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Motivation for self-care in older women with heart disease and diabetes

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Motivation for Self-Care in Older Women with Heart Disease and Diabetes: A Balancing Act

by

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Abstract

MOTIVATION FOR SELF-CARE IN OLDER WOMEN WITH HEART DISEASE AND DIABETES:

A BALANCING ACT

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University of California, San Francisco, 2003

From the outset of this study motivation was defined as what moves older women towards engaging in and sustaining self-care practices over time. Based on this working definition, this study's aims were: 1) To gain a better understanding of factors that influence motivation through perspectives and descriptions of experiences of community-dwelling older women, on what helps and what makes it more difficult for them to maintain self-care practices in the long course of a chronic disease, and 2) To learn how motivation is perceived or described by older women through accounts of their experiences in maintaining self-care in the long run. The design was cross-sectional, descriptive, and used qualitative grounded theory techniques for data collection and analysis. Fourteen women 65-84 years of age, with heart disease and/or diabetes were interviewed twice over a period of six months. Interview questions explored older women's motivation for maintaining self-care practices in chronic disease. Participants' meanings determined motivation. Negotiations and creative strategies to balance exercise, diet and medication were central to these women's attempts to sustain motivation for continuing long-term self-care practices. Findings add to current understandings of motivation the concept that older women's motivation is a tense, continuously renegotiated process that seeks to balance: what matters to them, recommended long-term self-care practices and quality of life.

Dedication

I dedicate this dissertation to the person I most admire in this world, my beloved partner and husband, **João Carlos Guerreiro Soares**. Without his companionship, support, love, understanding and patience I would not have been able to either undertake or complete the Ph.D. program at the University of California, San Francisco, School of Nursing.

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[1] Translation: Ministry of Education

[2] Translation: Coordination for Enrichment of Graduate Personnel

Qualifying Exam and Dissertation Committees, guiding, challenging my thoughts and fostering my academic growth: Dr. Patricia Benner, R.N., Ph.D., F.A.A.N. (Chair of my Qualifying Exams), Dr. Juliene G. Lipson, R.N., Ph.D., F.A.A.N., and Dr. Jeanie Kayser-Jones, R.N., Ph.D., F.A.A.N. I also had the privilege to receive guidance and support from Dr. Nancy Stotts, R.N., Ed.D., F.A.A.N.; Dr. Rosemary Plank, R.N., Ph.D., Academic Coordinator; and Dr. Rob Slaughter, Ph.D., Director, Office of Research.

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CHAPTER I: LITERATURE REVIEW

Introduction

Motivation is a construct that has been explored mainly though quantitative studies and from the perspective of the researchers accomplishing the studies. This research seeks to study motivation from the perspectives of older women and in the context of a chronic disease that requires maintenance of health care practices and changes in life style. The first chapter begins by briefly addressing the issue of chronic disease and older women and then focuses on: 1) Reviewing cumulative contributions to the conceptualization of motivation as well as ambiguous, uncertain, or contradictory findings about motivation; 2) Presenting an analysis of the literature on how motivation has been researched under different lenses (e.g. physiological, psycho-social); and 3) Identifying the gaps in the literature and presenting the research question and aims that originated this study on motivation for self-care in older women with chronic diseases.

Chronic Diseases

Background and Significance

According to the United States Department of Health and Human Services (1999) and Anderson (2002), the older adult population in the United States is growing faster than the general population. In the 1999 Centers for Disease Control - CDC report, adults over 65 years represented 13 per cent of the total population. Most of these individuals lived in the community with family members while approximately one-third lived alone and 4% were institutionalized. This latter percent rose to approximately 19% in those 85 years or older. Projections indicate that by the year 2030 adults over the age of 65 will account for 20 per cent of the total United States population.

In 1997, life expectancy in the United States was 79.4 years for women and 73.6 for men (United States Department of Health and Human Services, 1999). Women who survive to the age of 65 can expect to survive to age 85, and women who survive to age 85 can expect to live to age 92 (United States Department of Health and Human Services, 1999). For all adults over age 65 the leading causes of death in the US are heart disease, cancer, stroke, chronic obstructive pulmonary disease, pneumonia and influenza. However, the relative importance of causes of death vary according to race, ethnic background and sex. In 1997, diabetes ranked sixth for older White and Asian Americans, fourth for Hispanic and African Americans and third for Native Americans.

By definition, chronic diseases are long lasting health problems that can be rarely cured. Based on the data presented above, and on the United States Vital Statistics Report (Anderson, 2000), chronic diseases are the eight top leading causes of death in older adults, and are also leading causes of morbidity. Even though not all chronic diseases are life threatening, they impact older adults quality of life and are major concerns to the health and economic status of older adults, both at the individual and social levels (United States Department of Health and Human Services, 1999, p. 66).

Treatment and Self-Care Practices Across Time

Given the fact that many chronic diseases alternate between periods of quiescence and flair ups, the long-lasting nature of a chronic disease requires treatment strategies and self-care practices. These regimens have to be carried continuously across time (McLan, 1995; Colleman, 2002) and have adherence or compliance as desired outcomes. However, achieving long-term adherence or compliance necessitates a given level of motivation to initiate and, most important, to maintain self-care practices across time. In other words, motivation is viewed as fundamental to the maintenance of the self-care practices of adults over age 65 and antecedes any degree of adherence or compliance to prescribed treatments. From an economic perspective, learning how motivation is experienced by older adults may facilitate the development of effective strategies that will improve maintenance of self-care practices and potentially delay disability and reduce individual and social costs.

