate this process of adaptation (significant results indicated by *):

- culturally appropriate education (Bailey 200925)*
- written action plans adapted for children (Bhogal 200626)*
- asthma education delivered immediately following a period of exacerbation (children) (Boyd 200924)*
- limited (information only) education (Gibson 200227)
- self-management education with regular medical review (Gibson 200228)*
- education using interactive computer programs (Murray 200529)*
- asthma self-management education (Powell 200230)*
• education following acute asthma exacerbation (adults) (Tapp 2007<sup>31</sup>)*

• individualized asthma management plan to increase management (Toelle 2004<sup>32</sup>)

• asthma self-management education for children (Wolf 2002<sup>33</sup>).*

All asthma reviews reported the use of multiple strategies to implement these interventions including educational sessions, self-care management plans, the provision of educational material, telephone hot-lines and follow-up visits with health care professionals. The tailoring of these interventions to enhance the transfer of knowledge to individuals with asthma was a successful approach as eight of the ten reviews reported significant results.

Other interventions, particularly those using written self-care management plans, also tried a range of approaches to adapt to the specific populations of individuals who would be using them. For example, written self-care management plans could be individualized; provided in the individual’s own dialect; generated with a culturally appropriate focus; or illustrated in colour for children to follow. The three reviews adapting self-care management plans did report significant results, one of which reported a proportion of significant results over 50% of its result load.

The process of adaptation included a modification of either the knowledge or the method of transfer. For example, one intervention “incorporated the use of an asthma
self-management workbook modified to be specific to African-Americans,\textsuperscript{25,p.6} while another modified self-care management plans to include colourful drawings when targeting children.\textsuperscript{26}

The sustainment of knowledge was addressed by reviews that examined interventions to improve adherence to specific self-care activities. Seven reviews investigated adherence and their intervention foci included (significant results indicated by *):

- improving adherence to ocular hypotensive therapy (Gray 2009\textsuperscript{34})*
- education or support strategies to increase adherence to antiretroviral therapy medication regimes (Rueda 2006\textsuperscript{35})
- adherence to blood pressure lowering medication (Schroeder 2004\textsuperscript{36})
- adherence to treatment for malaria (Orton 2005\textsuperscript{37})*
- adherence to medication regimes for general medical disorders (Heneghan 2006\textsuperscript{38})*
- adherence to use of CPAP machines for obstructive sleep apnea (Smith 2009\textsuperscript{39})
- adherence to oral hygiene instructions for individuals with periodontal disease (Renz 2007\textsuperscript{40}).

These reviews also used multiple strategies to implement their interventions including educational sessions, the provision of educational material, prompts and reminders, unit-dose drug packaging, counselling sessions, strategies involving cognitive
and behavioural principles, follow-up sessions with health care professionals, and follow-up telephone support. However, the interventions aimed at sustainment were not as successful as the interventions that focused on adapting to the local population. Less than half (n= 3) of the seven reviews reported significant results.

**Systematic review outcomes**

Reviews organized their outcomes as primary (76 outcomes), secondary (90 outcomes) or not stated (80 outcomes). According to the Knowledge Use and Impact of Knowledge Use framework,\(^{23}\) patient/individual impact (the impact of knowledge use on patients’ or individuals’ health outcomes) was the most frequently measured at 151 outcomes. This was followed by system/organizational impact (the impact on the health care system by hospitalization, readmissions, emergency room visitation or health care costs). Forty outcomes measured this impact of knowledge use. The instrumental use of knowledge (behaviour based on the knowledge such as the individual’s self-care or self-management behaviours after receiving specific self-care information) was measured by 39 outcomes. *Conceptual use* (the changes in knowledge, attitudes, or intensions) was measured by 13 outcomes and enablers of knowledge use (assistive devices or reminders that enable the occurrence of the behaviour) was measured by five outcomes. Outcomes that measured conceptual use also reported the highest percentage of significant results (46%). Out of the total 248 outcomes, 72 were reported as significant results (Table 14).
The measurement of outcomes

Instruments used to measure outcomes were not reported consistently by all the reviews and consequently these data were not available to compare or discuss.

Table 14: Measures of Knowledge Use and its Impact (adapted from Graham Table 2.123,p.31-32) (with permission of Wiley-Blackwell)

<table>
<thead>
<tr>
<th>Outcome Description</th>
<th>Examples</th>
<th>Outcomes Measured (n= 248)</th>
<th>Significant Results (n=72) n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge use</td>
<td><strong>Conceptual</strong> – changes in knowledge levels or understanding</td>
<td>Knowledge, attitudes, intentions</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td><strong>Instrumental</strong> – changes in behaviour as a result of the use of the knowledge</td>
<td>Adherence to recommendations, adoption of a new behaviour, following of a medication regime</td>
<td>39</td>
</tr>
<tr>
<td></td>
<td><strong>Enablers of knowledge use</strong> – changes required to enable a change in behaviour</td>
<td>Assistive devices or reminders</td>
<td>5</td>
</tr>
<tr>
<td>Impact of knowledge use</td>
<td><strong>Patient/individual impact</strong> – changes in health status</td>
<td>Decrease in blood pressure, stability of blood sugar levels, decrease in asthma exacerbations</td>
<td>151</td>
</tr>
<tr>
<td></td>
<td><strong>System or organizational impact</strong> – impact on the health care system</td>
<td>Visits to the emergency department, readmissions, hospitalizations</td>
<td>40</td>
</tr>
</tbody>
</table>

Systematic review results

From the set of 243 results, 50 results were obtained from single studies only and were therefore excluded. A total of 193 results were therefore reported and overall 32% of these were significant. The number of results reported by the reviews ranged
from one to 20. Twenty-six reviews assessed educational sessions as implementation strategies. Of this set, 18 (18/26 69%) interventions reported significant results. Eleven reviews assessed self-care management plans as implementation strategies. Of this set, eight (8/11 73%) interventions reported significant results.

Of the 21 reviews that reported significant results, eight reviews reported a proportion of significant results that was over 50% of their total result load (Table 15). Of this set of eight reviews reporting a proportion of significant results of over 50%, five reviews had interventions focused on education, two interventions focused on adherence and one on self-care management. With respect to disease or impairment groupings, two reviews focused on asthma (Boyd 200924; Gibson 200228); two reviews focused on diabetes mellitus (Deakin 200541; Valk 200142); and one review each focused on glaucoma (Gray 200934); multiple chronic conditions (Murray 200529); malaria (Orton 200537) and rheumatoid arthritis (Riemsma 200343).
Table 15: Number of Significant Results per Review (n=30)

<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>Number of Results</th>
<th>Significant Results (%)</th>
<th>Positive Results (%)</th>
<th>Conflicting or Inconclusive Results (%)</th>
<th>No Significant Difference (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Duncan</td>
<td>2010</td>
<td>1</td>
<td>1 (100)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smith</td>
<td>2009</td>
<td>9</td>
<td>2 (22)</td>
<td>1 (11)</td>
<td>5 (56)</td>
<td>2 (40)</td>
</tr>
<tr>
<td>Boyd</td>
<td>2009</td>
<td>5</td>
<td>3 (60) *</td>
<td>1 (11)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bailey</td>
<td>2009</td>
<td>2</td>
<td>1 (50)</td>
<td>1 (50)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gray</td>
<td>2009</td>
<td>1</td>
<td>1 (100) *</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Engers</td>
<td>2008</td>
<td>8</td>
<td>2 (25)</td>
<td></td>
<td>6 (75)</td>
<td></td>
</tr>
<tr>
<td>Hawthorne</td>
<td>2008</td>
<td>6</td>
<td>2 (33)</td>
<td></td>
<td></td>
<td>4 (67)</td>
</tr>
<tr>
<td>Foster</td>
<td>2007</td>
<td>18</td>
<td>8 (44)</td>
<td>1 (6)</td>
<td>2 (11)</td>
<td>7 (39)</td>
</tr>
<tr>
<td>Effing</td>
<td>2007</td>
<td>9</td>
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<td></td>
<td>5 (56)</td>
<td>3 (33)</td>
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<td></td>
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<tr>
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<td>2006</td>
<td>9</td>
<td>2 (22)</td>
<td></td>
<td></td>
<td>7 (78)</td>
</tr>
<tr>
<td>Perkins</td>
<td>2006</td>
<td>9</td>
<td>1 (11)</td>
<td></td>
<td>8 (89)</td>
<td></td>
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<tr>
<td>Rueda</td>
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<td>5</td>
<td>3 (60)</td>
<td></td>
<td>2 (40)</td>
<td></td>
</tr>
<tr>
<td>Heneghan</td>
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<td>1 (50)</td>
<td></td>
<td>1 (50)</td>
<td></td>
</tr>
<tr>
<td>Deakin</td>
<td>2005</td>
<td>8</td>
<td>5 (62) *</td>
<td></td>
<td></td>
<td>3 (38)</td>
</tr>
<tr>
<td>Murray</td>
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<td>7</td>
<td>4 (57) *</td>
<td>1 (14)</td>
<td>2 (29)</td>
<td></td>
</tr>
<tr>
<td>Turnock</td>
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<td>4</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Welschen</td>
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<td>1 (33)</td>
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<tr>
<td>Orton</td>
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<td>1</td>
<td>1 (100) *</td>
<td></td>
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<td></td>
</tr>
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<td>Toelle</td>
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<td>4</td>
<td>1 (25)</td>
<td></td>
<td>3 (75)</td>
<td></td>
</tr>
<tr>
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<td>3</td>
<td></td>
<td></td>
<td>3 (100)</td>
<td></td>
</tr>
<tr>
<td>Riemsma</td>
<td>2003</td>
<td>20</td>
<td>12 (60) *</td>
<td></td>
<td></td>
<td>8 (40)</td>
</tr>
<tr>
<td>Thompson</td>
<td>2003</td>
<td>8</td>
<td>2 (25)</td>
<td>2 (25)</td>
<td></td>
<td>4 (50)</td>
</tr>
<tr>
<td>Powell</td>
<td>2002</td>
<td>8</td>
<td>1 (12.5)</td>
<td>1 (12.5)</td>
<td>2 (25)</td>
<td>4 (50)</td>
</tr>
<tr>
<td>Wolf</td>
<td>2002</td>
<td>8</td>
<td>1 (12.5)</td>
<td>2 (25)</td>
<td>4 (50)</td>
<td>1 (12.5)</td>
</tr>
<tr>
<td>Gibson</td>
<td>2002</td>
<td>7</td>
<td>5 (71) *</td>
<td></td>
<td>2 (29)</td>
<td></td>
</tr>
<tr>
<td>Gibson</td>
<td>2002</td>
<td>3</td>
<td></td>
<td>1 (33)</td>
<td>2 (67)</td>
<td></td>
</tr>
<tr>
<td>Valk</td>
<td>2001</td>
<td>3</td>
<td>2 (67) *</td>
<td></td>
<td>1 (33)</td>
<td></td>
</tr>
</tbody>
</table>

* = proportion of significant results over 50% of total result load
Comparison 1 – Significant results and measure of knowledge use

The measure of knowledge use was compared with reviews reporting over 50% significant results; reviews reporting 50% or less significant results; and reviews that did not report significant results (Table 16). We see that the measure of patient/individual impact is the most frequently measured outcome (73%, 64% and 38% respectively). Notably, reviews reporting no significant results were measuring instrumental use of knowledge more frequently (32%) than reviews reporting significant results (4% and 15% respectively). Measures of instrumental use of knowledge represent changes in behaviour, and in this context reflect the individual’s self-care behaviour in response to the intervention strategies.

Table 16: Comparison 1 – Significant Results and Measure of Knowledge Use

<table>
<thead>
<tr>
<th>Review Results</th>
<th>Total Number of Results</th>
<th>Conceptual Knowledge Use (%)</th>
<th>Instrumental Knowledge Use (%)</th>
<th>Enablers Of Knowledge Use (%)</th>
<th>Patient/Individual Impact (%)</th>
<th>System/Org Impact (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reviews with proportion of significant results over 50% (n=8)</td>
<td>52</td>
<td>3 (6)</td>
<td>2 (4)</td>
<td>1 (2)</td>
<td>38 (73)</td>
<td>8 (15)</td>
</tr>
<tr>
<td>Reviews with proportion of significant results 50% or less (n=13)</td>
<td>107</td>
<td>2 (2)</td>
<td>16 (15)</td>
<td>4 (4)</td>
<td>69 (64)</td>
<td>16 (15)</td>
</tr>
<tr>
<td>Reviews with no significant results (n=9)</td>
<td>34</td>
<td>1 (3)</td>
<td>11 (32)</td>
<td>2 (6)</td>
<td>13 (38)</td>
<td>7 (21)</td>
</tr>
</tbody>
</table>
Comparison 2 – Significant results by review group

Three review groups had more than one review included in this study: the Airways Group, the Consumers and Communication Group and the Metabolic and Endocrine Disorders Group (Table 17). All three review groups reported significant results, but most of these significant results accounted for a proportion of 50% or less of their total results measured. (i.e., only two reviews of the 12 from the Airways Group reported a proportion of significant results that were over 50% of their total result load).

Table 17: Comparison 2 - Significant Results by Review Group

<table>
<thead>
<tr>
<th>Review Group</th>
<th>Number of Reviews</th>
<th>Proportion of Significant Results over 50% (%)</th>
<th>Proportion of Significant Results 50% or less (%)</th>
<th>No Significant Results (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Airways Group</td>
<td>12</td>
<td>2 (17)</td>
<td>7 (58)</td>
<td>3 (25)</td>
</tr>
<tr>
<td>Consumers and Communication Group</td>
<td>4</td>
<td>1 (25)</td>
<td>2 (50)</td>
<td>1 (25)</td>
</tr>
<tr>
<td>Metabolic and Endocrine Disorders Group</td>
<td>4</td>
<td>1 (25)</td>
<td>2 (50)</td>
<td>1 (25)</td>
</tr>
</tbody>
</table>

Comparison 3 – Significant results by developmental grouping

Adults were the most frequently studied population group (Table 18). Those reviews studying adults only and adults & elders did report significant results. However, for the majority of these reviews, the proportion of significant results was 50% or less of their total results measured. For reviews studying only children, one review reported a proportion of significant results that was over 50% of their result load, and the other
review reported a proportion of significant results that was 50% or less of their result load.

**Table 18: Comparison 3 - Significant Results by Developmental Grouping**

<table>
<thead>
<tr>
<th>Developmental Grouping</th>
<th>Number of Reviews</th>
<th>Proportion of Significant Results over 50% (%)</th>
<th>Proportion of Significant Results 50% or less (%)</th>
<th>No Significant Results (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adults</td>
<td>15</td>
<td>4 (27)</td>
<td>6 (40)</td>
<td>5 (33)</td>
</tr>
<tr>
<td>Adults + Elders</td>
<td>7</td>
<td>1 (14)</td>
<td>4 (57)</td>
<td>2 (29)</td>
</tr>
<tr>
<td>Adults + Children</td>
<td>5</td>
<td>2 (40)</td>
<td>1 (20)</td>
<td>2 (40)</td>
</tr>
<tr>
<td>Children</td>
<td>2</td>
<td>1 (50)</td>
<td>1 (50)</td>
<td></td>
</tr>
<tr>
<td>Children + Adolescents</td>
<td>1</td>
<td></td>
<td>1(100)</td>
<td></td>
</tr>
</tbody>
</table>

**Methodology - the assessment of risk of bias**

The method used for the assessment of risk of bias was not consistent amongst the reviews (Table 19). Just under half of the reviews (11) reported using ‘the Cochrane method of assessment as per the Cochrane handbook’ and six reviews used review group specific assessment criteria. Four reviews did not state their method (Bailey 2009;25 Riemsma 2003;43 Schroeder 2004;36 Smith 200939), and one review (Renz 2007)40 reported their method as “using a component approach,” which was explained as: “This approach was adopted due to the higher use of this method in previous Cochrane reviews (Shea 2001), and its appropriateness to sensitivity analysis. The quality of each individual study was assessed against a number of components important to the review.”40,p.6 One review team used the Physiotherapy Evidence Database (PEDro) scale for the following reason:
The PEDro scale recognizes that while blinding is important, it is not always feasible. Accordingly, the PEDro scale assesses blinding at three different levels and other important criteria such as concealed allocation, intention to treat analysis and adequacy of follow up. Therefore, studies that are unable to be double blinded due to the study question, but that otherwise demonstrate high internal validity, are not unjustly penalized. (Bhogal 2006).  

Another approach was the use of two items from the 6 item Cochrane assessment scale – the randomization and concealment of allocation assessments - as these were considered the most important aspects to assess (Tapp 2007). Not all reviews assessed the quality of their trials in order to exclude the weak studies. Rueda (2009) clearly stated that they did not assess quality to exclude trials but to enable them to discuss quality of the methodological rigor of their included studies.

Table 19: Methods of Measurement for Risk of Bias (n=30)

<table>
<thead>
<tr>
<th>Method of Measurement</th>
<th>Number of Reviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cochrane system as per handbook</td>
<td>11</td>
</tr>
<tr>
<td>Review group based criteria</td>
<td>6</td>
</tr>
<tr>
<td>Not stated</td>
<td>4</td>
</tr>
<tr>
<td>Amsterdam/Maastricht consensus list (van Tulder 1997, 2003)</td>
<td>2</td>
</tr>
<tr>
<td>Cochrane system as per handbook plus Schultz (1995) and Jadad (1996) scales</td>
<td>1</td>
</tr>
<tr>
<td>Cochrane system as per handbook plus Jadad (1996) scale</td>
<td>1</td>
</tr>
<tr>
<td>Schultz (1995) and Jadad (1996) scales</td>
<td>1</td>
</tr>
<tr>
<td>Jadad (1996) scale</td>
<td>1</td>
</tr>
<tr>
<td>Sackett (1979) and the CONSORT Statement (Moher 2001, Altman 2001)</td>
<td>1</td>
</tr>
<tr>
<td>Physiotherapy Evidence Database (PEDro) scale</td>
<td>1</td>
</tr>
<tr>
<td>Component approach</td>
<td>1</td>
</tr>
</tbody>
</table>
Allocation of concealment was the most frequently measured risk with 29 reviews providing data on this assessment. However, only 27% of all the included trials (n=466) satisfied this criterion (Table 20). Follow-up was measured by 26 reviews with 46% of trials meeting this criterion adequately (i.e., follow-up >80%). Review authors reported that blinding was the most difficult risk to assess. The blinding assessment reported here refers to the most commonly assessed – the blinding of the outcome assessor and only 22% of the trials were able to meet this criterion.

Table 20: Totals for Risk of Bias Assessments for Included Trials (n=466)

<table>
<thead>
<tr>
<th>(missing data - number of reviews)</th>
<th>Yes (%)</th>
<th>Unclear (%)</th>
<th>No (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allocation concealment (n=29) (1 review)</td>
<td>124 (27)</td>
<td>177 (38)</td>
<td>38 (8)</td>
</tr>
<tr>
<td>Method of randomization (n=25) (5 reviews)</td>
<td>119 (26)</td>
<td>128 (27)</td>
<td>20 (4)</td>
</tr>
<tr>
<td>Blinding (n=24) (6 reviews)</td>
<td>103 (22)</td>
<td>109 (23)</td>
<td>49 (11)</td>
</tr>
<tr>
<td>Follow-up (n=26) (4 reviews)</td>
<td>213 (46)</td>
<td>60 (13)</td>
<td>46 (10)</td>
</tr>
</tbody>
</table>

Challenges in synthesizing the data

All reviews reported difficulty in the process of synthesis due to the heterogeneity of the data. The variety in the type of outcomes measured as well as the method of measurement made comparison of results challenging at best and at worst, totally impossible. Even for the same outcome such as knowledge, the range of instruments measuring changes prohibited the useful comparison of results. Furthermore, outcomes were not given the same priority in each study. Some reviews calculated the level of heterogeneity and issued caution with results when this level was
too high. Other reviews were reduced to providing results on a trial by trial basis, somewhat defeating the intention of synthesis.

The weakness of the methodological rigor of the included trials was also a problem for many reviews. This included elements such as the failure to address some of the risk of bias issues as well as the poor reporting of methodology and results. Although many review authors contacted the original trial authors for clarification (some were successful but others were not), the general weakness of methodological rigor remained a notable issue.

**Discussion**

This integrative study was guided by the following specific questions:

1. What intervention strategies to initiate or enhance self-care activities have been described?

Thirty reviews reported on three specific types of interventions: 1) to provide education and information; 2) to increase adherence to an existing regime; and 3) to assist and guide self-management. The majority of reviews (27) reported the use of multiple intervention strategies and the most common strategies were educational sessions (26 reviews) and self-care management plans (11 reviews). Educational sessions and self-care management plans were also the most effective implementation strategies. Other strategies included counselling sessions; sessions focused on cognitive
or behavioural aspects; telephone hotlines; follow-up visits by nurses; regular medical reviews with general practitioners; the distribution of educational material or use of videos; exercise and computer programs.

Intervention strategies varied considerably with respect to complexity, intensity, duration, frequency, setting, delivery and follow-up, and this made comparison across strategies difficult.

2. How have the outcomes of interventions to initiate or enhance individuals’ self-care activities been measured?

The outcomes were classified using the Measures of Knowledge Use and Impact framework, which indicated that the most frequently measured outcome was patient/individual impact, representing changes in health status. Following this, system or organizational impact was the most common measurement, as assessed by visits to the emergency department, readmissions, and hospitalizations.