Overall, chronic diseases are primarily classified on the basis of genetic-biological criteria and assume a range of variations in onset (acute or gradual), symptomatology (severity), course (progressive, constant or relapsing / episodic), and outcomes (changes, disability, reduction of lifespan, death). They are also influenced by different kinds of support and values (economic, social). In essence, the resulting diagnosis of a single chronic disease is an umbrella term for a complex phenomenon and its connections within the biological and psychosocial worlds (Rolland, 1993) of a person.

The event of a chronic disease in the lifeworld of an older person often does not correspond to its diagnosis; rather, it becomes "public" during a routine physical exam, a crisis or an acute or symptomatic situation. Additionally, older adults may also have more than one chronic condition with atypical symptom intensity or presentation, which increases the complexity and the need for thorough evaluation and treatment. Yet, within this multifaceted context, knowledge and technological advances have facilitated earlier and more accurate diagnosis, better management and improved treatments, helping people to live longer. Thus, once the diagnosis of a chronic condition is made by one or more health care providers, adherence and/or compliance to treatment and self-care practices to prevent or delay disability become major goals sought in its management.

In order to achieve these goals, interventions that have been shown effective in a large population are often used and have allowed health care practitioners to have a way of approaching patients. However, the findings from aggregate studies do not always translate to individual cases because they do not take the individual's needs and resources into consideration. Still, independent of available resources, health care providers encourage older persons to incorporate positive health care practices and to follow standard interventions involved in long term treatment plans. These practices, according to Corbin & Strauss (1988), often entail major modifications of health behaviors, as well as social and work life.

Incorporating changes into long-established ways of being in order to achieve adherence / compliance to complex treatments is difficult to initiate (Branin, 2001; Durso, 2001); even more difficult is maintaining them over extended periods of time. This may be especially true if these treatment regimens are demanding, or interfere with or require modifications in pleasurable, significant activities and habits, such as a grandchild's birthday party, eating out, or having coffee and muffins with long time friends.

Older people have ways of caring for themselves, which may or may not be congruent with health self-care practices recommended by health care providers, yet the research findings on what motivates self-care practices are influenced by the perspective of the research project as well as on how the research is designed and the data are collected, analyzed and reported. For example, a critical point to be observed in the 1972-

2003 PubMed and PyschInfo literature review on motivation for health care practices in chronic disease is that most studies that come up do not describe or even refer to non-prescribed health practices that may be carried out for the purpose of self-care. This indicates that the older adults' participation has been limited to what the researchers expected to find, and that the researchers were not really open to unaccounted possibilities. For this reason, for the purpose of this research the term self-care practice includes not only health care practices recommended by health care providers, but also those practices that are perceived and/or described by older adults as self-care.

It is important to note that the literature on adherence / compliance as goals to be achieved in chronic diseases and self-care in old age, combined with the literature on motivation, have contributed substantially to the conceptualization of motivation as perceived by researchers. These studies have also increased our knowledge about interventions and factors involved in motivation to initiate and maintain change in health behaviors in the face of critical situations and advanced stages of life-threatening diseases. However, what helps or motivates older adults with non-life threatening diseases to sustain self-care practices in the long run is under studied and poorly understood, especially from the individuals' perspectives.

Motivation

As a word, the term motivation is largely used in everyday language to describe feelings and situations that may be the cause of or effect of an event. It connects with people (someone motivates or is motivated), and with stimuli and actions (something motivates). Specifically in health sciences literature, motivation is considered a complex construct (Bandura, 1991, 1997; Ellingson & Yarber, 1997) that unfolds into types (physiological, psych-sociological; intrinsic, extrinsic) with specific attributes (protein or hormonally initiated; self-determined, non-self-determined). The word's multiple connotations for society at large and many applications in the scientific community posed significant difficulty in searching for select research-based working definitions of motivation for this review. An illustration of the broad scope of publications using motivation as a keyword from January 1970 to January 2003 can be seen by the numbers obtained on PubMed (over 4000 entries) and PsyINFO (over 3500 entries), thereby necessitating search refinements and theoretical selection. The subsequent process of organizing, analyzing and synthesizing how motivation in older adults has been researched led to the identification of commonalities and disparities. In some cases, questions raised by one study are partially answered by other studies' findings. Because of the small number of studies conducted on motivation for self-care with samples exclusively composed of older adults with non-life threatening chronic diseases, studies done on younger adults were also included in this review. The following discussion summarizes findings, identifies research gaps, and proposes possibilities for research on motivation in older adults.

Motivation Research

In the social and behavioral sciences health literature, the investigation of motivation as related to self-care and chronic diseases has focused on assessing different levels (e.g.: low, high) and kinds (e.g.: intrinsic, extrinsic); on tool development, refinement, and adaptation; and motivation in association with adherence, coping, health behaviors, relationships and self-efficacy. This section discusses the advances made by empirical studies' as well as their limitations.

Clinician ratings of patient motivation

Studies accomplished by Martin (1987), Dietrich (1996), Lukkarinen & Hentinen (1997), and Jayanti & Burns (1998) assess "levels of motivation" but have significant limitations because of lack of clarity, poor study design, and faulty development and description. The relevance of these studies lies in how they point to the need to consider not only whether the research's theoretical base, questions, method and design are cohesive, but also the extent to which terminology may indicate hidden biases in the research and the author's assumptions.

An example of a study that assesses levels of motivation and presents a number of the issues listed above is McArtor et al.'s (1992) twenty-month longitudinal study conducted in a family-practice residency. The study was designed to test two hypotheses: 1) That physicians use low-level involvement strategies, defined as self-care or community referral, for follow-up care when they assessed patients as poorly motivated, regardless of the health problem (diabetes and hypertension) being treated; and 2) That physicians choose low-level involvement approaches for health promotion-disease prevention problems (smoking, obesity and lack of physical activity) regardless of the level of patient motivation.

Data were collected on 3,318 patient visits (not patients) of persons ranging in age from 18-59 years who had a risk-evaluation and motivation form filled out during the first encounter. Data collected included patient demographics, physician assessment of the patients' level of motivation, physician assessment of presence or absence of social support, and disposition for follow-up care.

Resident physicians subjectively rated patients' motivation as high, medium or low, however no theoretical perspective or empirical basis was reported in support of how these "levels" were established. The resident physician's level of involvement was rated by researchers as high if they rescheduled the patient for a return visit and as low if the patient was relegated to self-care or to a community resource. Referral to community resources was noted by the authors to be practically nonexistent. In the data collection section there is no indication of inter-rater reliability checks or pilot testing to validate procedures and instruments. Chi-square was chosen to test samples that were not truly independent, violating a primary assumption of the test and compromising all statistical values presented in the article, with the exception of plain percentages from absolute numbers.

The authors described hypertension and diabetes mellitus as traditional medical problems and smoking, obesity and physical inactivity as health promotion-disease prevention. The above health conditions were observed in 1,049 of the 3,318 patient *visits*. For hypertension and diabetes, patient low motivation did not lead physicians to choose low involvement strategies for additional management of these conditions. Nevertheless, for smoking, obesity and physical inactivity patient low motivation led physicians to choose low involvement strategies, i.e., self-care more often than in cases of patient high motivation. Self-care, classified as a low physician involvement strategy, was more likely to be chosen for management of health promotion-disease prevention conditions than for management of hypertension and diabetes (P<.0000). Findings indicate that resident physicians rescheduled patients who had hypertension and diabetes to return in 72% of visits, versus 34% when participants were either overweight, or smokers, or sedentary. In the article, there was no reference to the mean age and gender of actual patients participating in the study. The theoretical background, the study design and data collection procedures were poorly described. All patients in the group with health promotion-disease prevention conditions who were rated as low on motivation received the same treatment, i.e., were relegated to self-care. However, regardless of patients' level of motivation, the lack of reimbursement for health promotion-disease prevention services may have influenced the physicians' decision to use low-level involvement strategies, constituting a major threat to the validity of the study. The physicians' motivation also may have been guided by financial constraints and possibilities.

Considering the methodological limitations of this study, the second hypothesis was supported by *visit* proportions and frequencies. Smokers rated as having low motivation were less likely to be rescheduled for office visits than those who were equally poorly motivated but had either diabetes and / or hypertension. However, the physicians' level of comfort in counseling for behavior change and in disease diagnosis was not assessed. An added limitation is that no accounts were analyzed to validate patients' high, medium or low motivation ratings, and besides making reference to limited community resources, no environmental and social variables were discussed. Thus, in this particular example, findings cannot be generalized, and are of poor value for clinical assessment of motivation and self-care practices in patients with chronic health problems.

Even though rating levels could be helpful in initial screenings on older adults' motivation for self-care, Martin et al. (1987), McArtor et al.'s (1992), Dietrich (1996), Lukkarinen & Hentinen (1997), and Jayanti & Burns (1998) studies suffered from insufficient information on participants and on the data sets, lack of statements on theoretical frameworks, and inadequate measurement of motivation. Thus, their findings do not provide enough evidence of reliable measures or evaluations of "levels" of patient motivation for self-care.

However, within the context of chronic disease and self-care, valuable research has successfully investigated either one (Glasgow, 1989; Markland & Hardy, 1993; Maclean & Pound, 2000) or more than one type of motivation (O'Connor & Vallerand, 1994; Brillhart & Johnson, 1997; Williams, Freedman, & Deci, 1998). Significant contributions made by these authors are presented in the following section, which discusses advances and limitations of the qualitative and quantitative designs and administration of single or combined measurement tools used to assess motivation. In addition, the section also addresses such issues related to motivation as types, adherence, coping, health behaviors, relationships and self-efficacy.

Intrinsic and extrinsic motivation

Despite the number of years that motivation has been studied, and the number of occurrences of the term in the literature, two theoretical perspectives have served as foundation for most of the empirical studies on the construct. The first, which will be the one used most frequently in the research discussed in this section, is self-determination theory. The second is social cognitive theory, which is also referred to in this section but will be more extensively discussed in the Theory Chapter under cognitive perspectives on motivation.

Self-determination theory (SDT) has been defined as:

> *"a macro-theory of human motivation concerned with the development and functioning of personality within social contexts. The theory focuses on the degree to which human behaviors are volitional or self-determined - that is, the degree to which people endorse their actions at the highest level of reflection and engage in the actions with a full sense of choice."* [3]

Deci & Ryan (2002) note that Self-Determination Theory emerged to explain the relationship of motivation and goals with well-being and health. Self-determinism or self-determination theory is actually composed of four smaller theories (Deci & Ryan, 2002): cognitive evaluation theory, organismic integration theory, causality orientations theory, and basic needs theory. Deci and Ryan's 2002 "Handbook of Self-Determinism Theory" presents the latter (basic needs theory) as the component of Self-Determinism Theory that has been used most frequently by researchers in the health and behavioral sciences under the umbrella term for self-determination theory.

Research on motivation related to adult health / disease using self-determination theory has been done by Cox (1985a, 1985b, 1987), Vallerand, O'Connor and Blais (1989), O'Connor and Vallerand (1994), Vallerand, O'Connor and Hamel (1995), Guay, Vallerand & Losier (1996), Williams et al. (1998), Murphy (2000) and Wang (2001). Yet, motivation related to older adults' health has been the focus of Vallerand et al. (1995), Williams et al. (1998) and Cox's (1987) studies, which will be discussed in this chapter.