Comparison 1 examined the measure of knowledge use assessed by reviews reporting a proportion of significant results over 50% of their result load; reviews reporting a proportion of significant results of 50% or less of their result load; and reviews that did not report significant results. This comparison indicated that reviews reporting no significant results were measuring instrumental use of knowledge much more frequently than reviews that did report significant results. This result is noteworthy because the measure of instrumental use of knowledge represents changes
in the individual’s self-care behaviour in response to the intervention strategies. The difficulty in measuring changes in behaviour is eclipsed by the challenges of instigating changes in human behaviour itself. Nevertheless, these changes are important indicators of the success of the intervention strategy as they provide concrete evidence of the individual’s engagement in self-care activities. The results of comparison 1 indicate that the trials reported on by those nine reviews attempted to provide this essential measure of change. What remains uncertain is, did the behavioural changes actually occur or was the instrument used to assess self-care behaviours not sensitive enough to identify these changes?

Information concerning the actual instruments used to measure the outcomes was provided inconsistently and therefore the data were not available for comment or comparison. All reviews did report difficulty in the synthesis of their data due to the variety in the type of outcome measured as well as the method of measurement.

3. What evidence has been provided by this cross-cutting investigation that is of value to rehabilitation practice?

The objective of this cross-cutting integrative study was to identify strategies to support self-care that would inform practice. Three issues were raised: a) the lack of available evidence for health care professionals in this area; b) the problem of multi-morbidity and the challenge of performing self-care with conflicting regimes; and c) the benefit of integrating evidence from multiple reviews to overcome inconclusive results.
a) With respect to providing current evidence for health care professionals, this integrative study has synthesized the highest level of evidence (systematic reviews) and provided a view across disease and impairment populations that is both unique and informative. Despite the variety of conditions a commonality was evident in the response to the range of intervention strategies. For example, the most frequently used and most effective strategy (determined by number of significant results) - educational sessions - were shown to be effective for asthma, general chronic conditions, COPD, Diabetes Mellitus, ocular hypertension, high cholesterol, lower back pain, malaria, sleep apnea, and Rheumatoid Arthritis. This endorses a move away from the focus on disease/impairment specific strategies to a ‘generic nature’ of self-care support. Notably, the tailoring of the educational strategies to the specific target audience will enhance the transfer of knowledge to this audience.

b) It was hoped that this integrative study across disease/impairment groupings would shed light on supportive care for individuals with multi-morbidities who engage in self-care. However, there was insufficient evidence and it was not possible to conduct a sub-analysis by co-morbidity. It is possible that generic strategies shown to be effective for a range of different diseases/impairments may be effective supportive strategies for individuals who have several of these conditions concurrently. However, further research in this area is necessary to provide conclusive evidence of effectiveness in these situations.
c) Summarizing the evidence across review groups has overcome some (but not all) of the inconclusive results found at the individual review level. The heterogeneity of the data at the intervention strategy level prevented comparison and conclusion, so desired by professionals, as to which strategy was the most effective in instigating change. The strategies that were highlighted as being the most successful were educational sessions and self-care management plans. Comparison 2 examined significant results by review group but did not offer useful information at this level. The integrative study has introduced the context of knowledge translation with which to view the process of implementing these strategies and this focus may be valuable for future research and the integration of evidence across population groups.

4. Is there a conceptual map or framework to facilitate the comprehension of this evidence?

The conceptual focus of this integrative study is the process of knowledge translation and the Knowledge-to-Action framework\textsuperscript{22} was used to aid the comprehension of this evidence. This framework separates the generation of knowledge and the action required to transfer that knowledge into practice. In this integrative study, the knowledge was transferred from health care professionals to individuals and families to support, assist and guide them in their engagement of self-care activities. The framework facilitated the identification of two main areas addressed by the
interventions to transfer this knowledge: adaptation to the local or specific population setting; and sustainment of knowledge use.

Using the interventions that addressed asthma as an example, the conceptual constructs of the framework helped to establish that, rather than a random variety of interventions, these interventions could be seen as having a common purpose, which was to adapt to the specific needs of this population. Hence they each approached the transfer of knowledge from a different perspective and we saw interventions that tried computers, education, limited education, individualized education, written self-care management plans, self-care management plans adapted for children, education adapted to deliver information immediately after exacerbations and even culturally appropriate delivery methods. Using the framework therefore facilitated understanding the range of interventions as being part of a process – that of adapting both the knowledge and method of transfer to the specific population.

Likewise, the range of interventions that addressed adherence, were assisting individuals who already had some degree of knowledge or engaged in self-care activities. These interventions sought to find ways to encourage these individuals to continue performing their self-care activities by adhering to specific regimes. At a conceptual level then, according to the framework, these interventions could be seen as striving to sustain both knowledge and behaviour.

The Knowledge-to-Action framework contextualized the purpose of the interventions aggregated across the 30 reviews. Firstly, the interventions were seen as
part of the process of knowledge translation and the transfer of knowledge from health care professionals to individuals and families. Second, the interventions included a process of adaptation whereby the implementing strategies were tailored to specific populations, or modified to assist individuals with sustaining both knowledge and behaviour.

5. What gaps in this area of research were revealed?

This integrative study reflects two levels of evidence: a) the systematic reviews which were the data for the study; and b) the primary studies which were the data for the systematic reviews. At the level of systematic reviews, not all reviews exhibited the same amount of methodological rigor despite Cochrane guidelines. For example, the explicit reporting of critical appraisal and data extraction procedures were lacking in some reviews. The reporting standard also varied amongst the reviews.

Likewise, at the primary study level, most review authors noted weaknesses in the methodological rigor and cautioned the use of the results from their syntheses. Both methodology and reporting were seen as being below standard for many trials.

Twelve reviews (40%) included fewer than ten trials, indicating that the gap in the research is one of both quantity as well as quality. There is certainly a need for more rigorous randomized controlled trials to assess the effectiveness of different intervention strategies both within disease or impairment groupings and as well as
across these groupings. Further research with a specific knowledge translation focus would also be most valuable.

Comparison 3 examined significant results by developmental grouping. Reviews studying children (2), and children & adolescents (1) reported only significant results. However, there were only a few reviews studying these populations, an indication that these populations (both children and adolescents) would benefit from further research.

As noted by analysis of the measurement of knowledge use and impact of the use of that knowledge, an area for further research is the measurement of the instrumental use of knowledge – in this context, the individual’s adoption or sustainment of self-care activities.

Further research on the effectiveness of implementation strategies in populations with multi-morbidities is timely and would be most valuable given the increase of individuals with these conditions.

**Cochrane systematic reviews – thoughts and recommendations**

Performing an “overview of reviews” provides a vantage point and ability to examine a constellation of systematic reviews in a manner that is not frequently done. The synthesis from this perspective highlights several problem areas that need to be addressed in order to maintain the standard of systematic reviews as the highest level of evidence available.
1. Assessment of bias: There was inconsistency in the method used to assess the risk of bias for included studies. Many reviews did not explain the method that was used and their rationale if deviating from the standard assessment scales.

2. Despite all Cochrane systematic reviews undergoing peer review, the reporting of the review process and findings was variable and in some cases lacked clarity and transparency.

3. Many reviews did not clearly describe the method of outcome measurement or did not provide adequate details of the instruments used for this assessment.

4. The reporting of results on a trial by trial basis makes a mockery of the systematic review process. Although review authors cannot be responsible for the heterogeneity of the data and inability to synthesize the results, including these results in a synthesis is misleading to the reader. If the results are disparate enough to require reporting singly, perhaps we need to find another term for the final product that indicates the systematic method of research but does not imply a synthesis of the results.

5. Although several review authors commented on the importance of clinically significant findings, only a couple (e.g., Duke 2006 and Gibson 2002) offer concrete evidence of obtaining these results. More frequently however, review authors reported that sample sizes in the included trials were too small to detect the minimal clinically significant differences, the length of follow-up was
inadequate or the heterogeneity of outcome measurements precluded obtaining this level of evidence.

**Recommendations:**

1. Review coordinators of different Cochrane Review Groups may find it useful to conduct an ‘overview of reviews’ both within their group and between groups to benefit from the insights gained from this vantage point.

2. Stronger emphasis on clarity and transparency of both methodology and reporting is necessary, with particular emphasis on assessment of risk of bias and reporting of outcome measurement.

3. The issue of heterogeneity and how best to synthesize these data needs to be approached with greater transparency.

4. The final product of a review that cannot avoid reporting results on a trial by trial basis (or only has one included study) could perhaps be called a ‘systematic summary’ – thereby setting it apart from the systematic review and the implication of synthesis.

5. The value of aligning statistically significant findings with minimal clinically important differences (MCID) will improve the overall contribution of this evidence to practice.
Conclusion

The focus of this integrative study can be perceived within the context of knowledge translation, where the purpose of the interventions was knowledge adaptation to specific populations or the sustainment of knowledge and supporting behaviours. The use of multiple strategies, including educational sessions and self-care management plans, has been identified as a generic option that may be effective to support adoption and sustainment of self-care behaviours for individuals either recently diagnosed with, or currently living with, a disease, disability or impairment.

In conducting this integrative study a unique view of the evidence across multiple population groups at the systematic review level was created. The approach used a care concept (self-care) as a basis for searching and synthesizing evidence. The critical element was concept clarity and several phases of work were completed prior to undertaking the care concept review. This research provides a foundation for further methodological development with regard to care concepts that are relevant for generic aspects of supportive care. The methodological template developed for this enquiry of self-care interventions requires further testing on other care concepts (such as capacity, continuity of care, caring).

Implications for Practice

There is an emerging body of evidence for effective self-care and this study identified two strategies - educational sessions and self-care management plans - that
could be used generically as supportive care by professionals as they assist individuals with this process. Evidence of the success of these implementation strategies and situations in which they are effective/not effective is valuable across disease/impairment groupings and has created a rich body of knowledge pertinent across the health care field.

**Implications for Research**

This study highlighted the pervasive problem of heterogeneous data at the primary research level preventing the effective synthesis of current evidence. Further research to standardize both the type of outcome measured and the method of measurement would advance our ability to determine ‘best practices’ with self-care support. Cochrane systematic review authors reported their systematic review methodologies in varying degrees of detail. Also of note was the range of different methods to assess risk of bias.

**Acknowledgements**

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Conflicts of interest

None.
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(37) Orton LC, Barnish G. Unit-dose packaged drugs for treating malaria [Systematic Review]. Cochrane Database of Systematic Reviews 2005;1.


Chapter 8: Knowledge about Self-Care: A Multi-Phase Enquiry

A self care vision:

- Individuals and carers have self care as a real choice
- Choice includes a range of self care options – available, accessible, convenient
- The right support is provided for that choice

Department of Health, UK. 2005

The concept of self-care is a many layered one with numerous factors associated with the term and as many different avenues to investigate it. As a complex concept it encompasses both therapeutic care (medication administration; self monitoring and self treatment) and personal care (activities of daily living – dressing, bathing, eating, etc.). It is a core concept relevant to multiple health care disciplines, including nursing, rehabilitation, medicine, psychology, sociology and social work. Self-care is also a key element from both political and health care industry perspectives as health systems attempt to transfer and support aspects of care to individuals and families.

Self-care has become an important focus of health care and health care reform in Canada today. Recent and notable research supported by Health Canada culminated in a major national report, entitled Supporting Self-Care: a Shared Initiative 1999-2002. Health Canada, in collaboration with several professional organizations, highlighted the instrumental role of self-care. A crucial insight contained in the Health Canada Report was the challenge of "educating health professionals in the support of self-care and in
integrating self-care support into professional practice. Further, the National Health Service in the United Kingdom, whose vision of self-care opens this chapter, also considers self-care to be an integral part of its service. “Self care was highlighted in the NHS Plan as one of the key building blocks for a patient-centred health service.” The final statement in their vision reflects the focus of this final chapter: The right support is provided for that choice.

To provide that ‘right support’, however, health care professionals need the right knowledge. In their 2005 report on Preventing Chronic Disease, the World Health Organization declared: “As a first step, it is essential to communicate the latest and most accurate knowledge and information to front-line health professionals and the public at large.”

My aim with this thesis was to seek out the best available evidence to provide best available evidence to inform ‘right support’. Evidence is the foundation of knowledge for health care professionals to use and rely on when supporting, guiding and assisting individuals who initiate or engage in self-care activities. To achieve this, my exploration of self-care was guided by the following objectives:

1. Explore and describe the construct of self-care as understood by individuals/families, health care professionals, researchers, policy-makers and industry.
2. Produce new knowledge for health care professionals about interventions for self-care across a range of population groups.

3. Develop a provisional framework to inform practice and research.

Four different methodologies provided the data for this exploration: a) systematic review of qualitative evidence – the individual’s experience of self-care (chapter 2); b) content analysis – the meaning of self-care revealed from self-care definitions (chapter 3); c) formal concept analysis - the delineation of the concept of self-care (chapter 4); and d) an overview of reviews (or “umbrella review”) – of the effectiveness of interventions to support self-care across multiple disease/impairment groupings (chapter 7). A brief tabular summary of the contribution of each of these studies to the enquiry and the emerging knowledge about self-care, as well as the overall contribution of this knowledge to practice is summarized in Table 21. In this chapter I will also address the last objective and propose a provisional framework to inform research and practice regarding self-care drawn from the culmination of this research.
## Table 21: Contribution to Knowledge About Self-Care: the Multi-Phase Enquiry

<table>
<thead>
<tr>
<th>Key elements</th>
<th>Evidence base</th>
<th>Methodology</th>
<th>Objective</th>
<th>Frameworks used</th>
<th>Contribution to knowledge</th>
</tr>
</thead>
</table>
| Experience of self-care: a systematic review (chapter 2)<sup>4</sup> | Qualitative studies (50 studies) | Systematic review | Explore and describe individual experiences of self-care | Orem’s theory of self-care<sup>7</sup> Data were categorized into one of three self-care requisites: universal; developmental or health deviation | 4 overarching themes  
• Care for self  
• Mastery and balance |
| Care of self – care by other – care of other: the meaning of self-care from research, practice, policy and industry perspectives (chapter 3)<sup>5</sup> | Theory, scholarship, discussion and reviews (75 papers) | Content analysis | Examine the diversity of definitions of self-care from different perspectives | Methodology proposed by Walker and Avant<sup>8</sup> that guides the process of concept analysis though 8 steps | 7 components of self-care definition  
• Expansion of the definition |
| Self-care: a concept analysis (chapter 4) | Qualitative studies; quantitative studies; theory, scholarship, discussion and reviews (141 papers) | Concept analysis | Delineate the attributes, structure and function of the concept of self-care | | 9 attributes of self-care  
• Individual’s |
<p>| Intervention strategies that support self-care activities: an integrative study across disease/ impairment groupings (chapter 7)&lt;sup&gt;6&lt;/sup&gt; | Cochrane systematic reviews (30 reviews) | Overview of reviews (modified to include a range of conditions) | Explore and evaluate the evidence on self-care interventions through a cross-cutting, integrative study | | Most effective and most frequently used implementation strategies are educational sessions and self-care |</p>
<table>
<thead>
<tr>
<th>Key elements</th>
<th>Experience of self-care: a systematic review (chapter 2)&lt;sup&gt;4&lt;/sup&gt;</th>
<th>Care of self – care by other – care of other: the meaning of self-care from research, practice, policy and industry perspectives (chapter 3)&lt;sup&gt;5&lt;/sup&gt;</th>
<th>Self-care: a concept analysis (chapter 4)</th>
<th>Intervention strategies that support self-care activities: an integrative study across disease/impairment groupings (chapter 7)&lt;sup&gt;6&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>●Sustaining self-care</td>
<td>including care of others; care by others; influence of environmental and socio-cultural contexts; meeting emotional needs and the different role of the health care professional</td>
<td>perspective is an important antecedent to the performance of self-care</td>
<td>management plans</td>
</tr>
<tr>
<td></td>
<td>●Disengagement from self-care</td>
<td>●Importance of self-care as continuity of care</td>
<td>●Positive outcomes such as independence and autonomy reinforce sustainment of self-care activities</td>
<td>●Specific interventions adapted to the audience are most successful</td>
</tr>
<tr>
<td></td>
<td></td>
<td>●Continuum of self-care</td>
<td></td>
<td>●The majority of the reviews (21/30) reported significant results</td>
</tr>
<tr>
<td>Limitations</td>
<td>●Aggregation of overall findings not generalizable to other care concepts</td>
<td>●Search strategy was limited to English</td>
<td>●Evidence base for analysis was limited to English studies</td>
<td>●8 reviews reported a high proportion of significant results (over 50% of their total result load)</td>
</tr>
<tr>
<td></td>
<td>●Aggregation of findings across developmental groupings for diabetes mellitus not generalizable to other conditions</td>
<td>●Despite comprehensive electronic and hand search strategy it is possible that some relevant articles were not located</td>
<td>●Concept analysis was conducted by one researcher, limiting the interpretation of the analysis</td>
<td>●Behavioural outcomes are important but remain difficult to assess or interpret</td>
</tr>
<tr>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

Footnotes:

6. Intervention strategies that support self-care activities: an integrative study across disease/impairment groupings (chapter 7).
Implications for Practice

The most notable and useful contribution to practice was the clarification of and distinction between: care of self, care by other and care of other. ‘Care of self’ was described by Levin in an early definition of self-care as “[a] process whereby a layperson functions on his/her own behalf in health promotion and prevention and in disease detection and treatment.”\textsuperscript{11,p.11} The concept of ‘care by other’ was referred to by Willamson\textsuperscript{12} who described self-care as being performed either by the person themselves, or by someone else. The inclusion of the concept of care by other acknowledges those individuals with disabilities or impairments who perform self-care with the assistance of others, but retain the ability to direct the care process.

The concept of ‘care of other’ emerged in the 1970s with the definition of self-care being a “care process whereby lay persons can actively function for themselves and/or others to 1) prevent, detect, or treat disease, and 2) promote health so as to supplement or substitute for other resources.”\textsuperscript{13,p.8} This feature accounted for the care of family members, friends, neighbours and community and many subsequent definitions specifically mentioned social support and the care of others. The World Health Organization further clarified this concept of self-care at the community level, which it described as: “Self help groups support self-care at the community level by creating an enabling environment. Experience sharing in self-care and care for
vulnerable family members, as well as improving required skills to support self-care are important examples.” 14, p.31

For some health care professionals, these distinctions and the inclusion of care by other and care for other into the concept of self-care may be new knowledge. The distinction of self-care as ‘care of other’ is not conceptually or practically helpful to health care professionals as they support, guide and assist individuals to engage in self-care behaviours because it refers to a larger social support system. Notably, Orem’s 7 theory of self-care, for example, which is one of the foundational theories in nursing, places the concept of care for others outside the realm of self-care, classifying it as dependent care. 15 Therefore within the context of interactions with health care professionals, the results from this enquiry would suggest the scope of self-care to encompass only care of self and care by other and not to include care of other.

To facilitate the move toward interprofessional care and, more appropriately, to maintain the focus on individual-centered care, it behoves health care professions to adopt the same definition of self-care, or at the very least, to be cognizant of the spectrum covered by other disciplines’ definitions. The expansion of the definition of self-care to include many other aspects such as maintaining good physical and mental health and meeting social and psychological needs 16 facilitates this integration across the health care team.
Another finding from the enquiry particularly relevant across the sectors of health care, was the view that self-care provided the continuity of care between interactions with the health care system, enabling individuals to manage their disease or disability and maintain well-being. The definition of self-care from the United Kingdom’s Department of Health explicitly makes this link, stating self-care includes maintaining “health and wellbeing after an acute illness or discharge from hospital."\textsuperscript{16,p.5} Individuals are transferred from acute to community care much earlier than in the past while still requiring a high level of care. The capacity of the individual to engage in self-care behaviours at this time is valuable not only for their ongoing care but also may decrease the demand on the health care system. The World Health Organization concludes: “Self-care will ease the burden of the overstretched health systems, reduce cost and increase its effectiveness...”\textsuperscript{14,p.5}

Probably the most central contribution to practice from the concept analysis was the window into the individual’s perception and how it serves as an antecedent of self-care behaviours. The individual’s perception of the efficacy of the self-care behaviour, seriousness of symptoms, their own health status, the importance of health to them and also their definition of health, were considered important factors that influenced the performance of self-care activities.\textsuperscript{17,18} Clearly this reinforces the philosophy of the individual being the centre of care, and directing what self-care behaviours they are able or willing to engage in. Practically speaking, the recognition of this contribution
highlights the need for improved assessment of self-care need(s), level of self-efficacy and self-care abilities in order to tailor care.

In considering what health care professionals can do to support self-care, there is emerging evidence that supports two strategies to support and guide self-care: educational sessions and self-care management plans. It is noteworthy that these strategies were identified and tested from multiple conditions and would therefore be good options for health care professionals to adopt. Furthermore, interventions that were adapted to specifically address their target audience, whether it was to create culturally appropriate education, or age appropriate self-care management plans, were much more successful than interventions that did not attend to this tailoring. This is a vital element to enhance supportive care with self-care. It validates the need to know the target audience and once again, reinforces the need for individual-centered care.

Education, which is an integral part of knowledge translation, needs to be part of a wider focus when supporting individuals and their engagement in self-care. Recognizing there was a need for individuals to participate more fully in decisions concerning their treatment and progress of chronic illnesses, the United Kingdom Department of Health launched an Expert Patient Program (EPP) in 2001. This innovative six-week course was based on the Chronic Disease Self-Management Program (CDSMP) developed by Kate Lorig at Stanford University. The aim of the program was “to deliver self-management support and improve the quality of life of
people with long-term conditions by developing generic self management skills and improving people’s confidence and motivation to take more effective control over their lives and illnesses.” Addressing the role of education within this approach, the Department of Health stated:

Patient self-management programmes, or Expert Patients Programmes, are not simply about educating or instructing patients about their condition and then measuring success on the basis of patient compliance. They are based on developing the confidence and motivation of patients to use their own skills and knowledge to take effective control over life with a chronic illness. Thus the educator has to look beyond the simple transfer of knowledge to inspire the individual’s confidence and willingness to engage in self-care behaviours.

A Commonality of Experience

Both integrative studies – the synthesis of qualitative evidence and the aggregation of systematic reviews - cut across disease/impairment groupings. Notably, there was a commonality when individuals related their experiences of self-care. While the details between gaining mastery of self-care behaviours for asthma were different from those for diabetes mellitus, for example, the process of engaging in self-care remained the same. The overarching meta-synthesis findings (care for self; mastery and balance; sustaining self-care; and disengagement from self-care) reflect the commonality of all experiences regardless of condition. Further, educational sessions were found to be an effective intervention strategy to increase or initiate self-care
behaviours for a range of conditions, including asthma; diabetes mellitus; lower back pain; COPD; high cholesterol; rheumatoid arthritis; sleep apnea; and ocular hypertension.

This finding has profound implications for practice. Despite the variety of physical, psychological, social and environmental factors that shape diseases or impairments, it appears that the core individual experience is similar when engaging in self-care, and also when responding to strategies that support self-care. This has implications for particularly challenging populations, i.e., individuals who have multiple-morbidities. Although their challenges may be compounded, there are commonalities in the process of engaging in self-care. Health care professionals are encouraged to know about the process of engaging in self-care, to recognize both the similarities between individuals as well as the uniqueness of individual experience when engaging in these behaviours.

Training health workers for self-care is not just about their gaining new knowledge and skills but changing the health worker’s attitude in empowering individuals, families and increasing their confidence in self-care. \cite{14,p.44}

**Implications for Research**

The results from the concept clarification highlighted areas for further investigation. For example, factors that are both pre-requisites for engaging in self-care, as well as consequences of the behaviour, are potential avenues for additional study. In
particular clarification is needed on how these factors influence the engagement of self-care. This understanding will assist health care professionals to be more effective when providing support to individuals as they engage in self-care behaviours.

As the definition of self-care is expanding and becoming less discipline specific, research into interprofessional care and team members’ roles in assessing and supporting self-care is also needed.

The experience of self-care reported by individuals provided insight into the challenges they face as they engage in these behaviours. These challenges suggest where further research is needed. For example, for conditions such as diabetes mellitus or asthma that may require ongoing self-care behaviours during the day, both adults and teenagers spoke about the stigma of having to engage in self-care behaviours in public. For adults, the added worry of discrimination in the workplace also hindered the performance of these behaviours. Research into how to break down social stigma with therapeutic self-care is essential and pertinent.

Quality clinical tool(s) are required in order to assess self-care need(s) and self-care abilities in a reliable and valid fashion. Only when this is possible will health care professionals be able to tailor interventions with greater accuracy and provide ‘person centered care’. From a knowledge translation perspective, this is an important aspect that has not as yet, been adequately researched and developed.
Outcome assessment is improving but requires more sophistication. One outcome in particular that warrants further research is the assessment of an individual’s behaviour in response to the supportive strategy. This was categorized by the Graham et al., Knowledge Use and Impact framework as the ‘instrumental use of knowledge.’ Systematic reviews that measured instrumental use of knowledge more frequently than others also obtained less significant results. It is not clear whether the behaviours did not change favourably or if the measurement of these behaviours was not sensitive enough to identify change. The positive consequence of engaging in self-care activities may serve to reinforce the sustainment of these activities, and further research into this area has been mentioned above. I would like to suggest that other social outcomes such as increased confidence to participate in society, or a sense of belonging within the community, may contribute to, or influence the individual’s engagement in self-care activities. These outcomes may be a valuable reservoir for health care professionals to access when encouraging individuals to engage in self-care.

Two implementation strategies (educational sessions and self-care management plans) emerged from the integrative study as effective and potential strategies when supporting individuals who engage in self-care activities. These strategies, although promising, require further investigation.

Having been through hundreds of studies related to self-care I reiterate the call made by other systematic review authors for more rigorous studies, complete with
accurate reporting that would provide the level of evidence worthy of translation into practice. With regard to self-care there is a pressing need for research on reliable and valid outcome measurement, including what is the most appropriate construct to be measured as well as the most effective method of measurement. All review authors struggled with heterogeneous data. Even when the construct was the same, such as knowledge, the range and quality of methods used to measure this outcome precluded the ability to synthesize the results. Researchers frequently either adapt instruments or invent their own for each trial. This compounds the problem at the synthesis level. What would be beneficial is a community of practice comprised of the researchers who focus on a particular area, (i.e., a care concept). Review groups are typically organized by medical focus (e.g., Infectious Diseases Group, HIV/AIDS Group) or body system (e.g., Airways group, Eyes and Vision Group, Back Group) thus evidence related to generic care concepts are challenging to find and synthesize. There would be enormous benefit to cooperatively establishing some standard taxonomy in determining outcomes and method of measurement within existing methodological collaborations such as Cochrane. Even if standardization simply confined the recommended instruments to a range of several options, that would make a difference at the synthesis level. It may also raise the rigor of the research by standardizing the outcomes to be measured and thereby encouraging researchers to use comparable and validated measures for outcome assessments.
Provisional Framework: The Moment of Transfer

Health care professionals support, guide and assist individuals to engage in self-care activities. They provide the necessary knowledge and skills through education and training programs. This process is, in essence, a process of knowledge translation, in which the knowledge is being transferred from health care professional to the individual or family. The Knowledge to Action framework by Graham and colleagues\textsuperscript{9} describes the process of knowledge generation and knowledge adoption. Several steps are described in the action circle of this framework. The provisional framework I am proposing takes the step titled ‘select, tailor, implement interventions’ to a pragmatic level. It is at this point that the knowledge transfer actually takes place. Using the more comprehensive understanding of self-care and the types and efficacy of supportive care, my proposed framework conceptually and from an evidence point of view, ‘unpacks’ and makes explicit this process of transfer.

There are several key factors for the health care professional to be aware of when interacting with individuals and assisting them to engage in self-care. First, it was suggested that the role of the health care professional be reframed to support and guide decision making, allowing the individual or family to take the lead. Second, the most effective and frequently used intervention strategies were educational sessions and self-care management plans, and therefore these become logical first options when beginning the process of knowledge transfer. Third, the integrative study indicated that
interventions that adapted their focus to their target audience were more successful that those that did not. Consequently, it is vital that health care professionals have as much knowledge about their target audience as possible. Finally, when measuring outcomes, it was suggested that both health and sociological outcomes be assessed, as this could provide rewards that might encourage the individual to engage in or sustain self-care.

The proposed provisional framework entitled ‘The Moment of Transfer’ depicts these elements (Figure 15). In the centre is the individual depicted within his or her socio-cultural context of family, community and culture. Below the individual is a circle containing the two elements of care that may be engaged in: care of self or care by other. On the far left we have the health care professional displayed and indicating three main elements of their role: to guide, assist and support. The mechanisms of transfer, in this instance, are the two options, educational sessions and self-care management plans. Knowledge is transferred through these mechanisms but it is not just one direction from the health care professional to the individual. The individual’s existing knowledge base, understanding and focus on what they need to know contribute to the flow of information, making this transfer a strong interchange. On the far right is the Self-Care Concept Schema depicting the triangle with the nine attributes of self-care, the circle representing the seven components of the self-care definition and the radial figure which represents the essence of the experience of self-care garnered
from the synthesis of qualitative evidence. This schema plus the socio-cultural aspects within which the individual is situated, represent a range of factors that health care professionals need to be apprised of, in order to effectively support, guide and assist individuals as they engage in self-care.

This proposed framework is an attempt to crystallize the moment of the transfer of knowledge and highlight aspects for health care professionals to be aware of to maximize this moment. The framework also provides indications for research – the potential for other transfer mechanisms beyond educational sessions and self-care management plans; plus other factors associated with both the health care professional and the individual that could influence the process of engaging in self-care.
Figure 15: Provisional Framework - The Moment of Transfer

- Self-care concept schema
- Health
- Illness/Disability
- Health care system
- Elements of care
- Performance
- Context
- Timeline
- Action
- Outcomes
- Performer
- Requirements
- Behaviour range
- Initiation
- Self-care and illness/disability
- Motivation

Attributes of self-care [9]
Aspects of self-care definition [7]
Individual experiences of self-care

Mechanism of knowledge transfer
Self-care management plans
Health care professional roles

Care of self
Care by Other
Educational sessions

Figure 15: Provisional Framework - The Moment of Transfer
Limitations of the thesis research

The multi-phase, mixed method, enquiry was undertaken to explore self-care from what is known and documented in research to date. Thus the various phases of enquiry used secondary data sources (documented primary studies and reviews) and involved no primary data collection. Whilst this may be considered a limitation, my preliminary work indicated the substantive need to bring together, in a rigorous manner, the research already in place that had not been fully used to explore and describe this commonly used yet poorly understood, complex care concept. In conducting this research and striving for rigorous ‘knowledge translation’, established methodologies for concept clarification and integrative studies were employed. In the final study, the Cochrane methodology for reviews provided a foundation to conduct the “care concept” review that would cut across existing reviews with different patient populations. However, additional modifications including concept clarification, which entailed a detailed exploration and delineation of the concept were added, and this modified approach is the first of its kind and will require further testing by others undertaking “care concept reviews”. To this end I am working as a lead with a group in the Cochrane Nursing Care Field - Nursing Care Review Integration Node (http://cncf.cochrane.org/nodes).
Furthermore, it was purposeful that each study phase would inform the enquiry and build towards an in-depth understanding of self-care. Ultimately this stepwise approach served to strengthen the design of the final exploratory study of interventions to support self-care.

There were two particular areas that remained beyond the scope of this thesis. a) Quantitative evidence that is not included in Cochrane reviews such as quasi-experimental studies and observational studies; and b) Health care professionals’ perspectives either on their ability to support and guide the engagement of self-care behaviours, or on the individual’s capacity and performance of self-care activities. It is recognized that this body of work would also contribute to our understanding of self-care and will be included in future work. The thesis research was focused on a particular body of evidence. Self-care is an expansive concept and at each stage, the supporting literature and capacity ‘to dig deeper’ or ‘go further’ into the concept was evident. For example, given the range of activities under the umbrella of self-care, the antecedents and consequences alone would provide enough material to be a thesis. Discerning a set of aspects to investigate from this constellation of factors has been challenging.
Conclusion

A self care vision:

- Individuals and carers have self care as a real choice
- Choice includes a range of self care options – available, accessible, convenient
- The right support is provided for that choice

Department of Health, UK. 2005

In summary, knowledge to enable health care professionals to provide ‘the right support for that choice’ can be drawn from this thesis enquiry:

- There is commonality in both the experience of engaging in self-care as well as in the response to supportive intervention strategies across different disease/impairments. The experience of self-care has a generic nature and generic interventions may also be appropriate if they are specifically tailored to the target audience.

- Viewing care concepts such as self-care as generic and gaining knowledge from how interventions are designed and delivered in many populations may be the next frontier in advancing this component of supportive care.

- Health care professionals’ awareness and inclusion of the concept of ‘care by other’ into the concept of self-care. This acknowledges the capacity of individuals with impairments to remain engaged in the self-care process, albeit with assistance from others.

- Self-care forms a significant role in the continuity of care between interactions with the health care system. Given the complexity of conditions now handled at the
community level, it is essential that individuals receive the knowledge, guidance and support they need to engage in self-care activities at these times.

- Reframing the health care professionals’ role to one of guidance and support would facilitate collaborative care and assist the individual to make their self-care decisions.

- There is emerging evidence that two intervention strategies, educational sessions and self-care management plans are valuable options when supporting individuals as they initiate or engage in self-care activities.

- Awareness of the full constellation of factors (antecedents and consequences) influencing the individual may be valuable for health care professionals as they encourage individuals to engage in self-care behaviours.

The methodology of performing an “overview of reviews” which entails an amalgamation of evidence from Cochrane systematic reviews is a relatively new concept. This thesis further tested and contributed to this evolving methodology. A novel aspect in this self-care study was tracking evidence across populations groups. The use of a cross-cutting approach to synthesize evidence from different disease/impairment groups with a generic care concept is unique strategy for the Cochrane Library. Synthesizing evidence at this level with multiple populations provided
a depth and breadth of evidence that is a new and valuable contribution both to the science of synthesis and to practice. Additionally, the systematic review of qualitative evidence across disease/impairment groupings confirmed the merit of this cross-cutting approach. The use of this method in these two studies highlighted the similarities in the experience of engaging in self-care as well as in the response to supportive interventions from health care professionals.

This new knowledge could assist health care professionals to understand the range of issues associated with self-care. Furthermore, it provides health care professionals with strategies to address and support the individual’s self-care needs and activities, thereby enabling the individual to maintain their highest level of functioning.
References


Appendix A – Search Strategy

Example of the Medline Search Strategy Aug 1 2009 used for chapters 2, 3 and 4.

Search History (134 searches)

1. exp *Disabled Persons/
2. *acute disease/ or *chronic disease/
3. *Health Care Sector/
4. exp *Health Policy/
5. or/1-4
6. exp *Self Care/
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9. self treatment.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
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13. (personal care adj3 recipient).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
14. (personal care adj3 caregiver).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
15. self management.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
16. or/6-15
17. (antecedent$ adj4 concept).ti,ab.
18. (attribute$ adj4 concept).ti,ab.
19. borderline case.ti,ab.
20. (clarif$ adj5 concept analysis).ti,ab.
21. (component adj3 concept).ti,ab.
22. (defin$ adj5 self care).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
23. composite concept.ti,ab.
24. concept analysis.ti,ab.

298
25. conceptual elements.ti,ab.
26. contrary case.ti,ab.
27. (delineat$ adj4 concept).ti,ab.
28. empirical referents.ti,ab.
29. model case.ti,ab.
30. related case.ti,ab.
31. (requisites adj3 concept).ti,ab.
32. or/17-31
33. dean k.au.
34. levin ls.au.
35. wilde mh.au.
36. sousa vd.au.
37. woods n.au.
38. or/33-37
39. 32 or 38
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subject heading word]
77. (self care adj5 believe).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
78. (self care adj5 comprehend$).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
79. (self care adj5 perception).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
80. (self care adj5 knowledge).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
81. (self care adj5 view).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
82. or/71-81
83. (self care adj5 doctor$).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
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85. (self care adj5 nurse$).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
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87. (self care adj5 practitioner$).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
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95. or/91-94
96. 70 or 82 or 90 or 95
97. (self care adj5 policy).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
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301
99. (self care adj5 organization).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
100. (self care adj5 health?care).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
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103. or/97-102
104. Randomized Controlled Trial/
105. Random Allocation/
106. Double-Blind Method/
107. Single-Blind Method/
108. Clinical Trial/
109. exp Clinical Trial/
110. Randomly allocated.mp.
111. (clinic$ adj trial$1).tw.
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113. cross sectional stud$.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
114. quantitative stud$.mp.
115. quasi experimental stud$.mp.
116. or/104-115
117. 5 or 45
118. 117 and 16
119. 60 or 96 or 103
120. 118 or 119
121. 120 not 116
122. limit 121 to English language
123. remove duplicates from 122
Appendix B – Critical Appraisal Instrument

JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research

<table>
<thead>
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<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Unclear</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is there congruity between the stated philosophical perspective and the research methodology?</td>
<td></td>
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<tr>
<td>Is there congruity between the research methodology and the research question or objectives?</td>
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<tr>
<td>Is there congruity between the research methodology and the methods used to collect data?</td>
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<tr>
<td>Is there congruity between the research methodology and the representation and analysis of data?</td>
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<tr>
<td>Is there congruity between the research methodology and the interpretation of results?</td>
<td></td>
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</tr>
<tr>
<td>Is there a statement locating the researcher culturally or theoretically?</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Is the influence of the researcher on the research, and vice-versa, addressed?</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Are participants, and their voices, adequately represented?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the research ethical according to current criteria or, for recent studies, is there evidence of ethical approval by an appropriate body?</td>
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</tr>
<tr>
<td>Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?</td>
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</table>

Overall appraisal: Include [ ] Exclude [ ] Seek further info [ ]

Comments (Including reasons for exclusion)


303
Appendix C – Data Extraction Instrument

JBI QAFI Data Extraction Form for Interpretive & Critical Research

Reviewer _____________________ Data ___________
Author _______________________ Year _________
Journal _______________________ Record Number _____

Study Description
Methodology ___________________
Method _______________________
Intervention ___________________
Setting _______________________
Geographical ___________________
Cultural ______________________
Participants ____________________
Data analysis ___________________

Authors Conclusions

Comments ______________________

<table>
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<tr>
<th>Findings</th>
<th>Illustration from Publication (page number)</th>
<th>Evidence</th>
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<td></td>
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<td>1. Unequivocal</td>
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<td></td>
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<td>2. Credible</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Unsupported</td>
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</table>

Extraction of findings complete YES ☐
Appendix D – Adapted Data Extraction Instrument
Appendix E – Search Decision Flow Diagram

Total # of citations found 9,560

# of studies meeting inclusion criteria

MEDLINE 1999
CINAHL 739
EMBASE 2354
PsyInfo 1038
AMED 630
Cochrane 14
Dissertn abstracts 419
Socialog abstracts 317
Scirus 525
Mednar 1525

169
37
19
17
13
0
2
3
0
0

Combined number of studies 273 minus 13 duplicates
Total 260 full reports retrieved

164 plus 41 from hand searching - 205

Hand searching
Disability & Society
Disability & Rehab
Rehab Nursing
Rehab Management
Care Management Journals
Int. Journal of Rehab Research
Jnl Social Work in Disability & Rehab
Reference Lists
Total 41

Studies removed:
Off topic - 96

Studies discarded:
Not meeting inclusion criteria - 151

Studies excluded: not meeting methodological criteria - 4

Final number of studies included in review
50
Appendix F – Experience of Self-Care - Included Studies


40 Plach SK, Stevens PE, Keigher S. Self-care of women growing older with HIV and/or AIDS. Western Journal of Nursing Research 2005;27(5):534-53.


Appendix G – Experience of Self-Care - Excluded Studies

   **Reason for exclusion:** Score 5/10. Congruity between philosophical perspective and methodology unclear; congruity between methodology and analysis unclear; no statement locating researcher culturally or theoretically; no statement regarding the influence of the researcher on the research or vice versa; no statement of receiving ethical approval.

   **Reason for exclusion:** Score 5/10. Congruity between philosophical perspective and methodology unclear; congruity between methodology and objectives unclear; no statement locating researcher culturally or theoretically; no statement regarding the influence of the researcher on the research or vice versa; participants’ voices not adequately represented.

   **Reason for exclusion:** Score 2/10. Congruity between philosophical perspective and methodology unclear; congruity between methodology and objectives unclear; congruity between methodology and methods unclear; congruity between methodology and analysis of data unclear; congruity between methodology and interpretation of results unclear; no statement locating researcher culturally or theoretically; no statement regarding the influence of the researcher on the research or vice versa; no statement of receiving ethical approval.