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[3] http://www.psych.rochester.edu/SDT/theory.html: March 27th, 2003 at 10:33am

One way of studying motivation related to older adults' health is through the use of instruments developed from conceptual understandings of motivation. Two measurement tools, Elderly Motivation Scale (EMS) and the Health Self-Determinism Index (HSDI), which have their underpinnings in self-determinism theory (Deci & Ryan, 1987, 1990, 2002) and which were refined and used in studies on motivation in older adults with chronic disease, give introduction to the next section and are followed by studies that used different tools to study motivation in association with adherence, coping, health behaviors, relationships and self-efficacy

Measurement tools: EMS and HSDI

EMS - Elderly Motivation Scale.

Vallerand et al. (1995) based much of their work on Deci & Ryan's self-determination theory and conceptualizations. It is important to note that Deci & Ryan's (1987, 1990) research collected data from community-dwelling younger and middle-aged adults and Vallerand et al. (1995) collected data from older adults living in nursing homes. Despite age group and environmental differences, both research groups focused on four major types of motivation, observed through of different kinds of behavior that fell on a continuum of self-determination, from low to high. Although different scales have been developed to measure motivation, Vallerand et al's (1995) work was selected for a more detailed discussion in this review because it presents a tool specifically designed to assess motivation in older adults.

Vallerand et al's (1995) described four distinct types of motivation as measured by the EMS (Elderly Motivation Scale). Intrinsically motivated behaviors are engaged in for the pleasure and satisfaction that is derived from their performance (Vallerand et. al, 1995). For example, walking along the beach for the inherent pleasure and satisfaction of doing so. Extrinsically motivated behaviors are not performed for their inherent experiential aspects but to receive or avoid something once the activity is finished. Vallerand et al. (1995) divide these behaviors into non-self-determined extrinsic and self-determined extrinsic motivation.

Non-self-determined extrinsic motivation occurs when a behavior is extremely regulated, generally through rewards or constraints. It can be observed when an activity is performed to avoid criticism from others. For example, walking along the beach for exercise because one does not want to be criticized by the health care provider or to be criticized by a spouse. This kind of motivation may also be fed by a desire for rewards or getting something in return for good behavior. For example, walking along the beach expecting to be praised for doing so, either by the health care provider or by a family member: "I will go for a walk now so that when my husband arrives I will be getting home too. He will be happy and will congratulate me on my walk".

On the other hand, self-determined extrinsic motivation takes place when a behavior is valued by the person and is seen as being chosen by oneself, i.e. internally regulated. Yet it is extrinsic because the task or activity is not performed for itself but as a means to an end. For example, the person goes for a walk along the beach because he/she has decided that exercising is beneficial, based on a recent news report that walking promotes good health. There is a sense of direction and purpose involved in the action to accomplish a health-related goal.

Finally, “amotivated” behaviors described the situation where a person perceives a lack of contingency between their behavior and the outcome. These behaviors are considered to be the least self-determined because there is no aim, and no will for something in return or even for changing possible outcomes (Vallerand et. al, 1995). This can be seen, for example, when a person does not see any purpose in exercising because he/she does not see what it can possibly do for him/her once the disease has become a chronic condition and will not be cured.

The purpose of the study conducted by Vallerand et al. (1995) was to cross-culturally validate the English version of the French EMPA scale ("Echelle de Motivation des Personnes Agees"). The eighteen-item English EMS (Appendix A) has four subscales corresponding to the four types of motivation. Responses were provided in a 7-point Likert scale ranging from "strongly disagree" to "strongly agree".

The study was designed: 1) To evaluate the reliability of the EMS (Elderly Motivation Scales, as an English version of the original EMPA); 2) To find out if there is a simplex pattern of correlations between the sub-scales, indicating a continuum in self-determination; and 3) To gather further evidence for construct validity by examining the relationships between different kinds of motivation and psychological variables.

The method used for translation followed standard procedures and was assessed by a committee (individuals who participated in the back translation procedures and authors of the original French version of the scale). Items that retained their original meanings were selected but were not specified in the text.

Participants (N=77) were fifty-eight women and nineteen men, with ages ranging from sixty to ninety-eight years, with a mean of 82.6 years. All were residents of two intermediate care nursing homes in Montreal, Canada. Older adults were screened for cognitive and physical fitness by the head nurse. Staff members informed eligible residents that they would be invited to participate in a study about attitudes and self-perception. Upon participant agreement data collection instruments were administered in interview style to approximately 80% of older adults living in the two sites, including the eighteen-item English EMS. Participants also completed other measures understood by the research team as being related to motivational styles, namely the Satisfaction With Life Scale (Pavot, Diener, Colvin, & Sandvik, 1991), five items from Rosenberg's Self-Esteem Scale (Rosenberg, 1979), three items from Beck Depression Inventory (Kane, 1981) and two items from the Locus of Desired Control Scale (Reid, 1977)[4]. Interestingly, only the two central items of the Locus of Desired Control Scale were described. Additional scales used in the data collection were: Philadelphia Geriatric Center Morale Scale (Lawton, 1972), five items from the Revised UCLA Loneliness Scale (Russell et al., 1980); and two unspecified items on fulfillment of experience in daily life[5]. Except for the Beck Depression Inventory, all items were on 7-point scales. Not all additional measures were administered to all participants due to time-related difficulties but there is no discussion of how missing or incomplete data were handled. The authors did not present the criteria used to select the items from the various scales. The study also lacks description of how missing values were handled.