   **Reason for exclusion:** Score 4/10. Congruity between methodology and interpretation of data unclear; no statement locating researcher culturally or theoretically; no statement regarding the influence of the researcher on the research or vice versa; participants’ voices not adequately represented; no statement of receiving ethical approval; conclusion does not follow clearly from data.
### Appendix H – Experience of Self-Care - Details of Included Studies (sorted by developmental grouping)

<table>
<thead>
<tr>
<th>Dev. Grouping</th>
<th>Author Year</th>
<th>Country Culture</th>
<th>Purpose of Study</th>
<th>Sample Size</th>
<th>Participant Age Range</th>
<th>Participant Gender</th>
<th>Context/Disease/Disability</th>
<th>Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>Universal</td>
<td>Chapparo</td>
<td>Australia</td>
<td>To explore 6-year-old children’s perception of self-care in their school day</td>
<td>24</td>
<td>6-7 years</td>
<td>female, male</td>
<td>health maintenance</td>
<td>naturalistic inquiry</td>
</tr>
<tr>
<td>Child, Adult</td>
<td>Moore</td>
<td>U.S.A. American</td>
<td>To examine the self-care practices of children with cancer and the dependent care practices of their parents</td>
<td>27 (9 children; 18 parents)</td>
<td>Child 1-21 years; parent 30-50 years</td>
<td>female, male</td>
<td>cancer</td>
<td>descriptive inquiry</td>
</tr>
<tr>
<td>Adolescent</td>
<td>Rew</td>
<td>U.S.A. American</td>
<td>To explore self-care attitudes and behaviours of homeless adolescents</td>
<td>15</td>
<td>16-20 years</td>
<td>female, male, male transgender</td>
<td>homeless, health maintenance</td>
<td>grounded theory</td>
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<tr>
<td>Adult</td>
<td>Dall’Agnol</td>
<td>Brazil</td>
<td>To learn about garbage pickers concepts and self-care actions, and attitudes towards health risks</td>
<td>10</td>
<td>unspecified</td>
<td>female</td>
<td>health maintenance</td>
<td>descriptive inquiry</td>
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<tr>
<td>Adult</td>
<td>Canales</td>
<td>U.S.A. American-Indian</td>
<td>To report on health care decision making of American Indian women residing in the North eastern United States</td>
<td>20</td>
<td>39-75 years</td>
<td>female</td>
<td>health maintenance</td>
<td>grounded theory</td>
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<tr>
<td>Adult</td>
<td>Mendias</td>
<td>U.S.A. Mexican</td>
<td>To learn how to better promote self-care practices</td>
<td>11</td>
<td>25-44 years</td>
<td>female</td>
<td>health maintenance</td>
<td>naturalistic inquiry</td>
</tr>
<tr>
<td>Dev. Grouping</td>
<td>Author Year</td>
<td>Country Culture</td>
<td>Purpose of Study</td>
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<tr>
<td>Child</td>
<td>Alderson 2009</td>
<td>United Kingdom English</td>
<td>To investigate the seldom published views of children with type 1 diabetes about their condition and ways in which they share in managing their medical and health care with adults</td>
<td>24</td>
<td>3-12 years</td>
<td>female, male</td>
<td>diabetes mellitus</td>
<td>descriptive inquiry</td>
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<tr>
<td>Child</td>
<td>Chapparo 2005</td>
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<td>health maintenance</td>
<td>naturalistic inquiry</td>
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<td>Child, Adult</td>
<td>Moore 2004 U.S.A. American</td>
<td>To examine the self-care practices of children with cancer and the dependent care practices of their parents</td>
<td>27 (9 children; 18 parents)</td>
<td>Child 1-21 years; parent 30-50 years</td>
<td>female, male</td>
<td>cancer</td>
<td>descriptive inquiry</td>
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<tr>
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<td>Schmidt 2003 U.S.A. American</td>
<td>To describe mothers’ perceptions of the diabetes-related self-care abilities and practices of their school-age children with Type 1 diabetes</td>
<td>12</td>
<td>child 11-12 years; mother 31-48</td>
<td>female, male</td>
<td>diabetes mellitus</td>
<td>naturalistic inquiry</td>
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<tr>
<td>Child</td>
<td>Pradel U.S.A.</td>
<td>To explore the knowledge, 32 (19 7yrs; 13 7 and 12 years</td>
<td>female, asthma</td>
<td>descriptive</td>
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and service utilization in women of Mexican origin living in Texas
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<tbody>
<tr>
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<td>To explore the daily routines that mothers construct in response to the emerging self-care skills of their young children with disabilities</td>
<td>7 children; 6 mothers</td>
<td>28-32 months</td>
<td>female, male</td>
<td>cerebral palsy, developmental delay, severe dyspraxia, Down Syndrome</td>
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<tr>
<td>Child</td>
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<td>U.S.A. American</td>
<td>To elicit information about independent self-care behaviours and understand how middle school children manage their asthma when they are away from home and must make decisions and take actions concerning their own well being</td>
<td>25</td>
<td>11-14 years</td>
<td>female, male</td>
<td>asthma</td>
<td>descriptive inquiry</td>
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<tr>
<td>Adolescent</td>
<td>Sawin 2009</td>
<td>U.S.A. American</td>
<td>To describe the experience of self-management in 31 adolescent women with spina bifida</td>
<td>31</td>
<td>12-21 years</td>
<td>female</td>
<td>spina bifida</td>
<td>descriptive inquiry</td>
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<td>To identify beliefs and self-care practices of adolescents with asthma in</td>
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<td>13.6 - 18 years</td>
<td>female, male</td>
<td>asthma</td>
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<tr>
<td>Adolescent</td>
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<td>2000</td>
<td>United Kingdom</td>
<td>To understand the reasons for non-compliance in adolescents with asthma</td>
<td>49</td>
<td>14 - 20 years</td>
<td>female, male</td>
<td>asthma</td>
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<tr>
<td>Adolescent</td>
<td>Hanna</td>
<td>2000</td>
<td>U.S.A. American</td>
<td>To identify adolescents' perceived benefits and barriers about their assumption of diabetes self-management from parents</td>
<td>16</td>
<td>11 - 18 years</td>
<td>female, male</td>
<td>diabetes mellitus</td>
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<tr>
<td>Adult</td>
<td>Arpanantikul</td>
<td>2006</td>
<td>Thailand Thai</td>
<td>To explore the process of self-care actions in promoting health among middle-aged Thai women</td>
<td>15</td>
<td>45-55 years</td>
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<td>Adult</td>
<td>Hanna</td>
<td>2000</td>
<td>U.S.A. American</td>
<td>To identify parents' perceived benefits and barriers about their decision making regarding their adolescents' assumption of diabetes self-management</td>
<td>17</td>
<td>Adult unspecified</td>
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<td>diabetes mellitus</td>
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<tr>
<td>Elder</td>
<td>Backman</td>
<td>1999</td>
<td>Finland Finnish</td>
<td>To develop a model to clarify the existing knowledge concerning the self-care of home-dwelling elderly people</td>
<td>40</td>
<td>75 years or older</td>
<td>female, male</td>
<td>health maintenance</td>
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<td>Berman</td>
<td>1998</td>
<td>U.S.A. American</td>
<td>To explore the notion of taking care of oneself by examining how 50 older</td>
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<td>55-91 years</td>
<td>female, male</td>
<td>health maintenance</td>
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<td>Country Culture</td>
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<tr>
<td>Adult, Elder</td>
<td>Punamaki</td>
<td>Finland Finnish</td>
<td>To study health maintenance, self-care practices, coping resources and feelings of helplessness, as indicators of daily mastery, among a group of 142 Finnish primary care patients</td>
<td>258</td>
<td>Mean age 48.7, S.D. 15.8</td>
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**Health Deviation**

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<th>Country Culture</th>
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<td>diabetes mellitus</td>
<td>descriptive inquiry</td>
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<td>Child, Adult</td>
<td>Moore</td>
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<td>cancer</td>
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<td>Schmidt</td>
<td>U.S.A. American</td>
<td>To describe mothers' perceptions of the diabetes-related self-care abilities and practices of their school-age children with Type 1 diabetes</td>
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<td>diabetes mellitus</td>
<td>naturalistic inquiry</td>
</tr>
<tr>
<td>Child</td>
<td>Pradel</td>
<td>U.S.A. American</td>
<td>To explore the knowledge, perceptions and autonomy of 7- and 12-year-old children relative to the management of their asthma.</td>
<td>32 (19 7yrs; 13 12yrs)</td>
<td>7 and 12 years</td>
<td>female, male</td>
<td>asthma</td>
<td>descriptive inquiry</td>
</tr>
<tr>
<td>Child</td>
<td>Kellegrew</td>
<td>U.S.A. American</td>
<td>To explore the daily routines that mothers construct in response to the emerging self-care skills of their young children with disabilities</td>
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<tr>
<td>Child</td>
<td>Horner</td>
<td>U.S.A. American</td>
<td>To elicit information about independent self-care behaviours and understand how middle school children manage their asthma when they are away from home and must make decisions and take actions concerning</td>
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<td>11-14 years</td>
<td>female, male</td>
<td>asthma</td>
<td>descriptive inquiry</td>
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<tr>
<td>Adolescent</td>
<td>Sawin</td>
<td>2009</td>
<td>U.S.A. American</td>
<td>To describe the experience of self-management in 31 adolescent women with spina bifida</td>
<td>31</td>
<td>12-21 years</td>
<td>female</td>
<td>spina bifida</td>
</tr>
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<td>Knight</td>
<td>2005</td>
<td>Hawaii Hawaiian</td>
<td>To identify beliefs and self-care practices of adolescents with asthma in a private high school</td>
<td>10</td>
<td>13.6 - 18 years</td>
<td>female, male</td>
<td>asthma</td>
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<tr>
<td>Adolescent</td>
<td>Buston</td>
<td>2000</td>
<td>United Kingdom Scottish</td>
<td>To understand the reasons for non-compliance in adolescents with asthma</td>
<td>49</td>
<td>14 - 20 years</td>
<td>female, male</td>
<td>asthma</td>
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<tr>
<td>Adolescent</td>
<td>Hanna</td>
<td>2000</td>
<td>U.S.A. American</td>
<td>To identify adolescents' perceived benefits and barriers about their assumption of diabetes self-management from parents</td>
<td>16</td>
<td>11 - 18 years</td>
<td>female, male</td>
<td>diabetes mellitus</td>
</tr>
<tr>
<td>Adult</td>
<td>Unger</td>
<td>2009</td>
<td>U.S.A. American</td>
<td>To analyze and define the concept of self-management for adults diagnosed with epilepsy in the previous 12 months</td>
<td>4</td>
<td>20-38 years</td>
<td>female, male</td>
<td>epilepsy</td>
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<tr>
<td>Adult, Elder</td>
<td>Chen</td>
<td>2008</td>
<td>Taiwan Taiwanese</td>
<td>To explore the self-management behaviours of patients with chronic obstructive pulmonary disease</td>
<td>18</td>
<td>55-81 years</td>
<td>male</td>
<td>COPD</td>
</tr>
<tr>
<td>Dev. Grouping</td>
<td>Author Year</td>
<td>Country Culture</td>
<td>Purpose of Study</td>
<td>Sample Size</td>
<td>Participant Age Range</td>
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</tr>
<tr>
<td>Adult</td>
<td>Furler 2008</td>
<td>Australia, Australian, Turkish, Arabic</td>
<td>To explore the perceptions of people with type 2 diabetes about their self-management strategies and how relationships with health professionals may support this</td>
<td>52</td>
<td>50-80 years</td>
<td>female, male</td>
<td>diabetes mellitus</td>
<td>exploratory inquiry</td>
</tr>
<tr>
<td>Adult, Elder</td>
<td>Kidd 2008</td>
<td>United Kingdom Scottish</td>
<td>To explore patients' experiences of self-care during a 6-month course of chemotherapy treatment for colorectal cancer</td>
<td>11</td>
<td>49-76 years</td>
<td>female, male</td>
<td>colorectal cancer</td>
<td>descriptive inquiry</td>
</tr>
<tr>
<td>Adult, Elder</td>
<td>Lippa 2008</td>
<td>U.S.A. American</td>
<td>To examine how patients with low, moderate, and good glycemic control conceptualize self-care</td>
<td>18</td>
<td>19-76 years</td>
<td>female, male</td>
<td>diabetes mellitus</td>
<td>naturalistic inquiry</td>
</tr>
<tr>
<td>Adult, Elder</td>
<td>Carbone 2007</td>
<td>U.S.A. Latino</td>
<td>To provide insight into the knowledge, attitudes, practices, and perceived barriers facing Latino patients and their providers regarding diabetes</td>
<td>37 patients; 15 health care professionals</td>
<td>30-79 years</td>
<td>female, male</td>
<td>diabetes mellitus</td>
<td>descriptive inquiry</td>
</tr>
<tr>
<td>Adult</td>
<td>El-Mallakh 2007</td>
<td>U.S.A. American</td>
<td>To describe the process by which individuals diagnosed with comorbid schizophrenia/schizoaffective disorder and</td>
<td>11</td>
<td>mean 50.3, SD 9.5 years</td>
<td>female, male</td>
<td>schizophrenia, diabetes mellitus</td>
<td>grounded theory</td>
</tr>
<tr>
<td>Dev. Grouping</td>
<td>Author</td>
<td>Country</td>
<td>Purpose of Study</td>
<td>Sample Size</td>
<td>Participant Age Range</td>
<td>Participant Gender</td>
<td>Context/Disease/Disability</td>
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<tr>
<td>Adult</td>
<td>Guidetti</td>
<td>Sweden</td>
<td>To identify the characteristics of the lived experience of recapturing self-care after a stroke or a spinal cord injury</td>
<td>5 stroke; 6 SCI</td>
<td>21-65 years</td>
<td>female, male</td>
<td>spinal cord injury, stroke</td>
<td>phenomenology</td>
</tr>
<tr>
<td>Adult, Elder</td>
<td>Wilson</td>
<td>United Kingdom</td>
<td>To explore whether the Expert Patients Programme enables empowerment or replicates traditional patterns of the patient-professional relationship</td>
<td>66</td>
<td>30-80 years estimate</td>
<td>female, male</td>
<td>general chronic conditions</td>
<td>grounded theory</td>
</tr>
<tr>
<td>Adult</td>
<td>El-Mallakh</td>
<td>U.S.A.</td>
<td>To develop a theory of self-care for individuals with comorbid schizophrenia/ schizoaffective disorder and diabetes mellitus</td>
<td>11</td>
<td>mean 50.3, SD 9.5 year</td>
<td>female, male</td>
<td>schizophrenia, diabetes mellitus</td>
<td>grounded theory</td>
</tr>
<tr>
<td>Adult</td>
<td>Persson</td>
<td>Sweden</td>
<td>To gain a deeper understanding of effective coping in physical disability and/or chronic illness</td>
<td>26</td>
<td>29-65 years</td>
<td>female, male</td>
<td>asthma, multiple sclerosis, visual impairments, heart disease, spinal cord injury, rheumatoid</td>
<td>grounded theory</td>
</tr>
</tbody>
</table>

diabetes mellitus developed health beliefs about the self-care of dual illnesses; and to examine the social context of their diabetic self-care
<table>
<thead>
<tr>
<th>Dev. Grouping</th>
<th>Author Year</th>
<th>Country Culture</th>
<th>Purpose of Study</th>
<th>Sample Size</th>
<th>Participant Age Range</th>
<th>Participant Gender</th>
<th>Context/Disease/Disability</th>
<th>Method</th>
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</thead>
<tbody>
<tr>
<td>Adult</td>
<td>Townsend 2006</td>
<td>United Kingdom Scottish</td>
<td>To illuminate how people negotiate multiple chronic illness, and everyday life</td>
<td>23</td>
<td>early 50's</td>
<td>female, male</td>
<td>multiple morbidity</td>
<td>descriptive inquiry</td>
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<tr>
<td>Adult</td>
<td>Donald 2005</td>
<td>Australia Australian</td>
<td>To examine the notion that adults with severe life threatening asthma would report delay in seeking treatment, and downplay the seriousness of their asthma symptoms</td>
<td>5</td>
<td>20-42 years</td>
<td>female, male</td>
<td>asthma</td>
<td>descriptive inquiry</td>
</tr>
<tr>
<td>Adult</td>
<td>Plach 2005</td>
<td>U.S.A. American</td>
<td>To describe the ways older women living with HIV perceive of and practice self-care</td>
<td>9</td>
<td>50-56 years</td>
<td>female</td>
<td>HIV</td>
<td>narrative</td>
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<tr>
<td>Adult</td>
<td>Canales 2004</td>
<td>U.S.A. American-Indian</td>
<td>To report on health care decision making of American Indian women residing in the North eastern United States.</td>
<td>20</td>
<td>39-75 years</td>
<td>female</td>
<td>health maintenance, breast cancer</td>
<td>grounded theory</td>
</tr>
<tr>
<td>Dev. Grouping</td>
<td>Author &amp; Year</td>
<td>Country Culture</td>
<td>Purpose of Study</td>
<td>Sample Size</td>
<td>Participant Age Range</td>
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<tr>
<td>Adult, Elder</td>
<td>Cicutto 2004</td>
<td>Canada Canadian</td>
<td>To explore factors that influence self-care from the perspective of individuals with chronic obstructive pulmonary disease</td>
<td>42</td>
<td>54-71 years</td>
<td>female, male</td>
<td>COPD</td>
<td>descriptive inquiry</td>
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<tr>
<td>Adult</td>
<td>Sieglof 2003</td>
<td>Australia Australian</td>
<td>To examine the way in which family carers of people living with mental illness in rural Victoria, experienced and perceived the nature of chronic illness management per se and self-management in particular</td>
<td>58</td>
<td>unspecified</td>
<td>female, male</td>
<td>cystic fibrosis, mental illness</td>
<td>descriptive inquiry</td>
</tr>
<tr>
<td>Adult, Elder</td>
<td>Paterson 2001</td>
<td>Canada Canadian</td>
<td>To investigate self-care decision making in diabetes</td>
<td>22</td>
<td>24-81 years</td>
<td>female, male</td>
<td>diabetes mellitus</td>
<td>grounded theory</td>
</tr>
<tr>
<td>Adult</td>
<td>Hanna 2000</td>
<td>U.S.A. American</td>
<td>To identify parents' perceived benefits and barriers about their decision making regarding their adolescents' assumption of diabetes self-management</td>
<td>17</td>
<td>Adult unspecified</td>
<td>female, male</td>
<td>diabetes mellitus</td>
<td>descriptive inquiry</td>
</tr>
<tr>
<td>Adult</td>
<td>Leenerts 2000</td>
<td>U.S.A. American</td>
<td>To explore the self-care practices of low-income White women diagnosed with HIV/AIDS</td>
<td>12</td>
<td>over 18 years</td>
<td>female</td>
<td>HIV</td>
<td>grounded theory</td>
</tr>
<tr>
<td>Dev. Grouping</td>
<td>Author</td>
<td>Year</td>
<td>Country Culture</td>
<td>Purpose of Study</td>
<td>Sample Size</td>
<td>Participant Age Range</td>
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<tr>
<td>Adult, Elder</td>
<td>Hjelm</td>
<td>1999</td>
<td>Sweden Swedish, Yugoslavian</td>
<td>To explore the beliefs about health and illness among migrant Yugoslav and Swedish diabetic subjects that might affect their self-reported self-care practices and care-seeking behaviours.</td>
<td>15 Swedes; 13 Yugoslavs</td>
<td>33-73</td>
<td>female</td>
<td>diabetes mellitus</td>
</tr>
<tr>
<td>Adult</td>
<td>Hunt</td>
<td>1998</td>
<td>U.S.A. Mexican</td>
<td>To examine how the different contexts and perspectives of patients and health care professionals result in distinct approaches to type 2 diabetes management</td>
<td>51 patients; 36 health care professionals</td>
<td>patients 29-69 years; health care professionals 25-68 years</td>
<td>female, male</td>
<td>diabetes mellitus</td>
</tr>
<tr>
<td>Adult</td>
<td>Clark</td>
<td>1995</td>
<td>U.S.A. American, Mexican</td>
<td>To examine household health production experiences from the perspective of poor women living in the south western United States</td>
<td>26</td>
<td>Mexican mean age 31.6; Anglo mean age 27.3</td>
<td>female</td>
<td>health promotion, acute conditions</td>
</tr>
<tr>
<td>Adult</td>
<td>Baker</td>
<td>1993</td>
<td>Canada Canadian</td>
<td>To investigate the evolution of readiness to self-manage a nonfatal chronic illness</td>
<td>12 patients; 9 nurses</td>
<td>18-65 years</td>
<td>female, male</td>
<td>diabetes mellitus, heart disease, renal failure, colostomy for bowel cancer</td>
</tr>
<tr>
<td>Adult</td>
<td>McLaughlin</td>
<td>1993</td>
<td>Denmark Danish,</td>
<td>To compare and contrast self-initiated self-care</td>
<td>51 Danish; 35 American</td>
<td>Danish 22-58; American 19-65</td>
<td>female, male</td>
<td>multiple sclerosis</td>
</tr>
<tr>
<td>Dev. Grouping</td>
<td>Author Year</td>
<td>Country Culture</td>
<td>Purpose of Study</td>
<td>Sample Size</td>
<td>Participant Age Range</td>
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<tr>
<td>Elder</td>
<td>Clark 2008</td>
<td>U.S.A. American</td>
<td>To describe and contrast perceptions of self-management among socioeconomic vulnerability and non-vulnerable older adults</td>
<td>35</td>
<td>65 years or older</td>
<td>female, male</td>
<td>multiple morbidity</td>
<td>phenomenology</td>
</tr>
<tr>
<td>Elder</td>
<td>Gorawara-Bhat 2008</td>
<td>U.S.A. American</td>
<td>To explore the role of social comparison in the self-management practices of older patients with diabetes, and develops a conceptual model depicting the process</td>
<td>28</td>
<td>65 years or older</td>
<td>female, male</td>
<td>diabetes mellitus</td>
<td>descriptive inquiry</td>
</tr>
<tr>
<td>Elder</td>
<td>Penney 2007</td>
<td>Australia Australian</td>
<td>To explore older people’s participation in their care in acute hospital settings and reveal both consumers’ and nurses’ view of participation</td>
<td>36</td>
<td>70 years or older</td>
<td>female, male</td>
<td>unspecified acute conditions</td>
<td>critical ethnographic</td>
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<tr>
<td>Elder</td>
<td>Koch 2004</td>
<td>Australia Australian</td>
<td>To explore self-management with older people who were diagnosed with asthma</td>
<td>24</td>
<td>60-92 years</td>
<td>female, male</td>
<td>asthma</td>
<td>exploratory inquiry</td>
</tr>
<tr>
<td>Dev. Grouping</td>
<td>Author Year</td>
<td>Country Culture</td>
<td>Purpose of Study</td>
<td>Sample Size</td>
<td>Participant Age Range</td>
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<tr>
<td>Elder</td>
<td>Kralik 2004</td>
<td>Australia Australian</td>
<td>To understand the way in which people who lived with chronic illness constructed the notion of self-management</td>
<td>9</td>
<td>48-75 years</td>
<td>female, male</td>
<td>arthritis</td>
<td>descriptive inquiry</td>
</tr>
<tr>
<td>Elder</td>
<td>Baird 2003</td>
<td>U.S.A. American</td>
<td>To understand the experience of living and caring for self with osteoarthritis and physical functioning difficulties</td>
<td>5</td>
<td>72-91 years</td>
<td>female</td>
<td>arthritis</td>
<td>phenomenology</td>
</tr>
</tbody>
</table>
### Appendix I – Relationship of Findings, Categories and Synthesized findings for Universal Requisites

#### Synthesis topic 1

**Supporting the self:** When meeting universal requisites, self-care activities require self-awareness; discernment of basic needs; taking responsibility for attending to those needs; and protecting oneself from harm.

#### Category 1

*When meeting universal requisites, self-care requires an awareness of self and understanding of one’s body*

- For homeless youth, the first step to self-care was becoming aware of oneself and circumstances of family life.
- For homeless youth, developing self-awareness was enhanced by gaining self-respect.
- For homeless youth, they developed self-awareness by increasing self-reliance.
- Universal self-care requisites - parents of children with cancer noted their children's struggle with self-care practices to related to air, water, food.
- For Native women, understanding the body influenced their efforts toward taking care of self.
- Some Native women described a deep understanding of their body and believed strongly in their intuition and the messages the body sends.
- For some Native women taking care of self was influenced by knowledge of their family history.

#### Category 2

*When meeting universal requisites, self-care involves taking responsibility for one’s own health or for someone else’s health*

- Children were rewarded for mastery of self-care skills.
- Children viewed self-care as an individual responsibility.
- Universal self-care requisites (elimination, activity, rest) - parents of children with cancer introduced specific activities to assist their children with their recovery.
- For Native women, taking care of self was simply a part of life.
- Most Mexican women reported learning self-care practices for use when not healthy.
- Most Mexican women initiated or wanted to initiate self-care practices for when they were not feeling healthy.

#### Category 3

*When meeting universal requisites, self-care is about self-protection*

- For homeless youth, staying alive with limited resources was possible by engaging in self-preservation.
- For homeless youth, part of their self-care involved planning for self-protection.
- For children self-care was experienced as personal safety and survival and was always linked to consequences.
Universal self-care requisites - both parents of children with cancer, and the children themselves did all they could to protect against risks to health or safety.

Some Brazilian garbage workers recognized the contamination of eating amidst the garbage without hand washing.

For the Brazilian garbage workers the option not to eat amidst the garbage but to move to the kitchen on the patio was weighed against loss of break time.

For most Brazilian garbage workers not using gloves when handling garbage was due to a lack of access to gloves. For others it was a preference.

Most Brazilian garbage workers changed their behaviour in the presence of visitors, indicating knowledge of risk and 'safe behaviour'.

### Synthesis topic 2

**Balancing inner and outer worlds**: When meeting universal requisites, self-care activities entail balancing both the inner world of mind, body and emotions, and time spent sharing oneself with others.

### Category 4

*When meeting universal requisites, self-care involves striving for balance between mental, physical and spiritual aspects of life, and between social interaction and solitude.*

Universal self-care requisites - children with cancer desired to maintain a balance between solitude and social interaction while in hospital.

Universal self-care requisites - children with cancer desired to lead a normal life.

For Native women health was a balance between mind, body, and spirit, a holistic approach toward living.

For Native women being healthy meant feeling the balance between the physical, mental and spiritual realms of their lives.

### Category 5

*When meeting universal requisites, self-care is facilitated by interacting with other people.*

For homeless youth, handling their own health was facilitated by interacting with other people.

For homeless youth, handling their own health meant confronting many obstacles. Sometimes this was done by establishing friendships.

For children self-care was linked to psychosocial survival within the world of school.
### Appendix J – Relationship of Findings, Categories and Synthesized findings for Developmental Requisites

#### Synthesis topic 3

**Continued engagement in self-care:** When meeting developmental requisites, continued engagement in self-care is facilitated by actively taking responsibility for one’s care, a positive attitude and the reinforcement of a sense of balance and vitality after performing self-care activities.

#### Category 6

When meeting developmental requisites, self-care is enhanced by knowledge, an awareness of self, and the ability to identify health needs.

<table>
<thead>
<tr>
<th>Topic</th>
<th>Description</th>
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<tbody>
<tr>
<td>Some children with diabetes have an awareness of the intense and life-threatening aspect of their illness.</td>
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<tr>
<td>Some parents perceived benefits for adolescents from their diabetes self-management in terms of the increase in the adolescent's knowledge and/or confidence.</td>
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<tr>
<td>For children with asthma it was important to recognizing personal symptoms and triggers of asthma.</td>
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<tr>
<td>Some children with asthma attributed their asthma to heredity or God's will.</td>
<td></td>
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<tr>
<td>Aetiology of an asthma attack - older children with asthma gave a more comprehensive list of environmental triggers.</td>
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<tr>
<td>Asthma symptoms - for most children with asthma the onset of an asthma episode seemed unforeseen and sudden.</td>
<td></td>
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<tr>
<td>Asthma management - identifying medicine and devices - most younger children with asthma used lay terms or physical characteristics (color, shape).</td>
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<tr>
<td>Perception of an asthma episode - older children with asthma were aware of the traumatic aspect of an asthma episode.</td>
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<tr>
<td>Children with asthma in both age groups (7 and 12) perceived the main cause of asthma as physical activity.</td>
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<tr>
<td>Most of the older children with asthma knew the appropriate actions to take when experiencing an asthma episode.</td>
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<tr>
<td>Elders followed instructions and performed routines but often not knowing why.</td>
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<tr>
<td>Middle aged Thai women felt that knowing how to assess health was important in monitoring any change occurring in their health.</td>
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<tr>
<td>Middle aged Thai women's self-awareness enables them to recognize their health conditions and demonstrate willingness to learn and perform self-care actions.</td>
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<tr>
<td>Middle aged Thai women said they started developing a sense of self as they got older and spent less time raising children.</td>
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<tr>
<td>The motivation for self-care for middle aged Thai women emerges from internal aspiration and the recognition of the need to know her own health and to perform self-care.</td>
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</tbody>
</table>
Most adolescents with diabetes perceived benefits of self-management in terms of having the knowledge of or confidence in their self-management abilities.

**Category 7**

*When meeting developmental requisites, individuals respond by taking charge and being responsible for their own self-care*

For some children with diabetes there was no relationship between age and ability to use needles.

Children with asthma performed particular activities during an episode of asthma.

Developmental self-care requisites - parents provided conditions to promote the continued development of children with cancer.

Developmental self-care requisites - children with cancer engaged in self-development, promoting their own mental, physical and emotional well-being.

Developmental self-care requisites - children with cancer and parents dealt with interferences with or interruptions to development.

Autonomy - deciding when to use medicine - younger children with asthma relied on caretakers, older children were autonomous.

For children with diabetes learning insulin administration was harder than glucose testing and the main source of motivation was a desire to be independent.

All children with diabetes were able to identify and treat episodes of hypoglycemia, but this was sometimes complicated by being at school.

Elders took charge of their own health care and well being - do and think for yourself.

Some elders reported consciously neglecting their own self-care when busy caring for others.

For some elders the social context of self-care was important. Self-care occurred within the context of a health care professional's office.

For some elders the majority of their self-care efforts were undertaken at home, by themselves or with assistance of family and friends.

Elders took charge of their health and engaged in a variety of behaviours such as home remedies, diet, exercise and other routines.

Elders assumed responsibility in all activities of daily living and caring for health and illnesses - self-care as a life habit.

Some elders desired to listen to their inner voice and be self-directed in all care activities, in health and illness.

Elders who prescribed to formally guided care had been used to taking care of other people and they did not identify their own needs. They also experienced ageing realistically.

Elders who practiced independent self-care aimed to manage their lives independently and had always been very independent and determined in their lives.

For middle aged Thai women, self control involves a personal sense of responsibility for one's health. A few women said it was their duty to keep healthy because others needed their care.
Children with asthma demonstrated a capacity for problem solving with regard to prevention of asthma attacks or unanticipated events

Children with diabetes were motivated to learn blood glucose testing to decrease the pain involved in this procedure

Teaching children to assume responsibility for their health - Mexican American mothers empowered their children to take responsibility for their own cure

Teaching children to assume responsibility for their health - Anglo American mothers encourage their children to apply their own medications

**Category 8**

*When meeting developmental requisites, elders find it easier to engage in self-care if they have a positive attitude toward aging, plus they value health and achieving goals*

For elders a precondition for responsible self-care was a positive orientation towards the future and a positive experience of ageing

Middle aged Thai women put value on health and developed the ability to identify physical

Finish primary care patients' self-care practices focused on seeking and safeguarding the meaning and purposefulness of life

For Finish primary care patients engaging in work and hobbies and achieving important goals was seen as a means of health maintenance and self-care

Finish primary care patients felt helpless when confronting aspects in their own lives such as aging, loss of physical and mental vigor, poverty, unemployment, loneliness and alienation

**Category 9**

*When meeting developmental requisites, positive consequences of self-care behaviours reinforce the engagement in self-care*

'Feeling good' was most frequently identified as the children's motivation to adhere to diabetes related tasks. Avoidance of punishment or concern about the future were not strong motivators

For middle aged Thai women evaluating the consequences of self-care activities referred to the conscious assessment of oneself and one's self-care activity

For middle aged Thai women, besides the positive influence on physical health, self-care activities provided benefits to mental health, including mood improvement and stress reduction

Some adolescents with diabetes perceived benefits of self-management in terms of having more freedom

Some adolescents with diabetes perceived benefits of self-management in terms of receiving the approval of others

Some adolescents with asthma self-efficacy was facilitated through positive experiences

**Synthesis topic 4**

*Abandoning self-care activities:* When meeting developmental requisites, self-care activities may be abandoned when overwhelmed by symptoms and disabilities or when feeling helpless in the face of aging
### Category 10

*When meeting developmental requisites, individuals with a negative attitude to aging or who felt helpless in the face of aging, or were hampered by a lack of knowledge and found it difficult to care for themselves, relinquished control and relied on others for care.*

For middle aged Thai women, financial problems denial, anxiety, fear, shame or lack of social support could affect her motivation to keep on her self-care plan. A lack of understanding or knowledge could result in the improper performance of self-care.

Some elders discussed their inability to do anything about their own health and allowing others to take care of them. They managed what they could by cutting back or reducing activities.

Elders who were unable to do anything to alter their health status spoke about relying on others, such as physicians, family members or paid caregivers for advice or care.

Some elders did what they could to address a health crisis or their most debilitating condition but accepted their health was due to the normal process of aging and did very little to take care of themselves.

Some elders abandoned self-care - they were no longer able to make the effort to care and felt a sense of helplessness.

Elders who abandoned self-care felt that their whole life had been miserable and had a negative attitude towards ageing. Their life was full of symptoms, different pains and disabilities.

### Synthesis topic 5

**Positive experience of self-care:** When meeting developmental requisites, self-care activities are facilitated when individuals give priority to establishing balance in their lives, remain connected with family, friends and community and for some individuals, to allow time to gain mental and spiritual peace.

### Category 11

*When meeting developmental requisites, self-care involves maintaining a balance between health and illness, and between work and play.*

For some children with diabetes, their goals were to be normal and just get on with life.

For some middle aged Thai women barriers to self-care performance included family responsibilities, financial restrictions, lack of knowledge, lack of time and need for assistance. However, some women were able to overcome these obstacles.

For Finnish primary care patients engaging in recreation activities and the conscious release of tension and stress reflected the goal of on-going self-care. Attaining a balance between work and leisure was seen as important in this process.

The majority of Finnish primary care patients strove to achieve and maintain good health through organized sports, exercise and diet. Avoiding risk behaviour and attending to personal hygiene was also an important aspect of this self-care.

### Category 12

*When meeting developmental requisites, self-care activities are facilitated by remaining*
connected to family, friends and communities

Social motivation influences a middle aged Thai woman's self-care performance, either positively or negatively

Finnish primary care patients' self-care practices involved seeking and maintaining social support and feelings of belonging. Feelings of togetherness with family, friends and colleagues are important. Giving social support as well as receiving it, was reported as a means of health maintenance and self-care

**Category 13**

*When meeting developmental requisites, for some individuals mental and spiritual practices are important components of self-care*

Middle aged Thai women perceived that psychological health status was important. When their mind was suffering their whole lives seemed to be terrible

Middle aged Thai women recognized the importance of mental and spiritual practice which brought happiness, good relationships with others and success in their work and lives

For middle aged Thai women religion is a significant outer motivation influencing women to take care of their mental and spiritual health

For middle aged Thai women a vital point was mind control. Before they could control themselves to perform self-care, they needed to control their minds

For many middle aged Thai women mental and spiritual practice provided good physical health and good social health

**Synthesis topic 6**

*Influence of outer and inner worlds: When meeting developmental requisites, acquisition and mastery of self-care behaviours may be influenced by level of maturity and capacity to execute the behaviour, or by external conditions such as mothering style and values or support from others*

**Category 14**

*When meeting developmental requisites, a child or adolescent's acquisition and mastery of self-care behaviours could be influenced by mother's values, schedules and child rearing styles*

Children with disabilities self-care tasks and activities - mothers placed a higher value on skills (such as eating) which have the potential for public scrutiny

Mother's self-care goals and values for children with disabilities - tying goals to children's future such as preschool that requires the child be potty trained

Mothers fine-tuned daily routines and expectations in accordance with their perceptions of their child with disabilities abilities at that moment.

A mother's 'child-centered' rearing style allowed the child with disabilities to exercise her choice in her daily routines

A mother's 'fixed template' of child behaviour had higher expectations of the child with disabilities and what could be accomplished in daily routines

Some mothers of children with disabilities accommodated to the child's changing skill
ability and adjusted the level of independence they anticipated of the child during daily routines.

Some mothers of children with disabilities anticipated their child’s future needs and orchestrated daily routines that would reinforce or develop those skills seen as beneficial to the child’s success.

The influence of mother’s time on daily routines - children with disabilities either lost or retained independent activities.

Introducing new activities - letting the child with disabilities take the lead.

Influence of mothers’ expectations on their children's acquisition of diabetic related self-care skills - mothers of girls expected them to master the skill and whereas mothers of boys were more protective of their sons and performed the task for them.

For adolescents with spina bifida, self-management was made more difficult with restrictive parenting.

For adolescents with spina bifida, self-management was facilitated by balanced parenting.

Learning approaches - children with diabetes learn from many sources and 'as we go' not pre-planned.

**Category 15**

*When meeting developmental requisites, a child or adolescent's vigilance with self-care behaviours could be influenced positively or negatively by their developmental stage and level of maturity.*

Some parents perceived benefits related to adolescents' diabetes self-management in terms of confidence and pride in their children's abilities and maturity.

For children with asthma there was a change in asthma symptoms from earlier years - as they matured and changed their activity level it was less disruptive.

Children with diabetes acquiring skills - girls learn the skills fast and boys appeared not to be motivated.

Children with diabetes readiness to prepare and inject insulin - girls were proficient, some boys injected insulin, but not regularly.

Honesty in glucose measurement - some children with diabetes were not concerned with accuracy of blood sugar levels and occasionally were fabricating the results.

Despite eating forbidden foods at some time, most children with diabetes were used to nutritional restrictions and usually adhered to their prescribed diets. However, timing of meals and snacks was often problematic.

Influence of developmental stage on children's vigilance with diabetes self-care practices - children are not consistently attentive and vigilant to diabetic self-care - inability to reason.

Incorporating diabetes self-care into daily life - children not wanting to be different or interrupt activities to perform diabetic self-care.

Not wanting to be set apart from their peers - some children with diabetes were embarrassed by diabetes care routine - such as wearing an ID bracelet or carrying...
Some adolescents with asthma felt embarrassment at having to take medication. Some adolescents with asthma were too lazy to follow the medication regime.

**Category 16**

*When meeting developmental requisites, a child or adolescent's self-care behaviours may be facilitated by supporting adults.*

Children with asthma needed to maintain the balance between being supported and not overwhelmed - parents who offer the right amount of support.

Children with asthma found it difficult to deal with people who were unsupportive and anxious.

**Category 17**

*When meeting developmental requisites, control over the care behaviour is an issue for children, adolescents and parents.*

Most parents perceived benefits related to adolescents' diabetes self-management in terms of relief from burden.

Some parents perceived benefits for adolescents from their diabetes self-management in terms of an increase in the adolescent's freedom, independence, and/or control.

Some parents perceived disadvantages of their adolescents' diabetes self-management in terms of their own sense of loss of control or authority/supervision.

Most parents perceived disadvantages of their adolescents' diabetes self-management in terms of not knowing what the adolescent was doing and worrying that they would not be able to assist the adolescent if they had any problems.

All adolescents with diabetes perceived benefits for parents from their self-management as being parents' relief from responsibility, stress and worry.

Most adolescents with diabetes perceived disadvantages for parents from their self-management in terms of increased worry and guilt for parents.

A couple of adolescents with diabetes perceived disadvantages for parents from their self-management in terms of parental loss of control.

For children with asthma it was unpleasant having someone else decide the legitimacy of their asthma symptoms.
## Appendix K – Relationship of Findings, Categories and Synthesized findings for Health Deviation Requisites

### Synthesis topic 7
**Interacting with health care professionals:** When meeting health deviation requisites, engaging in self-care may be influenced by the health care professional’s attitude. Collaborative models of care plus acknowledging the individual’s or his/her family caregiver’s knowledge about the condition helped to empower some individuals to engage in self-care activities.

### Category 18
When meeting health deviation requisites, individuals felt empowered when health care professionals acknowledged their knowledge and recognized their engagement in self-care behaviours. Individuals felt disempowered when health care professionals doubted their knowledge and questioned the reliability of their self-care behaviours.

- Medical model - most elders with asthma found themselves in a medical management model - they were not invited to take part in their asthma management and the doctor managed the disease process.
- Many adults/elders with diabetes found few health care professional whose practices were empowering.
- Several adults/elders with diabetes indicated that attempts to assume an active role in decisions about their care were met at times with obvious scepticism and, at other times, with anger by health care professionals. Doctors encouraged them to participate in decisions about their care, but then immediately discounted their experiential knowledge.
- Several adults/elders with diabetes remarked that health care professionals discounted their experiences if they differed or contradicted textbook information.
- Adults/elders with diabetes stated that the way information is given affects their willingness and ability to engage in decision making with the health care professional. For example, when health care professionals spoke in medical jargon they could not understand, they perceived it as accentuating the power differential between the health care professional and themselves.

### Category 19
When meeting health deviation requisites, medication plays an important role in self-care behaviours. Individuals recognize the relationship between medication and their functional ability, but are wary of medication side effects. Some individuals want to take on the responsibility of adjusting their medication as their condition and functionality fluctuates. The ability to choose the type of treatment modality engaged in (conventional and/or traditional/alternate) reinforces self-care activities.

- Some adolescents with asthma believed that their preventive meds made a positive difference.
- Health deviation - children with cancer and parents secured medical assistance, dealt
with the effects of illness, and carried out prescribed measure

Health deviation - children with cancer struggled with the negative effects of therapy

Children with asthma perceptions of asthma medicines - different reactions to asthma medications; sometimes feeling better or sometimes feeling worse

All aging women with OA reported OA medications were not always effective and they used a variety of other treatments

For the socioeconomically vulnerable group self-care was reduced to compliance with prescribed medications, there was little mention of the role of medical care in health maintenance

Elders reported frustration at not being able to participate in the self-care of daily medication administration - dealing with changes to medications that happened without their knowledge, or the addition of unknown medications

Taking the prescribed medications was another way older women with HIV cared for themselves

For older women with HIV, side effects from treatments were another confusing factor in dealing with symptoms

To control backache 50% of Americans with MS took both prescription and over the counter drugs while 11% of Danes used medicine (OTC drugs not available in Denmark)

The majority of Americans with MS (60%) and 20% of Danes with MS adjusted their medications, either changing dosage, or abandoning the medications altogether

Adult/elderly men with COPD engage in different self-care activities according to the type and severity of symptoms, to cope with them and avoid the risk of recurrence

Adult/elderly men with COPD engage in regular self-care behaviours such as exercise or taking their medications to prevent the occurrence of symptoms

Adults/elderly people with COPD relied on breathing exercises and medication as the most effective strategies to deal with their illness

All adults with asthma placed a great deal of importance on having reliever medication readily at hand

Many adults with schizophrenia and diabetes were able to recognize the relationships between antipsychotic medications, elimination of symptoms, and improvement in functioning

Some adults with multiple chronic illnesses aligned resisting symptomatic medication with maintaining control over the body, over symptoms and over their identity. Antidepressants, in particular, were resisted when associated with negative self-image. However, if congruent with a more favourable identity, they were more likely to be regarded as a self-management tool.

Some adults with epilepsy were able to adapt their self-management of the condition to increase their functionality

Over half of adolescents with asthma reported forgetting to take medication particularly when routines changed

Several adolescents with asthma reported believing that the medication is ineffective
Two adolescents with asthma reported difficulty using the inhaler.
Several adolescents with asthma discussed the inconvenience of the medication regime.
Some adolescents with asthma were afraid of side effects from the medications.

**Category 20**

*When meeting health deviation requisites, a collaborative model of sharing the power and responsibility between health care professionals and individuals supports the engagement of self-care behaviours. However, not all individuals want to interact in this model.*

All Native women described strategies for taking care of self. For some women this included routine conventional health care.

Some Native women preferred to care for themselves rather than seek conventional services.

A few Native women chose to combine traditional and conventional approaches when taking care of self.

For Native women, breast self exams were a common strategy for taking care of self.

For Native women taking care of self also involved integrating natural practices.

For Native women the integration of natural practices strengthened their resolve to initially take care of their health needs themselves before seeking care from conventional providers.

Both Danes with MS (53%) and Americans (40%) with MS contacted a non-allopathic health care professionals such as a chiropractor for treatment of back problems.

Most adults/elderly people with COPD recognized the importance of their relationship with health care professionals for their well-being.

Most adults/elderly people with COPD were comfortable working in collaboration with their doctors in managing their illness.

Some adults with asthma used their management plan to determine the end point of self management when an ambulance would be called, although they tended to delay seeking help until they were at levels below those recommended by their plans.

For all adults with asthma the doctor played an important role in their asthma management and having a doctor who knew them, and they could trust, was helpful.

Adults/elders with colorectal cancer engaged in self-care behaviours to manage the physical impact and side effects of their treatment. Some individuals replied upon health care professionals for total support, others asked for help only when their own self-care behaviours no longer worked.

Collaborative model - some elders with asthma engaged in collaborative care in which management was a joint effort between them and the health care professional.