Data on the subscales for the four types of motivation had mostly high Cronbach's alpha coefficients: amotivation .91, non-self-determined extrinsic motivation .72, self-determined extrinsic motivation .92, intrinsic motivation .89, suggesting apparent internal consistency. The EMS subscales correlations indicate support for Deci

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[4] Locus of Desired Control Scale Items included: "How important is it for you to be able to decide on what your everyday behaviors are going to be?" and "How often can you yourself decide what your everyday behaviors are going to be?"

and Ryan's proposed self-determination continuum. Scales that were theoretically close showed positive correlations (e.g., intrinsic and self-determined extrinsic motivation: $r = .64$) whereas scales farther away from each other showed negative correlations (e.g., intrinsic motivation and amotivation: $r = -.59$). An additional finding presented by Vallerand et al. (1995) was an association between locus of desired control and motivation variables. These variables showed positive correlation with adjustment variables but unfortunately they were measured at only one point in time

Even though the study reports satisfactory reliability for the individual life domains / psychological variables from the instruments used in the study, only alpha ranges[6], were presented. Overall, the EMS may be useful for investigating kinds of motivation. However, it does not provide data on how different kinds of motivation are experienced by older adults. In addition, the findings cannot be generalized because the sample was exclusively composed of nursing home residents. Replication of this study with community dwelling older adults would be a valuable contribution to the field in broadening the scope of the tool and in identifying differences within the older adults' population.

Vallerand et al.'s (1995) work facilitates an understanding of Deci and Ryan's theory on different kinds of motivation in older adults through the evaluation of a tool with potential for assessing the perspective of motivation in a continuum. On one hand, Deci & Ryan's (1985,1990) and Vallerand et al.'s (1995) studies address the permeability of boundaries among the different types of motivation, but on the other hand, these researchers' idea of a continuum is still limited due to its linearity. This approach

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[5] "There is not enough to do to keep myself busy" and "I do not feel needed"

describes the different types of motivation functioning in a continuum between the two poles varying from intrinsic motivation and amotivation. However, reports from Brillhart & Johnson (1997), Williams et al. (1998), and Maclean & Pound (2000) indicate that the dynamics of these four kinds of motivation may interplay in a non-linear fashion in relation to health-disease situations, given the diverse aspects of age groups, environment, bio-socio-psychological contexts and possibilities. In other words, both Deci and Ryan as well as Vallerrand et al's work do not address issues of meaning, values, environment, experiences and emotions from older adults' perspectives.

HSDI - Health Self-Determinism Index.

Cox et al. (1987) conducted a cross-sectional study to test the reliability and validity of the HSDI - Health Self-Determinism Index[7] as a measure of intrinsic motivation (Deci, 1980; Deci & Ryan, 1987) in the older adult population. The HSDI originally had 20 items. However, the author decided to use a shorter version of the tool - in which item numbers 6, 11 and 16 were dropped – based on the findings of previous psychometric evaluations of the measure (Cox, 1985; Macius, 1985), in which these items had low standard deviations, low item-to-total correlations and decreased alpha coefficients within subscales. The reliability for the seventeen-item instrument has been described in previous studies (Cox, 1985a; Cox, 1985b; Macius, 1985) as having acceptable alphas coefficients (Nunnally, 1994): 0.84 (N=199), 0.80 (N=68), 0.87 (N=54), 0.83 (N=55) and 0.81 (N=72).

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[6] Alphas range - 3 item scales from .67 to .97

[7] Consists of four subscales that address: self-determined heath behavior, perceived competency in health issues, and internal-external cue responsiveness. Except for sex and race all measures are in intervals.

Randomly selected, participants (N=379) were 77% women, 66% widowed, 66% white, 33% black and 1% other. The age range was from 59 to 101 years, the mean age was 76.2 years, and the mean number of years of education was 8.9. All participants lived at four specialized residences for the elderly in a large U.S. Mid-Western city and its suburbs. Cronbach's alpha coefficient was used to evaluate homogeneity of the scale. The total 17—item scale got an alpha coefficient of 0.78.

Initially, linear regression was performed with age as the independent variable and each of the HSDI seventeen items as the dependent variable. Only item 19, "What MD/RN thinks is more important than what I think", was significantly associated with age, i.e., the older the participant, the more important the health care provider's opinion. The number of symptoms and chronic health problems reported by participants predicted item 17, "I prefer that MD/RN help me plan my health care", but only higher functional ability was associated with item 2, "I know what to do without contacting MD". However, symptoms, chronic health problems, and functional capacity were associated with item 12, "I do things to help my health without MD/RN". Although the authors do not make reference to prescribed or recommended self-care practices, this item brings up two concerns: first, that older adults may make and carry on treatment decisions based on their lived experience of symptoms, chronic health problems, and functional capacity, and second, that older adults may take responsibility and/of feel independent, wanting to initiate health care practices that either work for them or that they feel like doing.

Even though the authors make reference to other publications that were also reviewed (Cox, 1985a; Cox, 1985b; Macius, 1985), the 1987 publication would benefit from presenting more information on participants' demographics and health status was collected and on the number and nature of tools and questions that were used, other than the HSDI.

Despite its limitations and the need for further testing Cox et al.'s (1987) study of the HSDI as a measure of intrinsic motivation in older adults' health behavior is at least significant in part for its focus on elderly individuals with chronic disease. The authors acknowledged the need for further construct validation and descriptive application, but did not refer to the sample of older adults living at specialized residences as an important limitation for cohort generalization and as contributing to the higher incidence of health problems. Even though Cox et al.'s (1987) study on the HSDI as a measurement of motivation in older adults could benefit from further testing and refinement, the inclusion of item 12 ("I do things to help my health without MD/RN") is a step ahead because it acknowledges the existence of unofficially prescribed or recommended health self-care practices.