For low-income white women with HIV, nurses became the catalyst in 'switching things around' toward locating resources for self-care. Women began to search for a way to live with HIV and nurses assisted them in building relationships that supported their self-care practices.

**Category 21**
When meeting health deviation requisites family caregivers assisting their relatives to engage in self-care activities feel that health care professionals do not acknowledge their roles or value their input regarding care.

Most family assisting individuals with mental disease engage in self-care said that their knowledge of when their family member's self-management was faltering and how best to manage this change in status was ignored or devalued by health professionals.

**Synthesis topic 8**

**Accepting the disability or disease as part of life**: When meeting health deviation requisites, individuals engage in self-care when they are able to find symbolic meaning in the disability/disease or are able to reframe the implications positively; have a positive sense-of-self; acknowledge the emotional dimension of their condition; maintain a balance in their lives; and have the capacity to integrate spiritual support if so desired.

**Category 22**

When meeting health deviation requisites, the capacity to find symbolic meaning in the disability/disease or reconstruct the implications positively facilitates the individual’s engagement in self-care by providing hope for the future, strengthening coping mechanisms, enabling a positive sense-of-self, allowing the individual to acknowledge the vulnerability that accompanies the disability/disease but still maintain a balance in their lives in which the individual is seen as focus not the condition.

Health deviation - children with cancer coped by altering their self image or modifying their self-concept.

Health deviation - children with cancer adjusted to living with the long term effects of the disorder and its therapy.

Holding on to the present self - recognizing themselves as aging women with OA, living with the pain.

Holding on to ableness - all aging women with OA desired to hold onto their capability and competence in moving which they achieved through exercise and movement.

Holding on to being interested and being interesting - aging women with OA remained engaged in the world by maintaining an attitude of growth.

Some elders (9/28) with diabetes strived to retain a sense of normalcy beyond diabetes and just do things which they felt enhanced their sense of overall well-being.

Both Danes with MS and Americans with MS practiced self-care because it empowered them.

All African-American women with HIV saw themselves as being strong women who came from a tradition and heritage of women who were also strong.

To take care of themselves, many of these older women who were HIV infected looked inward and drew on strengths they had developed during a lifetime.

Adults with disabilities were required to re-evaluate their lives and what was truly important, find meaning with the disability, engage in new interests less in conflict with the disability and, conversely, not feel bitter about what has been lost because of the disability.
Adults with disabilities minimized or ‘played down’ the personal threat enforced by the illness and/or disability. They strived to turn negative aspects of the disability into hope giving and positive experiences. They often compared themselves with others who were more afflicted.

Mexican patients with diabetes evaluated the achievement of their self-care goals by assessing how well they feel and how well they are able to maintain their normal activities rather than on their glucose levels.

Adults with chronic illness who were not able to find symbolic meaning in their illness were not able to embrace self-care behaviours. Instead they searched for cures, blamed doctors for not fixing them or gave up on life.

Adults with chronic illness who were able to find symbolic meaning in their illness were able to adopt self-care behaviours.

Adults with chronic illness who had found meaning in their illness were able to tune in to self-care teaching given by health care professionals.

Adults with chronic illness who had found meaning in their illness were able to integrate the various strands of self-care messages together and perceive the management of their illness as a whole.

Adults with chronic illness who had not accommodated to their illness saw themselves as incapacitated, whereas those who found meaning in their illness were able to be active in managing their illnesses, and reframe their experience from being 'sick' to being normal.

Adult/elderly men with COPD adapted to the condition by changing perspectives and getting used to the symptoms.

Most adults/elderly people with COPD needed to find a balance between living life and disease management.

For many adults with schizophrenia and diabetes, acknowledging their vulnerability to mental illness was the first step in mastering the illness.

For adults recovering from SCI, recapturing self-care was perceived as training, and self-care was seen as part of rehabilitation.

For adults recovering from stroke, self-care was something ordinary to do in their everyday life and in their drive for independence, they reclaimed self-care activities with or without their affected limb. Training was seen as an activity focused on body functions.

For some adults recovering from stroke, self-care activities were strongly related to their identity. Changes in their ability to perform these activities challenged their attempts to reconnect with and express themselves through past identities.

For adults/elders with colorectal cancer it was important to preserve their identity and maintain a sense of normality in daily life. Self-care strategies included continuing with social routines, adapting to changes in physical appearance and retaining their roles within the family.

Mobilizing resources - adults/elders with arthritis needed to identify, understand and
make the most of what was available to help them to live well

Shift in identity - adults/elders with arthritis experienced a profound loss of self and had to develop an altered perception of self such that illness may become a part of life

Adults/elders with arthritis incorporated balancing, pacing, planning and prioritizing into their self-care activities to cope with the fluctuations in pain and functional capacity

Adults with multiple chronic illnesses negotiated symptoms and symptom management and valued social roles such as 'being a worker'. Being employed was important for their identities and their striving to 'not give in' to the illness.

The majority of expert patients described themselves as systematically organized in terms of the self-management of their condition, such as maintaining a drug regimen, as well as the work involved in minimizing the impact of the condition on their lifestyle.

For low-income white women with HIV caring about self was central to the development of self-care attitudes and practices. Women who experienced a loss of self failed to engage in proactive self-care strategies.

In response to their diagnosis, low-income white women with HIV grappled with alienation from self and others. They went through a process of focusing, an investment in self and in self-care, characterized by searching for a sense of self. To engage in self-care women had to confront the loss of self that kept them from practicing self-care. They did this by either hiding – not telling or selective telling.

For low-income white women with HIV, investing meaning in self-care meant searching for what was important in life, and involved creative strategies for living while facing death.

For low-income white women with HIV, finding meaning also involved planning for the future. This creativity captures the complexity of incorporating others’ needs into their own self-care

Category 23
When meeting health deviation requisites, for some individuals, spirituality and faith are important components of self-care

Older women with HIV embarked on self-care by caring not only for the physical body but the heart, mind, and soul as well

Self-care for a majority of the older women with HIV also entailed having faith in God. This faith was not dependent on church membership or religious affiliation... Although HIV diagnosis brought with it spiritual turmoil, over time most came to view themselves in personal relationship with God

One Native woman embraced traditional beliefs, specifically spirituality into her approach to health care

Spirituality was especially important for breast cancer survivors. For these Native women spiritual beliefs and practices provided the strength during their treatment and recovery

Many Latinos with diabetes acknowledged the importance of the role of spirituality and faith in their lives
For all of the African-American women with HIV spirituality and religious practices were significant means of self-care that provided healing and strength to get through difficult times, and acceptance of themselves and their lives with HIV/AIDS

**Category 24**

*When meeting health deviation requisites, emotions are seen as an important component of self-care. Individuals recognize the need to acknowledge and express their feelings of hope and despair*

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<td>Danes with MS were able to receive emotional care from their doctors whereas Americans with MS found their doctors either prescribed drugs or referred them to psychologists</td>
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<td>Almost all American with MS found talking to their spouse or another person to be an effective coping mechanism whereas very few Danes did so, being unwilling to share their negative feelings</td>
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<td>In response to loneliness and isolation, most Americans with MS tried to understand more about their illness through reading or talking to others, while very few Danes with MS did so</td>
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<tr>
<td>For adults/elderly people with COPD the emotional adjustment to living with the condition was important in facilitating their physical survival</td>
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<td>For adults with schizophrenia and diabetes ‘hope’ represented their goals for the future and expectations of positive outcomes resulting from self-care</td>
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<td>Australian adults with diabetes saw managing their diabetes as a process of coping with loss</td>
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<td>For Turkish and Arabic adults, self-managing diabetes was a process of staying calm and attending to one's emotional balance</td>
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<td>Turkish and Arabic adults with diabetes who sought to maintain calm and avoid stress, tended to look for reassurance in the relationship with the health professional</td>
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<td>Adults/elders with colorectal cancer distinguished between self-care activities they carried out to deal with the physical and the emotional impacts of chemotherapy. Emotional self-care activities included strategies related to helping to learn what to expect from the therapy.</td>
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<td>Many expert patients described how over time they learned not to discuss their emotional needs within the medical consultation but kept to strict biomedical boundaries, thus compartmentalizing emotion away from the medical encounter</td>
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<td>For low-income white women, having HIV meant investing emotions in self-care, capturing the movement through emotions of despair and the development of self-confidence in expressing feelings</td>
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**Synthesis topic 9**

*Embracing on self-care and overcoming challenges:* When meeting health deviation requisites, acquiring knowledge, perceiving oneself as being in control and receiving support from others motivates the performance of self-care. Numerous resources have to be mobilized to overcome challenges such as stigma, financial and workplace
When meeting health deviation requisites, the motivation to engage in self-care behaviours includes family and social roles, especially role of mothering (particularly to an ill child), support of others, role models with the same condition who lead effective lives, comparison with other who were worse off, valuing health, positive consequences of self-care behaviours and the desire to decrease the pain or discomfort caused by the condition or its treatment.

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<tr>
<th>Constraint</th>
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<tr>
<td>Category 25</td>
<td>Having a role model - children with diabetes felt that having a friend or celebrity that had diabetes, made them feel better about themselves</td>
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<td>For both socioeconomically vulnerable and non vulnerable adults caring for family members and others was important</td>
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<td>Elders with diabetes often described their motivations for self-management couched in aspects of life goals, and in functional rather than biomedical terms</td>
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<td>The majority of elders with diabetes displayed an &quot;external&quot; motivation for self-care by comparison with others</td>
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<td>The majority of elders with diabetes made downward comparisons to others who were doing poorly in comparison to themselves</td>
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<td>Very few elders with diabetes made upward comparisons to others doing better than themselves as motivation to improve health behaviours</td>
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<td>Elders with diabetes used comparisons with others to promote their awareness and understanding of risks</td>
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<td>Comparison with others could also provide elders with diabetes with a sense of empowerment</td>
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<td>Most Latinos with diabetes turned to others when in need and felt they gained tremendous strength from family and friends</td>
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<td>To cope with loneliness or alienation, Danes with MS joined activity groups, where participants rode horseback, swam, and traveled together. Americans with MS joined mutual aid groups, whose members provided support, encouragement, and information to each other</td>
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<td>For African-American women with HIV providing for their children was the first priority, ensuring that they had shelter, food, clothing, education, and health care, as well as love, affection, and attention. For the child who was HIV positive mothers were also responsible for the child’s health care, a large part of which was giving medications</td>
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<td>For African-American women with HIV, Maintaining supportive relationships with family was a method by which the women were able to sustain and maintain some semblance of health</td>
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<td>For African-American women with HIV, mothering was inextricably linked to self-care and was a motivation for staying healthy and for continuing to live. All of the women talked about the importance of taking care of themselves so that they might live to see their children graduate from high school.</td>
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</table>
Adults with disabilities report the importance of having close and supportive relationships with family, friends or relatives – a realization that they have people around them that care about them despite their disability. They found it was important not to be ashamed of asking for help when they needed it.

Adults with disabilities tried not to worry about the personal threats from the disability, but still changed the situation or themselves along with progressions of the disability. Similarly, they tried to do as much as possible by their own force, but also to trusted and found support from others.

Families caring for individuals with mental illness indicate that their relatives need significant support in order to develop self-care practices.

When coming to terms with their illness, adults with chronic illness compared themselves to others who were worse off.

Adults with chronic illness found positive aspects in their situations by identifying others with similar health problems who were living particularly effective and worthwhile lives.

Adult/elderly men with COPD select self-care behaviours for their daily activities and exercise based on past experiences.

Adult/elderly people with COPD were motivated to survive their illness for the sake of family.

Adults/elderly people with COPD were motivated to continue or enhance their self-care behaviours when comparing themselves to others, some who achieved more and others who were worse off than them.

When taking responsibility for their illnesses, adults with schizophrenia and diabetes recognized the need to continuously engage in consistent self-care. They engaged in self-care for dual illnesses because they valued health and their own future.

Adults recovering from SCI used previous experiences to find new ways of performing self-care, whereas adults recovering from stroke sought to be the way they had been before their stroke.

Some adolescents with asthma responded positively to social support - support from others who had asthma or knew about asthma (family, friends, teachers, health care professionals).

For adolescents with spina bifida, self-management was helped by sharing decision making to enhance optimal outcomes.

**Category 26**

*When meeting health deviation requisites, individuals encounter numerous challenges and constraints which hamper their self-care behaviours. These include financial limitations, workplace constraints, co-morbid conditions, health care professionals who were disempowering, costs and time wasted to attend appointments, habitual lifestyle patterns, stigma of their condition, and a sense of helplessness. Individuals need to mobilize many resources to overcome these challenges.*

For adolescents with spina bifida, self-management experiences entailed confronting discrimination and stigma and embracing self-advocacy.

For adolescents with spina bifida, self-management experiences entailed confronting...
| discrimination and stigma and accepting peer and adult advocacy |
| For aging women living with OA life is having difficulties |
| Most individuals in the socioeconomically vulnerable group reported difficulty affording their medication copayments and both medications and food were sometimes insufficiently available |
| Older women with HIV and insufficient incomes found it hard to buy the so-called right foods, vitamins were also unaffordable |
| For some older women, contending with physical symptoms was complicated, because HIV and/or AIDS was superimposed on other chronic conditions, compounding symptom experience |
| Latinos with diabetes expressed a perception of limited capacity to manage their diabetes citing the ongoing difficulty of breaking familiar habits and usual routines |
| Most Latinos with diabetes spoke of the challenges of changing dietary behaviours while keeping their spouse or children happy |
| Latinos with diabetes talked about the many other medical conditions they had, which prevented them from being able to manage in their daily lives |
| Many Latinos with diabetes reported financial constraints that impeded their diabetes self-care |
| Latinos with diabetes reported constraints in the workplace that did not allow them to adequate time to eat regularly |
| Use of a wheelchair to conserve energy was seen as enabling by Americans with MS (56%) and as a potential trigger for pity by the Danes with MS (31%) |
| Americans with MS rearranged their living environment to prevent falls more often than Danes with MS |
| In response to depression Americans with MS took specific steps to avoid fatigue more often than Danes with MS |
| In response to urinary problems most individuals with MS adapted by drinking less or wearing protective pads to minimize accidents. Additionally, the majority of American respondents took medications, and had learned to recognize symptoms of urinary tract infection to avoid dangerous complications |
| In response to vision disturbances, a majority of Americans (57%) with MS took medications compared to 15% of Danes with MS |
| Danes with MS were able to move to housing that accommodated their degree of disability (subsidized in Denmark), while Americans with MS were more likely to adapt current housing to their needs |
| Most of the African-American women with HIV worked minimum-wage jobs that were physically demanding and insecure |
| For some African-American women with HIV, having sufficient resources to provide for their children was challenging |
| For African-American women with HIV, a key dimension of their mothering role was protecting their children against the stigma of HIV |
Poor African-American women with HIV did not have the time, freedom, energy, and financial resources to follow prescribed methods of self-care. Most adults with disabilities reported the importance of maintaining a belief in one’s capacity to master challenges caused by the disability; to be independent and fight feelings of helplessness. Adults with disabilities engaged in the disability and took action to reduce or circumvent the problems created by or connected to the disability. They maintained a conviction that change and relief were possible and fought feelings of passivity or ‘giving up’. Mexican patients with diabetes found it particularly difficult to establish dietary changes on their limited budgets. For adults/elderly people with COPD conserving energy required a lot of planning and pacing of activities. Adults with schizophrenia and diabetes reported 'doing the best they can' to overcome the constraints placed upon them from two illnesses. For adults with schizophrenia and diabetes, economic constraints were a major factor in their ability to manage their illnesses. Many adults with schizophrenia and diabetes frequently lacked the basic necessities because of financial problems. Adults with schizophrenia and diabetes emphasized the importance of perseverance to overcome financial constraints and economic barriers to self-care. Several adults with schizophrenia and diabetes regularly relied on community resources or assistance from aging parents. Adults with schizophrenia and diabetes were aware of the efforts required to conduct adequate self-care despite the challenges they faced. Australian adults with diabetes had an emotional response to being diagnosed with diabetes and acknowledged the ongoing challenge involved in sustaining strategies of self-care. Recognizing and monitoring boundaries - for adults/elders with arthritis, pain created the boundaries in everyday activities and would remind them that their bodies could not consistently be relied upon. Adults with multiple chronic illnesses expressed frustration around their symptoms, and the impact of their illnesses on their daily lives. Adults/elders with diabetes agreed that another constraint to participatory decision making was the costs associated with long waiting times for appointments. They often had to leave work, find child care and pay parking costs in order to attend appointments.

**Category 27**

When meeting health deviation requisites, self-care was enhanced when individuals perceived they had control over themselves and control over their condition. The environment was seen as being beyond control but self-care behaviours were engaged in to minimize the effect of the environment.
Some adolescents with asthma recognized their limited ability to control their environment.

Aging women with OA held on by purposefully choosing and acting - maintaining control and modifying their self-care activities.

For aging women with OA choosing whether to take medication or not allowed them some control of their health care.

A small number of elders with diabetes displayed an "internal" motivation for self-care by referring to personal goals that were driving them toward self-care.

Elders equated participation in their care and being involved in self-care with being independent.

For some older women with HIV, a sense of responsibility and control over their destinies helped them deal with being infected with HIV.

In response to information of poor metabolic control Swedes with diabetes increased self-monitoring and related the condition to habits such as diets and stress.

In response to information of poor metabolic control Yugoslavs with diabetes related the condition to wrong diet or fate.

Individuals in both groups engaged in self-care practices because it gave them a feeling of independence. Other reasons included the belief that some practices may keep their symptoms from getting worse, having a feeling of security and the reassurance of knowing they were helping themselves, and having a routine to follow.

Mexican patients with diabetes stated their main goal was to get control of their diabetes, despite their highly stressed lifestyles. They wanted to figure out exactly what they needed to be doing and finding ways they could do it.

Mexican patients with diabetes balanced their management of their condition by a dual concept of control, control of diabetes and self-control, which they termed ‘taking care of myself’.

Adult/elderly men with COPD were aware of the impact of the environment on their symptoms and avoided going to places with poor air quality.

Turkish and Arabic adults with diabetes spoke predominantly of the need to manage their daily lives to avoid or minimise stress, which they saw as causative.

All adults recovering from stroke or SCI sought to reclaim control over their bodies and activities in their daily life.

Self-agency model - for some elders with asthma taking control of their own lives was crucial and indicated a strong focus of self-management of the condition. They took action to deal with the asthma as part of every day life.

All adults with epilepsy engaged in self-care activities to cope with the disease, such as setting up prompts for medication administration, ensuring they received sufficient sleep, planning each day ahead in detail, and telling people they had epilepsy.

**Category 28**

*When meeting health deviation requisites, for some individuals, knowledge of the*
**condition was considered important prior to engaging in self-care**

For some adolescents with asthma symptom recognition and knowledge acquisition was enhanced by exposure to multiple educators.

Aging women with OA held on by seeking to know about arthritis and how to perform self-care and be self-caring.

Socioeconomically vulnerable adults had limited knowledge of prescription medications and health care.

Elders reported limited opportunity for participation in their self-care with examples such as: not being listened to, not being given sufficient information, and medication administration.

Elders received insufficient information to be active in their care - information was 'not being passed on' due to lack of time.

Not receiving sufficient information impacted the elders’ self-care once back home - due to communication problems such as 'speaking over the top of you' when health professionals spoke amongst themselves and not to the consumer; foreign accents and hearing problems.

Several Native women who had strong connections to their Native heritage identified Native elders and medicine people as sources of health information.

Beliefs about diabetes - Yugoslavs provided rather intangible examples regarding explanation about diabetes.

Beliefs about diabetes - Swedes provided more specific knowledge of diabetes. Factors related to the individual and their behaviours.

Potential causes of diabetes, Swedes with diabetes gave more alternatives, focusing on genetic factors, obesity, infection, drugs, etc.

Potential causes of diabetes, Yugoslavs with diabetes mentioned factors in the social sphere (disturbed relations) and supernatural causes mainly expressed as fate and evil spirits.

As a response to tiredness, feebleness, being "out of sorts" in combination with loss of appetite Swedes with diabetes acted specifically with hyperglycemia as the cause.

As a response to tiredness, feebleness, being "out of sorts" in combination with loss of appetite Yugoslavs with diabetes acted with both hypoglycemia and hyperglycemia as the cause.

Swedes with diabetes treated peripheral neuropathy by addressing footwear whereas Yugoslavs with diabetes addressed the circulatory system.

Most of the individuals with MS ate a balanced diet; some Danes with MS increased their alcohol consumption whereas Americans with MS decreased it.

Some adults with asthma changed their asthma self-care behaviours after an exacerbation and hospitalization, but not all individuals recognized the need to change their self-care behaviours.

Adults with schizophrenia and diabetes applied their acquired knowledge of mental illness to diabetes care. They understood the implication of adherence to medication.
regimes and recognized that stability of their psychiatric symptoms was a crucial precursor to effective diabetic self-care.

Australian adults with diabetes who sought discipline and disease control, focused primarily on acquiring knowledge and looked for the best health professional to provide that information.

Adults recovering from stroke or SCI described the early rehabilitation process as ‘becoming familiar with a new body’. This phase was characterized by passive receiving in the form of assistance with self-care.

Expert patients described their communication with doctors in terms of being clear and succinct. They were very precise in what they wanted to gain from the consultation.

For adolescents with spina bifida, opportunities to engage in self-management activities required specialized knowledge and skills related to managing SB.

For adolescents with spina bifida, opportunities to engage in self-management activities required general skill building tasks to achieve independence.

Adults/elders with diabetes who had poor glycemic control appeared to have an insufficient understanding of self-care. They over simplified the rules (bread is bad, vegetables are good); had a poor understanding of the purpose of recommended self-care; and little understanding of the functional dynamics of glucose control.