In addition to studies on levels, types and measurement tools, research on motivation in older adults has also focused on associations of the construct with adherence, coping, health behaviors, relationships and self-efficacy. The next section discusses empirical studies on older adults' motivation.

Motivation for Adherence

Williams, Rodin, Ryan, Grolnick & Deci (1998) conducted a cross-sectional study to test the predictive power of self-determination. The hypothesis was that patients' perceptions of physicians' support of their autonomy would relate to their adherence to a long-term medication regimen and that the patients' autonomous regulation, that is, self-determination, would mediate this relationship. The sample was composed of adults

(N=126) from North Carolina who had been taking either pills, tablets or capsules as prescription medication for one month prior to joining the study, and were expected to continue for at least one more month after enrollment.

Recruitment was done by telephone from a list of 438 individuals from the Subject Register of the Duke Center for the Study of Aging and Human Development. Eligible adults (n=126) were 95 women and 31 men who had been taking prescription medication for at least one month, expected to continue for another month and agreed to participate in the study. Participants' ages ranged from 37 to 65 years with a mean of 56.3 years. The mean number of years of education for both men and women was high, 16.1. Upon consent, participants were informed that they should bring their medications in original bottles to the interview and that their answers would not be shared with their health care providers. The data collection session consisted of a one hour structured interview, a pill count for establishing a baseline for a prospective pill count, and the filling out of instruments and questionnaires.

The measurement tools used in the study included: 1) the Demographics and Health Status (8 items); 2) the Perceived Barriers Survey (46 items); 3) the Multidimensional Health Locus of Control Scale (24 items); 4) the Treatment Self-Regulation Questionnaire. This instrument is based on self-determination theory but did not clearly specify what items were included; 5) the Health Care Climate Questionnaire (HCCQ) on autonomous support, which assessed the patients' perceptions of their physicians' autonomy support: the number and identification of the four items (i.e., which ones) used were not objectively specified; and 6) questions on adherence (quantified based on participants' responses in the interview and on pill counts). When both the interview and the filling out of instruments session was completed, participants were asked for consent to be contacted by phone two weeks from that date for further data collection. Statistical tests used for data analysis included: correlation (health status, adherence, severity of illness, locus of control, perceived barriers, perceived autonomy support, and autonomous regulation); logistic regression to test the central hypothesis (entering first, demographics; next, psychological variables[8], which significantly correlated with the composite adherence variable[9]); and structural equation modeling (LISRELVIII - four items from the HCCQ as the latent variable perceived autonomy support; and three items of autonomous regulation and adherence).

Correlation analysis showed that: 1) the perceived barriers scale was negatively correlated with the composite adherence scale; 2) autonomous regulation was correlated with the composite adherence; and 3) perceived autonomous support was positively correlated with autonomous regulation and with the composite adherence. Hence, these variables were included in the regression. Autonomous regulation was the only variable that demonstrated a significant partial correlation with the composite adherence scale.

The structural equation model analysis included 3 latent variables, i.e., autonomy support, autonomous regulation and composite adherence. Four items of the HCCQ were used as indicators of perceived autonomy support. Autonomous regulation and adherence had three indicators each.

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[8] Psychological variables: autonomy support, perceived barriers, and autonomous regulation

[9] Was divided into the dichotomous variable of those who reported taking more than 80% of their medications and those who reported taking 80% or less, adherence was regressed onto age, gender and educational level

In the self-determination model of adherence, perceived autonomous support predicted autonomous regulation, and autonomous regulation predicted medication adherence. Direct and indirect individual relationships between variables and perceived autonomy support significantly predicted autonomous regulation directly (parameter estimate = .37, $p < .001$) and adherence indirectly (parameter estimate = .29, $p < .001$). Adherence was directly predicted by autonomous regulation (parameter estimate = .78, $p < .001$). Two models were used to test whether autonomous regulation mediates the relationship between perceived autonomy support scale and adherence: 1) perceived autonomy support directly predicting adherence, not including autonomous regulation; and 2) perceived autonomy support directly predicting both autonomous regulation and adherence; and autonomous regulation directly predicting adherence. Results indicated that in the first model, perceived autonomy was a direct predictor of adherence; and in the second model, autonomy support did not directly predict adherence. Hence, the mediation hypothesis was confirmed.

In the more clinically significant logistic regression model, autonomous regulation was the only variable that had a significant partial correlation with the composite adherence (self-report/pill count) and in the LISREL model autonomous regulation accounted for 68% of the variance in the composite adherence. Thus, both findings indicate that autonomous self-regulation is related to self-reports and pill counts.

Previous studies done in different populations but using the same theoretical background (Curry et al.1991; Deci et al., 1994; Williams & Deci, 1996) have indicated that self-regulation becomes more autonomous when providers and intervention programs support autonomy. From this perspective, one may formulate the hypothesis that interventions that support patients' autonomy may enhance autonomous regulation and consequently improve adherence.

Perceived barriers were negatively correlated with autonomous regulation, i.e. fewer barriers were perceived by those who felt support for autonomy from their health care providers. However, the authors acknowledge that the cross-sectional nature of the study does not permit causal inferences.

Williams et al. (1998) conclude that medical education should consider personal skills as key factors for facilitating patients' autonomy-support and better health care outcomes. However, the authors do not make any reference to learning from patients' experiences as an information source for improving health outcomes.