Adults/elders with diabetes who had moderate glycemic control appeared to understand the basics and attempted to make sense of the principles behind self-care. However, they had difficulty in complex and atypical situations.

Adults/elders with diabetes who had good glycemic control appeared to have a detailed understanding of the requirements of self-care, knew why each of the actions they took were effective, and viewed diabetes as a dynamic control system involving taking actions, monitoring feedback, and adjusting activity accordingly.

**Category 29**

*When meeting health deviation requisites, family caregivers assist their relatives to establish a sense of self, personal identity and self-esteem. Family caregivers provide the support needed by their relatives to develop self-care practices.*

The family's role in caring or managing an individual with mental disease was seen as both practical - eating, taking meds; and complex - providing emotional and psychological support.

Families caring for individuals with mental disease went beyond normal care routines to perform activities their relative was unable, such as handling finances, providing transport, and ensuring they were occupied each day.

Families caring for individuals with mental illness were concerned with their relative either developing or negotiating independence.

Families caring for individuals with mental illness assisted their relatives with retaining a sense of self, of personal identity and self-esteem.
Appendix L – Search Decision Flow Diagram

Total # of citations found 9,560

# of studies meeting inclusion criteria

169 MEDLINE 1999
37 CINAHL 739
19 EMBASE 2354
17 PsycInfo 1038
13 AMED 630
0 Cochrane 14
2 Dissertn abstracts 419
3 Socialog Abstracts 317
0 Scirus 525
0 Mednar 1525

Combined number of studies 273 minus 13 duplicates Total 260 full reports retrieved

Studies discarded: Off topic 162

98 plus 41 from hand searching 139

Removed: Not discussion papers 58

Studies excluded: No definition of self-care 6

Final number of studies included in review 75

Hand searching
Disability & Society
Disability & Rehab
Rehab Nursing
Rehab Management
Care Management Journals
Int. Journal of Rehab Research
Jnl Social Work in Disability & Rehab
Reference Lists
Total 41
Appendix M – Meaning of Self-Care - Included Studies

1 Albert NM. Promoting self-care in heart failure: state of clinical practice based on the perspectives of healthcare systems and providers. [Review] [38 refs]. Journal of Cardiovascular Nursing 2008 May;23(3):277-84.


Appendix N – Meaning of Self-Care - Excluded Studies

   Reason for exclusion: No definition of self-care

   Reason for exclusion: No definition of self-care

   Reason for exclusion: No definition of self-care

   Reason for exclusion: No definition of self-care

   Reason for exclusion: No definition of self-care

   Reason for exclusion: No definition of self-care
### Appendix O – Meaning of Self-Care - Details of Included Studies (n=75)

<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>Country</th>
<th>Type Of Text</th>
<th>Purpose of Paper</th>
</tr>
</thead>
<tbody>
<tr>
<td>World Health Organization</td>
<td>2009</td>
<td>Thailand</td>
<td>conference proceeding</td>
<td>To discuss self-care in the context of primary health care</td>
</tr>
<tr>
<td>Albert</td>
<td>2008</td>
<td>U.S.A.</td>
<td>review</td>
<td>To summarize what is known about self-care from the perspective of health care system personnel and health care professionals</td>
</tr>
<tr>
<td>Wilkinson</td>
<td>2008</td>
<td>New Zealand</td>
<td>review</td>
<td>This paper explores the development of the concept of self-care through health related literature and reviews the factors that have shaped the concept</td>
</tr>
<tr>
<td>McGowan</td>
<td>2007</td>
<td>encyclopedia</td>
<td></td>
<td>Definition of self-care</td>
</tr>
<tr>
<td>Hoy</td>
<td>2007</td>
<td>Denmark</td>
<td>review</td>
<td>To review the literature related to self-care and health promotion for elders and to develop an understanding of self-care as a health resource</td>
</tr>
<tr>
<td>Redman Health Canada</td>
<td>2007</td>
<td>U.S.A.</td>
<td>discussion paper</td>
<td>The purpose of this paper is to examine ethical issues facing the self-management movement as it is currently conceptualized and being practiced, urging ways in which these issues must be addressed as the movement continues to evolve.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Canada</td>
<td>report</td>
<td>A committed and growing group of health care professionals and consumers in Canada has been working to describe and implement a more effective approach to health care, an approach involving the collaboration of health care professionals and consumers.</td>
</tr>
<tr>
<td>Kendall</td>
<td>2007</td>
<td>Australia</td>
<td>discussion paper</td>
<td>The aim of this paper is to critically appraise the principles of the CDSMP as a national self-care policy initiative in the context of existing formations and ideological approaches to self-care.</td>
</tr>
<tr>
<td>Cayton</td>
<td>2006</td>
<td>United Kingdom</td>
<td>review</td>
<td>To discuss the concept of individuals as co-creators in their own health</td>
</tr>
<tr>
<td>Webber</td>
<td>2006</td>
<td>United Kingdom</td>
<td>discussion paper</td>
<td>To identify the potential impacts and implications for physicians of the increasing prevalence of self-care.</td>
</tr>
<tr>
<td>Richards</td>
<td>2006</td>
<td>Switzerland</td>
<td>monograph</td>
<td>This monograph considers the role of nurses in promoting and maintaining health through self-care and through responsible self-medication using over-the-counter medicines</td>
</tr>
<tr>
<td>Non prescription Drug Manufacturers of Canada</td>
<td>2005</td>
<td>Canada</td>
<td>report</td>
<td>A report of the self-care health products industry in Canada</td>
</tr>
<tr>
<td>Author</td>
<td>Year</td>
<td>Country</td>
<td>Type Of Text</td>
<td>Purpose of Paper</td>
</tr>
<tr>
<td>--------------------------------</td>
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</tr>
<tr>
<td>Department of Health</td>
<td>2005</td>
<td>United Kingdom</td>
<td>report</td>
<td>This compendium sets out to draw together evidence from service models in the UK and elsewhere, together with published articles and reports, to consider how self-care support models might be more widely transferred and used.</td>
</tr>
<tr>
<td>Tanner</td>
<td>2004</td>
<td>U.S.A.</td>
<td>review</td>
<td>To discuss the chronic illness demands for self-management in older adults</td>
</tr>
<tr>
<td>Non prescription Drug Manufacturers of Canada</td>
<td>2004</td>
<td>Canada</td>
<td>report</td>
<td>Report of a weekly omnibus poll of 1,058 Canadian adults nationwide about issues related to self-care</td>
</tr>
<tr>
<td>Sidani</td>
<td>2003</td>
<td>Canada</td>
<td>book chapter</td>
<td>To review the available literature on self-care to determine the extent to which self-care is an outcome that is sensitive to nursing.</td>
</tr>
<tr>
<td>McCormack</td>
<td>2003</td>
<td>Canada</td>
<td>discussion paper</td>
<td>To describe the origin of self-care, examining the response of the nursing discipline to citizen self-care initiatives and the subsequent effects this response has had on the development of nursing knowledge.</td>
</tr>
<tr>
<td>Schilling</td>
<td>2002</td>
<td>U.S.A.</td>
<td>concept analysis</td>
<td>An evolutionary concept analysis was undertaken to clarify the concept of self-management of type 1 diabetes in children and adolescents</td>
</tr>
<tr>
<td>Leenerts</td>
<td>2002</td>
<td>U.S.A.</td>
<td>review</td>
<td>The purpose of the current analysis was to synthesize knowledge about self-care in older community-dwelling people, identify essential dimensions of self-care related to health promotion and well-being in aging, and to organize the findings into an integrated model with applicability to practice, research, and education.</td>
</tr>
<tr>
<td>Shore</td>
<td>2001</td>
<td>U.S.A.</td>
<td>discussion paper</td>
<td>To discuss the concept of empowering individuals as carers of their own health</td>
</tr>
<tr>
<td>Orem</td>
<td>2001</td>
<td>U.S.A.</td>
<td>book chapter</td>
<td>To discuss the Self-Care Deficit Nursing Theory and its integration into the processes of nursing practice</td>
</tr>
<tr>
<td>Mullett</td>
<td>2000</td>
<td>Canada</td>
<td>report</td>
<td>To report on the efficacy of self-care resources to enhance individuals’ self-care skills and to gather information that would be helpful in implementing a larger scale program</td>
</tr>
<tr>
<td>World Self-Medication Industry</td>
<td>1999</td>
<td>United Kingdom</td>
<td>report</td>
<td>To discuss elements of a number of government policies promoting better health through responsible self-medication</td>
</tr>
<tr>
<td>Konrad</td>
<td>1998</td>
<td>U.S.A.</td>
<td>book chapter</td>
<td>To discuss and explore the patterns of self-care among older adults in western industrialized societies</td>
</tr>
<tr>
<td>Stoller</td>
<td>1998</td>
<td>U.S.A.</td>
<td>book chapter</td>
<td>To explore the social context of self-care practices in old age, including the role of informal support networks, environmental factors, and situational contexts in facilitating or impeding the likelihood of</td>
</tr>
<tr>
<td>Author</td>
<td>Year</td>
<td>Country</td>
<td>Type Of Text</td>
<td>Purpose of Paper</td>
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</tr>
<tr>
<td>Dean</td>
<td>1998</td>
<td>Denmark</td>
<td>book chapter</td>
<td>To provide an overview of the international perspectives on self-care research.</td>
</tr>
<tr>
<td>McColl</td>
<td>1998</td>
<td>Canada</td>
<td>book chapter</td>
<td>To propose a broader definition of caring for the self, including not only the physical self, but also the emotional, intellectual and spiritual self.</td>
</tr>
<tr>
<td>Soller</td>
<td>1998</td>
<td>U.S.A.</td>
<td>review</td>
<td>To discuss the evolution of self-care with over-the-counter medications.</td>
</tr>
<tr>
<td>Health Canada</td>
<td>1998</td>
<td>Canada</td>
<td>report</td>
<td>To provide separate proceedings of the two supporting self-care workshops and a summary of the main barriers and the key avenues for action identified by the participants.</td>
</tr>
<tr>
<td>World Health Organization</td>
<td>1998</td>
<td>Switzerland</td>
<td>report</td>
<td>To discuss the role of the pharmacist in the health care system.</td>
</tr>
<tr>
<td>Henry</td>
<td>1997</td>
<td>U.S.A.</td>
<td>review</td>
<td>The purpose of this article is to review the evidence linking variations in care delivery system with achievement of appropriate self-care.</td>
</tr>
<tr>
<td>Health Canada</td>
<td>1997</td>
<td>Canada</td>
<td>report</td>
<td>To conduct a study to explore how nurses and physicians stimulate and support self-care.</td>
</tr>
<tr>
<td>Lachman</td>
<td>1996</td>
<td>U.S.A.</td>
<td>review</td>
<td>To provide a review of the theory underlying self-care and the influence of related disciplines on the concept. This review also examines the concept of stress and focuses almost exclusively on studies that suggest helpful coping mechanisms for nurses in the workplace.</td>
</tr>
<tr>
<td>Dean</td>
<td>1995</td>
<td>Denmark</td>
<td>conference proceedings</td>
<td>To discuss the emergence of the concept of self-care and the reasons for its relative lack of acceptance.</td>
</tr>
<tr>
<td>Easton</td>
<td>1993</td>
<td>U.S.A.</td>
<td>discussion paper</td>
<td>To present an overview of self-care theory as described by Henderson, Hall, and Orem, and to discuss the application of self-care in clinical practice.</td>
</tr>
<tr>
<td>Northrup</td>
<td>1993</td>
<td>U.S.A.</td>
<td>discussion paper</td>
<td>To elucidate the social and political construction of nursing knowledge with a view to self-care.</td>
</tr>
<tr>
<td>Padula</td>
<td>1992</td>
<td>U.S.A.</td>
<td>review</td>
<td>To review the concept of self-care and discuss its implications for the elderly.</td>
</tr>
<tr>
<td>Rourke</td>
<td>1991</td>
<td>United Kingdom</td>
<td>discussion paper</td>
<td>To explore the issue of self-care in relation to Orem's Self-Care Model of Nursing (1980) and Becker's Health Belief Model (Becker &amp; Rosenstock 1984), highlighting possible areas of difficulty in practice and offering strategies to increase patient motivation for health.</td>
</tr>
<tr>
<td>Sorofman</td>
<td>1990</td>
<td>U.S.A.</td>
<td>discussion</td>
<td>This article presents a model of self-care within the context of a response to a symptom.</td>
</tr>
<tr>
<td>Author</td>
<td>Year</td>
<td>Country</td>
<td>Type Of Text</td>
<td>Purpose of Paper</td>
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</tr>
<tr>
<td>Gantz</td>
<td>1990</td>
<td>U.S.A.</td>
<td>discussion</td>
<td>To discuss self-care from the perspective of six disciplines</td>
</tr>
<tr>
<td>Hartweg</td>
<td>1990</td>
<td>U.S.A.</td>
<td>scholarship</td>
<td>The concept of health promotion self-care is developed after an analysis of statements by Pender and Orem for their logical congruence. Further in-depth analysis of Orem's model facilitates the placement of the new concept within its current structure. The potential strength of the model for guiding health promotion practice is discussed, as well as areas for needed development.</td>
</tr>
<tr>
<td>Raven</td>
<td>1989</td>
<td>Australia</td>
<td>discussion</td>
<td>To develop a personal conceptual framework with which to examine the nature of cares for people with developmental disability in group homes. The paper examines the nature of care and its corollary self-care, both in general terms as well as those specific to the field of developmental disability. It also analyses the nature of nursing and its relationship to the care and training of people with developmental disabilities.</td>
</tr>
<tr>
<td>Woods</td>
<td>1989</td>
<td>U.S.A.</td>
<td>review</td>
<td>To analyze the major conceptual orientations underlying empirical work published on self-care since 1980; to link the conceptual orientation of health underlying self-care literature to research approaches and the nature of research findings; and to suggest how contemporary conceptualization of self-care may facilitate or limit understanding of the relationship of self-care to health.</td>
</tr>
<tr>
<td>Dean</td>
<td>1989</td>
<td>Denmark</td>
<td>review</td>
<td>To discuss the conceptual, theoretical and methodological issues in self-care research</td>
</tr>
<tr>
<td>Kickbusch</td>
<td>1989</td>
<td>Denmark</td>
<td>discussion</td>
<td>To discuss the emergence of self-care in the context of health promotion</td>
</tr>
<tr>
<td>van Agthoven</td>
<td>1989</td>
<td>Netherlands</td>
<td>report</td>
<td>To discuss the interpretation of self-care, and compare the perspective of clients and home-nurses</td>
</tr>
<tr>
<td>Vickery</td>
<td>1986</td>
<td>U.S.A.</td>
<td>discussion</td>
<td>To review the concept of medical self-care and the relevant program models</td>
</tr>
<tr>
<td>Hickey</td>
<td>1986</td>
<td>U.S.A.</td>
<td>review</td>
<td>This paper reports some of the outcomes of an international project which reviewed geriatric self-care in different countries and health care systems.</td>
</tr>
<tr>
<td>Dean</td>
<td>1986</td>
<td>Denmark</td>
<td>review</td>
<td>To discuss lay care in illness with special reference to research and development in Northern Europe. The discussion concentrates on two components of lay care: individual self-care in illness and self-help groups.</td>
</tr>
<tr>
<td>Dean</td>
<td>1986</td>
<td>Denmark</td>
<td>book chapter</td>
<td>The purpose of the chapter is to focus on the components of self-care behaviour which generally have been neglected in research concerned with health and illness behaviour, and about which, therefore,</td>
</tr>
<tr>
<td>Author</td>
<td>Year</td>
<td>Country</td>
<td>Type Of Text</td>
<td>Purpose of Paper</td>
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</tr>
<tr>
<td>Green</td>
<td>1985</td>
<td>U.S.A.</td>
<td>discussion paper</td>
<td>To review conceptualizations of self-health management, or self-care, from three perspectives. Positions held (pro and con) on self-care, theoretical or definitional papers, and empirical usage of self-care were examined to isolate commonalities and differences in ideas about what self-health management or self-care are.</td>
</tr>
<tr>
<td>Orem</td>
<td>1985</td>
<td>U.S.A.</td>
<td>discussion paper</td>
<td>To describe concepts of self-care and rehabilitation and the relations between them.</td>
</tr>
<tr>
<td>Steiger</td>
<td>1985</td>
<td>U.S.A.</td>
<td>book chapter</td>
<td>To discuss the history of self-care, self-care today and the self-care perspective in nursing theory</td>
</tr>
<tr>
<td>Russell</td>
<td>1985</td>
<td>United Kingdom</td>
<td>review</td>
<td>To review the concept of self-care as it relates to illness</td>
</tr>
<tr>
<td>Green</td>
<td>1984</td>
<td>U.S.A.</td>
<td>review</td>
<td>To examine recent developments specifically in those applications leading to interventions designed to modify or develop health behaviour, and to highlight some issues of policy, ethics, and research confronting future applications of behavioural change in public health.</td>
</tr>
<tr>
<td>Knust</td>
<td>1983</td>
<td>U.S.A.</td>
<td>discussion paper</td>
<td>To describe the integration of self-care theory with rehabilitation nursing</td>
</tr>
<tr>
<td>Levin</td>
<td>1983</td>
<td>U.S.A.</td>
<td>discussion paper</td>
<td>To synthesize the modest understanding we now have of self-care, recognizing the theoretical and methodological limits of available data; and (b) to identify what appear to be productive directions for research and public health policies and programs</td>
</tr>
<tr>
<td>Grieco</td>
<td>1983</td>
<td>U.S.A.</td>
<td>discussion paper</td>
<td>To review some cultural and epidemiological factors leading to a new emphasis on self-care in chronic illness, and to provide some examples of applications of self-care in medicine.</td>
</tr>
<tr>
<td>DeFriese</td>
<td>1982</td>
<td>U.S.A.</td>
<td>discussion paper</td>
<td>To discuss the effects of self-care instruction and practice on the utilization of professional medical care</td>
</tr>
<tr>
<td>Verschure</td>
<td>1981</td>
<td>Netherlands</td>
<td>discussion paper</td>
<td>To discuss self-care within the context of good health and well being</td>
</tr>
<tr>
<td>Dean</td>
<td>1981</td>
<td>Denmark</td>
<td>review</td>
<td>This paper reviews literature concerned with self-care responses to illness. Questions arising from the data are discussed and future research needs are identified</td>
</tr>
<tr>
<td>Spradley</td>
<td>1981</td>
<td>U.S.A.</td>
<td>book chapter</td>
<td>To discuss the opportunities and challenges of community health nursing</td>
</tr>
<tr>
<td>Sullivan</td>
<td>1980</td>
<td>U.S.A.</td>
<td>discussion</td>
<td>To discuss the notion of self-care and the value of a model of self-care for nursing</td>
</tr>
<tr>
<td>Author</td>
<td>Year</td>
<td>Country</td>
<td>Type Of Text</td>
<td>Purpose of Paper</td>
</tr>
<tr>
<td>----------</td>
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<td>----------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>King</td>
<td>1980</td>
<td>U.S.A.</td>
<td>discussion paper</td>
<td>To familiarize nurse practitioners with the concepts of self-help and self-care</td>
</tr>
<tr>
<td>Kemper</td>
<td>1980</td>
<td>U.S.A.</td>
<td>discussion paper</td>
<td>Discussion of self-care in the context of health education and health promotion</td>
</tr>
<tr>
<td>Levin</td>
<td>1979</td>
<td>U.S.A.</td>
<td>conference proceeding</td>
<td>To present the results of the first international symposium on The Role of the Individual in Primary Health Care, in Copenhagen August 1975</td>
</tr>
<tr>
<td>Levin</td>
<td>1979</td>
<td>U.S.A.</td>
<td>conference proceeding</td>
<td>To discuss the emergence of self-care as the new challenge to individual health</td>
</tr>
<tr>
<td>Norris</td>
<td>1979</td>
<td>U.S.A.</td>
<td>discussion paper</td>
<td>To discuss self-care in relation to the health care system and nursing</td>
</tr>
<tr>
<td>Levin</td>
<td>1978</td>
<td>U.S.A.</td>
<td>conference proceeding</td>
<td>To discuss changes in the health care system and the emergence of self-care as a component of the health care system</td>
</tr>
<tr>
<td>Levin</td>
<td>1977</td>
<td>U.S.A.</td>
<td>discussion paper</td>
<td>To discuss the forces and issues in the revival of interest in self-care</td>
</tr>
<tr>
<td>Williamson</td>
<td>1977</td>
<td>United Kingdom</td>
<td>discussion paper</td>
<td>To delineate some useful characteristics of health care resources into a taxonomy aimed at facilitating investigations into the needs for health ward care</td>
</tr>
<tr>
<td>Levin</td>
<td>1976</td>
<td>U.S.A.</td>
<td>conference proceeding</td>
<td>To discuss the advances of self-care and the layperson as the primary health care practitioner</td>
</tr>
<tr>
<td>Levin</td>
<td>1976</td>
<td>U.S.A.</td>
<td>discussion paper</td>
<td>To summarize the discussions held during the International Symposium on Self-Care (Copenhagen); touching on why self-care is of such great interest today; what initiatives have been taken thus far; issues related to self-care that have aroused considerable interest; and research needs in self-care.</td>
</tr>
</tbody>
</table>
Appendix P – Intervention Strategies that Support Self-Care - Search Strategy

Comprehensive Medline search strategy formed the basis of all strategies.
Ovid MEDLINE(R) and Ovid OLDMEDLINE(R) 1948 to February Week 4 2010

1. exp *Disabled Persons/
2. *acute disease/ or *chronic disease/
3. *Health Care Sector/
4. exp *Health Policy/
5. or/1-4
6. exp *Self Care/
7. self care.mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
8. self?care.mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
9. self treatment.mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
10. lay care.mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
11. self maintenance.mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
12. (personal care adj3 service$).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
13. (personal care adj3 recipient).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
14. (personal care adj3 caregiver).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
15. self management.mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
16. or/6-15
17. (self care adj5 theoretical model).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
18. (self care adj5 framework).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
19. (self care adj5 model).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
20. (self care adj5 conceptual framework).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
21. (self care adj5 conceptual model).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
22. or/17-21
23. (self care adj5 chronic illness).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
24. (self care adj5 chronic disease).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
25. (self care adj5 comorbidity).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
26. or/23-25
27. (self care adj5 disability).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
28. (self care adj5 handicap$).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
29. (self care adj5 personal care).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
30. (self care adj5 activities of daily living).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
31. (self care adj5 disabled).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
32. or/27-31
33. (self care adj5 accident).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
34. (self care adj5 acute care).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
35. (self care adj5 emergency).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
36. or/33-35
37. 26 or 32 or 36
38. (self care adj5 industry).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
39. (self care adj5 commercial).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
40. (self care adj5 money).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
41. (self care adj5 pharmaceutical).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
42. (self care adj5 natural health product$).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
43. (self care adj5 supplement$).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
44. (self care adj5 assistive devices).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
45. (self care adj5 business).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
46. (self care adj5 financ$).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
47. or/38-46
48. (self care adj5 comprehend).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
49. (self care adj5 concept).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
50. (self care adj5 notion).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
51. (self care adj5 perceive).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
52. (self care adj5 understand).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
53. (self care adj5 belief).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
54. (self care adj5 believe).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
55. (self care adj5 comprehend$).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
56. (self care adj5 perception).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
57. (self care adj5 knowledge).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
58. (self care adj5 view).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
59. or/48-58
60. (self care adj5 doctor$).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
61. (self care adj5 physician$).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
62. (self care adj5 nurse$).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
63. (self care adj5 therapist$).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
64. (self care adj5 practitioner$).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
65. (self care adj5 provider$).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
66. (self care adj5 health care professional$).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
67. or/60-66
68. (self care adj5 caregiver$).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
(self care adj5 care recipient$).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]

(self care adj5 informal care).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]

(self care adj5 formal care).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]

or/68-71

(self care adj5 policy).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]

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(self care adj5 power).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]

(self care adj5 political).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]

or/73-78

5 and 16

37 or 47 or 59 or 67 or 72 or 79

80 or 81

"cochrane database of systematic reviews".jn.