Four limitations were acknowledged by the authors: because the study was cross-sectional, causal relationships could not be inferred; self-reports and pill counts may have not reflected real adherence to pill-taking behavior; the sample was not representative of the general population; and participants could have been the most motivated since they agreed to participate at the onset (all the 126 participants completed the study, with a US$5.00 reimbursement for their time).

This study provided some evidence that participant adherence was associated with autonomous motivation. However, the design could still benefit from refinement and the hypothesis should be tested further considering: that the 60-day medication regimen is a relatively short period of time from which to make reliable inferences; there was insufficient description of participants' health problems (e.g. chronic, acute, severity); the nature and characteristics of the prescribed medication were not included; there was no data on when the medication regimen was started; and there was no data on the participants' lived experiences while taking the medication. The study also suffers from lack of data on the patients' perspective of what helped or motivated them to adhere to and to cope with a medication regimen.

Motivation and Coping

The association between motivation and coping has been described in the literature on addictive behaviors (Conrod et al., 2000; Kelly, 2000; Kelly, Meyers & Brown, 2002; McKay et al., 2001; Stotts et al., 2001), on immigrating and living in foreign countries (Abramovitch, Schereier & Koren, 2000; Lewis, 2000) on learning and achievement (Ntoumanins, Bibddle & Haddock, 1999; Lepola, Salonen & Vauras, 2000) and on health (Brillhard & Johnson, 1997; Zauszniewski, Chung & Kraficik, 2001). Overall, these data suggest that in the face of stressful situations, motivation facilitates people's choices and management of coping strategies.

As related to the health of older adults, Zauszniewski et al. (1997) were primarily focused on older adults' resourcefulness as a coping strategy. However, in 2001, Zauszniewski et al., (2001) sought to test Conner and Norman's(1996) social cognitive model[10] to predict the health of older adults with chronic disease, in which motivation became of interest as an effect of social cognitive factors.

The 2001 study used self-determinism as a theoretical perspective, had a cross-sectional design, and included a convenience sample (N=137) of older adults age 62 to

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[10] A five-stage model and its "relevant" components as described by Zauszniewski et al., (2001): Pre-contemplation (demographics, situational factors, chronic conditions, social networks); Contemplation (enabling skills, learned resourcefulness); Motivation (intrinsic motivation, health self-determinism); Initiation (help responses, self-help, informal help-seeking, formal help-seeking); and Maintenance (health; physical, psychosocial).

102 years old, (M=80.2). Percentages by gender and ethnic groups were described as 71.5% women, 70.1% Caucasian, 29.9% African American. Data collection procedures included in-person administration of 1) four standardized instruments to assess: a) learned resourcefulness: the 36-item Self-Control Schedule – SCS; b) health self-determinism / intrinsic motivation as assessed by the 17-item Health Self-Determinism Index – HSDI; c) help responses / initiation of activities to promote health assessed by a 25-item list of physical and psychological behaviors: the Help-Seeking Behavior Scale – HSBS; and d) physical and psychosocial health as assessed by an abbreviated version of the Sickness Impact profile – SIP 68; and 2) non- standardized measures and reports: participants' self-report of demographic information and social network size; chronic conditions from a list identified as 26 common conditions of elders described by the National Center for Health Statistics in 1990.

The authors report that initial data analyses included descriptive statistics and a test of multiple regression assumptions, which showed no violation. In order to learn if self-help and informal and formal help-seeking responses were predicted by learned resourcefulness and by health-self-determinism (i.e., internal motivation for health), the authors separately regressed each variable (self-help[11], formal and informal help-seeking) on resourcefulness, health self-determinism and the interaction of resourcefulness and health self-determinism. Beta values were used to examine relationships with variables reflecting learned resourcefulness (contemplation), help responses (initiation) and health self-determinism (motivation). The findings indicated that health self-determinism, i.e., motivation, had a direct positive association with self-help (β=.20, p<.05) and a direct

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[11] Mobilization of internal resources and engagement in self-care activities.

negative association with formal help (β=-.22, p<.01) responses; older adults with higher self-determinism did more self-help and sought less formal help.

Hierarchical regression was applied to verify whether older adults' psychosocial and physical health could be predicted by demographic and situational (social networks, chronic conditions) factors, learned resourcefulness, health self-determinism and help responses – when entered successively, as conceptualized in Conner and Norman's (1996) social cognitive model. None of the help responses were significant predictors of health.

The regression analysis showed that race and social network size were associated with health; African American older adults with larger social networks had better health. Nonetheless, when resourcefulness and health self-determinism were entered both alone and in interaction, the β of social network was not significant. Race (β= -.20, p< .05) and resourcefulness (β= -.24, p< .01) continued to be significant predictors of health. When the three responses were added, race and resourcefulness continued to be significant predictors of health. In conjunction, the variables explained 18% of the variance in health.

Albeit most participants were older women, findings reported include that women were more resourceful than men and African Americans were more resourceful than Caucasians. In relation to motivation, older adults who were more intrinsically motivated performed more self-help and sought less formal help. However, it was it was not related to the use of informal help. Even though the study was based on self-determinism theory, references only indicate empirical studies that used Deci and Ryan's work. No reference was made to original publications or primary sources on the theorists' conceptualization.

The study would benefit from a bigger sample and from a more diverse group of participants, given the number of instruments / items that were used (Nunnally, 1994).

The authors also suitably critique the HSDI because in their study it was observed that the tool measures two extremes – either extrinsic or intrinsic motivation and does not capture different aspects if motivation is considered as a continuum.

Although some of the associations within Conner and Norman (1996) model were supported, findings suggest that physical health and psychological health status were not associated with health self-determinism. Additional concerns are that there may be some sort of problem with the tool or even with the measure of the outcome. This suggests that self-determinism is not a synonym for motivation, and that further studies are needed to explore motivation and health in older adults.