82 and 83
Appendix Q – Assessment of Methodological Quality

JBI Critical Appraisal Checklist for Systematic Reviews

<table>
<thead>
<tr>
<th>Reviewer</th>
<th>Date</th>
<th>Author</th>
<th>Year</th>
<th>Record Number</th>
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</thead>
<tbody>
<tr>
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</tbody>
</table>

1. Is the review question clearly and explicitly stated? [ ] Yes [ ] No [ ] Unclear

2. Was the search strategy appropriate? [ ]

3. Were the sources of studies adequate? [ ]

4. Were the inclusion criteria appropriate for the review question? [ ]

5. Were the criteria for appraising studies appropriate? [ ]

6. Was critical appraisal conducted by two or more reviewers independently? [ ]

7. Were there methods used to minimise error in data extraction? [ ]

8. Were the methods used to combine studies appropriate? [ ]

9. Were the recommendations supported by the reported data? [ ]

10. Were the specific directives for new research appropriate? [ ]

Overall appraisal: [ ] Include [ ] Exclude [ ] Seek further info. [ ]

Comments (Including reasons for exclusion)

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

369
## JBI Data Extraction Form for Systematic Review of Experimental/Observational Studies

<table>
<thead>
<tr>
<th>Reviewer</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Author</td>
<td>Year</td>
</tr>
<tr>
<td>Journal</td>
<td>Record Number</td>
</tr>
</tbody>
</table>

### Included studies
- [ ] RCT
- [ ] Quasi-RCT
- [ ] Longitudinal
- [ ] Retrospective
- [ ] Observational
- [ ] Other: ____________

### Participants
- Setting: ______________________________________
- Population: __________________________________

### Interventions

<table>
<thead>
<tr>
<th>Intervention 1</th>
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<td>____________________________</td>
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<table>
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<th>Intervention 3</th>
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<td>____________________________</td>
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### Clinical outcome measures

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<th>Outcome Description</th>
<th>Scale/measure</th>
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### Meta-analysis results

#### Dichotomous data

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<tr>
<th>Outcome</th>
<th>Intervention ( )</th>
<th>Intervention ( )</th>
<th>Statistic: Combined measure (CI)</th>
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</thead>
<tbody>
<tr>
<td></td>
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<td>number / total number</td>
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</tbody>
</table>

#### Continuous data

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Intervention ( )</th>
<th>Intervention ( )</th>
<th>Statistic: Combined measure (CI)</th>
</tr>
</thead>
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<td>number / total number</td>
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</tbody>
</table>

### Summary of Narrative Results

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### Authors Conclusions

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### Comments

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- 
- 

Appendix S – Adapted Data Extraction Instrument
Appendix T – Search Decision Flow Diagram

Medline/Cochrane Database of Systematic Reviews as Journal 1948-Feb week 4 2010
3

Cochrane Database of Systematic Reviews through OVID 2005 - Jan 2010
40

Cochrane Database of Systematic Reviews through Wiley 2010 Issue 3
2643

Total combined 2686

Removed duplicates and off topic: 2590

Full article read to determine match with inclusion criteria
96

Discarded Not meeting inclusion criteria: 53

Excluded Not meeting methodological criteria: 0

Excluded Reporting results from single studies: 13

Final number of reviews included in the study 30
Appendix U – Intervention Strategies that Support Self-Care - Excluded Studies

Reason for exclusion: Synthesis not possible, results presented from single studies only.

Reason for exclusion: Synthesis not possible, results presented from single studies only.

Reason for exclusion: Synthesis not possible, results presented from single studies only.

Reason for exclusion: Synthesis not possible, results presented from single studies only.

Reason for exclusion: Synthesis not possible, results presented from single studies only.

6 Johnson A, Sandford J, Tyndall J. Written and verbal information versus verbal information only for patients being discharged from acute hospital settings to home [Systematic Review]. Cochrane Database of Systematic Reviews 2003.  
Reason for exclusion: Synthesis not possible, results presented from single studies only.

Reason for exclusion: Synthesis not possible, results presented from single studies only.

Reason for exclusion: Synthesis not possible, results presented from single studies only.

Reason for exclusion: Synthesis not possible, results presented from single studies only.

Reason for exclusion: Synthesis not possible, results presented from single studies only.

Reason for exclusion: Synthesis not possible, results presented from single studies only.

Reason for exclusion: Synthesis not possible, results presented from single studies only.

Reason for exclusion: Synthesis not possible, results presented from single studies only.
Appendix V – Intervention Strategies that Support Self-Care - Included Studies


6 Duncan E, Best C, Hagen S. Shared decision making interventions for people with mental health conditions [Systematic Review]. Cochrane Database of Systematic Reviews 2010.


16 Orton LC, Barnish G. Unit-dose packaged drugs for treating malaria [Systematic Review]. Cochrane Database of Systematic Reviews 2005;1.


## Appendix W – Intervention Strategies that Support Self-Care - Details of Included Studies

<table>
<thead>
<tr>
<th>Author/Year/Country</th>
<th>Develop. Stage/ # of Participants</th>
<th>Disease/Impairment</th>
<th># of Included Trials</th>
<th>Review Objective</th>
<th>Intervention Focus</th>
</tr>
</thead>
<tbody>
<tr>
<td>Airways Group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smith 2009</td>
<td>Adult 1,070</td>
<td>Obstructive sleep apnea</td>
<td>17</td>
<td>To critically assess strategies that are educational, or supportive, or behavioural in encouraging people who have been prescribed or offered CPAP to use their machines.</td>
<td>Adherence to use of CPAP machines for individuals with sleep apnea.</td>
</tr>
<tr>
<td>Boyd 2009 Australia</td>
<td>Child 7,843</td>
<td>Asthma</td>
<td>38</td>
<td>To conduct a systematic review of controlled trials to identify whether asthma education leads to improved health outcomes in children who have attended the emergency department for asthma (with or without hospitalization). A secondary aim is to identify the characteristics of the asthma education programs that had the greatest positive effect on health outcomes.</td>
<td>Asthma education following an exacerbation episode.</td>
</tr>
<tr>
<td>Bailey 2009</td>
<td>Adult, child 617</td>
<td>Asthma</td>
<td>4</td>
<td>To determine whether culture-specific asthma programs in comparison to generic asthma education programs, improve asthma related outcomes in children and adults who suffer from asthma and who belong to minority groups.</td>
<td>Culturally appropriate asthma education for minority groups of children and adults.</td>
</tr>
<tr>
<td>Tapp 2007 Canada</td>
<td>Adult 1,954</td>
<td>Asthma</td>
<td>12</td>
<td>To assess the effectiveness of educational interventions administered following an acute exacerbation of asthma leading to presentation in the emergency department.</td>
<td>Educational interventions following acute asthma exacerbation.</td>
</tr>
<tr>
<td>Author/ Year/ Country</td>
<td>Develop. Stage/ # of Participants</td>
<td>Disease/ Impairment</td>
<td># of Included Trials</td>
<td>Review Objective</td>
<td>Intervention Focus</td>
</tr>
<tr>
<td>-----------------------</td>
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<td>-----------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>Effing 2007 Netherlands</td>
<td>Adult, elder 2,239</td>
<td>COPD</td>
<td>14</td>
<td>a) To evaluate whether self-management education programs in COPD lead to improved health outcomes. b) To evaluate whether self-management education programs in COPD lead to a reduction of health-care utilization.</td>
<td>Self-management education for individuals with COPD.</td>
</tr>
<tr>
<td>Bhogal 2006 Canada</td>
<td>Child 355</td>
<td>Asthma</td>
<td>4</td>
<td>The objective of this review is to evaluate the independent effect of providing a written action plan vs. not providing a written action plan in children and adolescents with asthma. More specifically to quantify any beneficial effect on asthma morbidity associated with the provision of a written action plan. Also to examine the efficacy of different types of action plans to identify the key elements of a written action plan that may be associated with greater effectiveness in terms of format, instructions for daily treatment, instructions for step-up therapy, other ancillary instructions, and specific symptom versus peak-flow based instructions as to when to seek emergency help.</td>
<td>Effect of written action plans for children and adolescents with asthma.</td>
</tr>
<tr>
<td>Turnock 2005 Australia</td>
<td>Adult, elder 367</td>
<td>Chronic Obstructive Pulmonary Disease</td>
<td>3</td>
<td>The primary objective for this review was to determine whether action plans for the management of exacerbations improve health outcomes in people with COPD.</td>
<td>Management plans for individuals with COPD.</td>
</tr>
<tr>
<td>Toelle 2004</td>
<td>Adult, child 967</td>
<td>Asthma</td>
<td>7</td>
<td>The primary objective of this review was to determine whether providing a person who has asthma with an</td>
<td>Individualized asthma management plans to</td>
</tr>
<tr>
<td>Author/Year/Country</td>
<td>Develop. Stage/ # of Participants</td>
<td>Disease/ Impairment</td>
<td># of Included Trials</td>
<td>Review Objective</td>
<td>Intervention Focus</td>
</tr>
<tr>
<td>---------------------</td>
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<td>-------------------</td>
</tr>
<tr>
<td>Australia</td>
<td></td>
<td>Asthma</td>
<td></td>
<td>individualized written asthma management plan increases adherence to specified asthma management behaviours, as detailed in the individual components of the written plan (i.e. primary outcome measures). A secondary objective was to observe the effect of individualized management plans on clinical outcomes (i.e. secondary outcome measures).</td>
<td>Increase self management.</td>
</tr>
<tr>
<td>Powell 2002 Australia</td>
<td>Adult 2,460</td>
<td>Asthma</td>
<td>15</td>
<td>We evaluated programs that: (1) Optimized asthma control through inhaled corticosteroid use by regular medical review or optimized asthma control by individualized written action plans; (2) Used written self-management plans based on peak expiratory flow self-monitoring compared with symptom self-monitoring; (3) Compared different options for the delivery of optimal self-management programs.</td>
<td>Asthma self-management education.</td>
</tr>
<tr>
<td>Gibson 2002 Australia</td>
<td>Adult 6,090</td>
<td>Asthma</td>
<td>36</td>
<td>The objective of this review was to assess the effects of asthma self-management programs, when coupled with regular health practitioner review, on health outcomes in adults with asthma.</td>
<td>Asthma self-management education with regular practitioner review.</td>
</tr>
<tr>
<td>Author/Year/Country</td>
<td>Develop. Stage/ # of Participants</td>
<td>Disease/ Impairment</td>
<td># of Included Trials</td>
<td>Review Objective</td>
<td>Intervention Focus</td>
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</tr>
<tr>
<td>Gibson 2002 Australia</td>
<td>Adult 2,026</td>
<td>Asthma</td>
<td>12</td>
<td>The objective of this review was to assess the effects of limited (i.e. information only) asthma education on health outcomes in adults with asthma.</td>
<td>Limited (information only) education for individuals with asthma.</td>
</tr>
<tr>
<td>Engers 2008 Netherlands</td>
<td>Adult 7,139</td>
<td>Low back pain</td>
<td>24</td>
<td>To determine whether individual patient education is effective for pain, global improvement, functioning and return-to-work in the treatment of non-specific low-back pain, and to determine which type of education is most effective. The following comparisons were investigated: 1) individual patient education versus no intervention; 2) individual patient education versus non-educational interventions; 3) individual patient education versus another type of individual patient education.</td>
<td>Individual patient education for lower back pain.</td>
</tr>
<tr>
<td>Duncan 2010 United Kingdom</td>
<td>Adult 518</td>
<td>mental health condition</td>
<td>2</td>
<td>To assess the effects of provider-, consumer- or carer-directed shared decision making (SDM) interventions for people of all ages with mental health conditions, on a range of outcomes including: patient satisfaction, clinical outcomes, and health service outcomes.</td>
<td>Shared decision making for individuals with mental health conditions.</td>
</tr>
<tr>
<td>Foster 2007 United Kingdom</td>
<td>Adult, elder 7,442</td>
<td>Chronic conditions</td>
<td>17</td>
<td>To assess systematically the effects of lay-led self-management education programs for people with chronic conditions.</td>
<td>Lay-led self-management education for individuals with general chronic conditions.</td>
</tr>
<tr>
<td>Author/ Year/ Country</td>
<td>Develop. Stage/ # of Participants</td>
<td>Disease/ Impairment</td>
<td># of Included Trials</td>
<td>Review Objective</td>
<td>Intervention Focus</td>
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</tr>
<tr>
<td>Heneghan 2006 United Kingdom</td>
<td>Adult, elder 1,137</td>
<td>medical disorder</td>
<td>8</td>
<td>To determine the effects of reminder packaging aids used to enhance patient adherence to self-administered medication/s taken for one month or more.</td>
<td>Adherence to medication regimes for individuals with general medical disorders.</td>
</tr>
<tr>
<td>Murray 2005 United Kingdom</td>
<td>Adolescent, adult, child, elder 3,739</td>
<td>Chronic conditions</td>
<td>24</td>
<td>The objectives of this systematic review were to determine the effects of interactive health communication applications (IHCAs) on patients in terms of: • knowledge; • social support; • self-efficacy; • emotional outcomes; • behavioural outcomes; • clinical outcomes; and to determine the effects of IHCAs on economic outcomes, in terms of resource utilization.</td>
<td>Education using interactive computer programs for individuals with general chronic conditions.</td>
</tr>
<tr>
<td>Perkins 2006 United Kingdom</td>
<td>Adult 987</td>
<td>Eating disorders</td>
<td>15</td>
<td>To evaluate the evidence from randomized (RCTs) and controlled clinical trials (CCTs) for the efficacy of pure self-help (PSH) and guided self-help (GSH) treatments with respect to eating disorder symptoms, compared to waiting list or placebo/attention control, other psychological or pharmacological treatments (or combinations/augmentations) in people with eating disorders.</td>
<td>Self-help (guided or pure) compared to other strategies for individuals with eating disorders.</td>
</tr>
<tr>
<td>Thompson</td>
<td>Adult</td>
<td>Increased blood</td>
<td>12</td>
<td>To assess the effects of dietary advice given by a dietitian</td>
<td>Dietary advice for</td>
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<tr>
<td>Author/Year/Country</td>
<td>Develop. Stage/ # of Participants</td>
<td>Disease/Impairment</td>
<td># of Included Trials</td>
<td>Review Objective</td>
<td>Intervention Focus</td>
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<td>2003 United Kingdom</td>
<td>2,174</td>
<td>cholesterol</td>
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<td>compared with another health professional, or the use of self-help resources, in reducing blood cholesterol in adults.</td>
<td>reducing blood cholesterol.</td>
</tr>
<tr>
<td>Gray 2009 United Kingdom</td>
<td>Adult 690</td>
<td>Glaucoma, Ocular hypertension</td>
<td>8</td>
<td>To summarize the effects of interventions for improving adherence to ocular hypotensive therapy in people with ocular hypertension (OHT) or glaucoma.</td>
<td>Improving adherence to ocular hypotensive therapy.</td>
</tr>
<tr>
<td>Rueda 2006 Canada</td>
<td>Adult, child 2,159</td>
<td>HIV/AIDS</td>
<td>19</td>
<td>To conduct a systematic review of the research literature on the effectiveness of patient support strategies and education for improving adherence to highly active antiretroviral therapy (HAART) in people living with HIV/AIDS.</td>
<td>Education or support strategies to increase adherence to antiretroviral therapy medication regimes.</td>
</tr>
<tr>
<td>Schroeder 2004 United Kingdom</td>
<td>Adult 15,519</td>
<td>Hypertension</td>
<td>38</td>
<td>To determine the effectiveness of interventions aiming to increase adherence to blood pressure lowering medication in adults with high blood pressure.</td>
<td>Adherence to blood pressure lowering medication for individuals with hypertension.</td>
</tr>
<tr>
<td>Orton</td>
<td>Adult, child Malaria</td>
<td>5</td>
<td>To summarize the effects of unit-dose packaged treatment</td>
<td>Adherence to treatment</td>
<td></td>
</tr>
<tr>
<td>Author/Year/Country</td>
<td>Develop. Stage/ # of Participants</td>
<td>Disease/ Impairment</td>
<td># of Included Trials</td>
<td>Review Objective</td>
<td>Intervention Focus</td>
</tr>
<tr>
<td>---------------------</td>
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<tr>
<td>2005 United Kingdom</td>
<td>2,013</td>
<td></td>
<td></td>
<td>On treatment failure and treatment adherence in people with uncomplicated malaria.</td>
<td>In people with uncomplicated malaria.</td>
</tr>
<tr>
<td>Hawthorne 2008 United Kingdom</td>
<td>Adult, elder 1,603</td>
<td>Diabetes Mellitus</td>
<td>11</td>
<td>To assess the effects of culturally appropriate health education interventions for people with type 2 diabetes mellitus in ethnic minority groups.</td>
<td>Culturally appropriate education for individuals with diabetes mellitus.</td>
</tr>
<tr>
<td>Duke 2006 Australia</td>
<td>Adult 1,359</td>
<td>Diabetes Mellitus</td>
<td>9</td>
<td>To evaluate the effectiveness of individual patient education on metabolic control, diabetes knowledge and psychosocial outcomes.</td>
<td>Individual face-to-face patient educational sessions for individuals with diabetes mellitus.</td>
</tr>
<tr>
<td>Deakin 2005 United Kingdom</td>
<td>Adult, elder 1,532</td>
<td>Diabetes Mellitus</td>
<td>11</td>
<td>To assess the effects of group-based (six or more people), patient centred diabetes training on clinical, lifestyle and psychosocial outcomes both in the short (four to six months) and longer-term (more than 12 months) compared with routine care delivered on a one-to-one basis, or a combination of the two. To observe whether the setting (primary / secondary care), the educator (physician, nurse, dietitian, other health professional, peer educator), the type of educational model or the duration/intensity of the group-based education programme affects the outcomes.</td>
<td>Group based patient centered education for individuals with diabetes mellitus.</td>
</tr>
<tr>
<td>Author/Year/Country</td>
<td>Develop. Stage/ # of Participants</td>
<td>Disease/ Impairment</td>
<td># of Included Trials</td>
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<tr>
<td>Welschen 2005 Netherlands</td>
<td>Adult, elder 1,285</td>
<td>Diabetes Mellitus</td>
<td>6</td>
<td>The objective of this review was to assess the effects of self-monitoring blood glucose (SMBG) in patients with type 2 diabetes mellitus who are not using insulin.</td>
<td>Self monitoring of blood glucose in individuals with diabetes mellitus.</td>
</tr>
<tr>
<td>Riemsma 2003 United Kingdom</td>
<td>Adult 8,683</td>
<td>Rheumatoid arthritis</td>
<td>50</td>
<td>To examine the effectiveness of patient education interventions on health status (pain, functional disability and psychological wellbeing) in patients with rheumatoid arthritis (RA).</td>
<td>Patient education for individuals with rheumatoid arthritis</td>
</tr>
<tr>
<td>Renz 2007 United Kingdom</td>
<td>Adult, elder 344</td>
<td>Periodontal disease</td>
<td>4</td>
<td>The aim of this review was to determine the impact of interventions aimed to increase adherence to oral hygiene instructions in adult periodontal patients based on psychological models and theoretical frameworks.</td>
<td>Adherence to oral hygiene instructions.</td>
</tr>
</tbody>
</table>