Brillhart & Johnson (1997) conducted a qualitative descriptive study about motivation and the ability to develop successful coping skills after injury, from the clients' viewpoint. Participants (N=13) were 9 men and 3 women, ranging in age from 18 to 77 years, with mean age of 33.92 years. Participants, who had a spinal cord injury, were college students, workers, and homemakers at the time of their injury. All had taken part in an inpatient program at a freestanding regional rehabilitation hospital in the USA.

Eligibility criteria for participation included having returned to an active lifestyle after rehabilitation and being able to describe their rehabilitation experience. An interview that lasted from 30 to 60 minutes was the primary data collection procedure. Participants were asked two initial questions: "What occurred during your rehabilitation to help you develop a productive life after your injury or illness?" and "What did your health care providers, especially nurses, do to promote your motivation level and coping ability during rehabilitation?" These questions were followed by additional probes to clarify information and to obtain examples. Data analysis was initiated at the same time of the study and continued up to six months after the data collection was concluded.

Following Guba and Lincoln's (1994) guidelines, content areas, domains, categories, and concepts were coded and reviewed by principal investigators, by independent rehabilitation nurse experts and by key participants. Brillhart and Johnson's (1997) analysis of the interviews suggest the existence of domains of "motivation" that influence coping with disabilities: independence, education, socialization, self-esteem, and realization; all of which were categorized into positive and negative categories and organized by frequency of participants' citations.

Findings on independence indicate that participants stressed the importance of independence itself, goal setting, and responsibility for self-care practices upon returning home. Their coping ability was influenced by their family's positive expectations about their performance, by the removal of environmental and physical barriers, and by resources (care, equipment, housing). Education was seen by all participants as a fundamental key to responsibility and self-care, stressing nurses' individualization of teaching strategies for carrying out activities of daily living.

On the socialization domain, participants reported initial refusal to join socialization opportunities, which would be resolved over time by fear that invitations would cease. Attendant care was included under socialization, because for some participants it was an invasion of privacy, while for others it was critical for preventing family members from "*having two functions*", loved one and personal helper.

Self-esteem was boosted by the nurses' attention to detail, by personal and individualized attention before and after discharge, and by being remembered when returning for outpatient visits.

Realization of the extent of their new physical health status was progressive, from initial thoughts that it would be temporary until the recognition of the permanent status of the injury and awareness of the limitations it caused.

Although Brillhart and Johnson (1997) did not describe in detail what theoretical and methodological background the data analysis was based upon, nor did they evolve a theory based on their findings, it can be derived from the references and from the content analysis that elements of both grounded theory and phenomenology were used, with grounded theory being the predominant method. This attempt to better understand the ability to develop successful coping skills after injury, from the clients' viewpoint, was positive since it identified independence, education, socialization, self-esteem, and realization as domains related to motivation and coping ability. For a better picture of the research context, a more in depth description of the environment, of the nurses' practices and of the hospital policies and mission are needed. In addition, questions were not really open but quite directive. A significant limitation of the study is that the findings on motivation, coping abilities and health behaviors were delineated exclusively from the perspective of the most successful clients. The study suggests that resources from a variety of areas are important.

Motivation and Health Behaviors

Using grounded theory, Fleury (1996) conducted a qualitative study to learn how individual motivation influences initiation and maintenance of health-related behavior over time, and to investigate validity and cultural relevance of the concept of *wellness motivation*[12]. Participants (N=14) were low-income African-American adults, 10 women (~70%) and 4 men (~30%) with an age range of 55 to 83 years, mean age 74 years. All had one or more of the following conditions: coronary artery disease, diabetes mellitus, hypertension, elevated serum cholesterol, and obesity and were recruited at a rural multipurpose community center. The main data collection procedure was open-ended interviews with duration of 20 minutes to one hour.

An additional selection criteria was participants' acknowledgement that they had either attempted to change or made changes in health behavior in order to adhere to suggested changes in lifestyle. Three participants identified themselves as non-adherent. Nine of them had less than 8 years of formal education. Even though it was not described in detail, the author states that eligibility was based on theoretical relevance, meaning that the selection process identified those who were most able to share experiences and refine concepts as Strauss & Corbin (1988a; 1998b) recommend.

The questions that initiated the interviews were "*Tell me about some recent health-related changes that you've made*" and "*Tell me about some of the ways that you take care of yourself*". Both questions were intended to explore the process of change in health behavior in African American adults. Data were analyzed using constant comparison methodology (Strauss & Corbin, 1990). The study's methods, results and discussion sections suggest it had a good design, data collection procedure and analysis. Fleury's (1996) work was in reality a refined replication of a study published in 1991

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[12] The individual's intention to initiate and sustain both preventive and secondary health behavior (Fleury 1991a, 1991b).

(Fleury, 1991b) and seems to have as its theoretical basis an earlier article about health models and primary motivational theories[13] (Fleury, 1991b). The fundamental design difference between the two research works was the inclusion of another preliminary question[14] in the second study, which addressed participants' self-care practices.

Findings revealed that adoption of different and positive health behaviors (e.g., smoking cessation, antihypertensive medication pill taking; practice of physical exercise) in older African Americans was facilitated by the empowering potential, which was recognized as an active process for goal-directed intention and behavior. This empowering potential emerged from Fleury's (1991b) study - also on individuals who were attempting to initiate and sustain programs of cardiac risk factor modification - as a basic three-stage process identified through grounded theory data analysis, which she described as follows:

> "Empowering potential was a continuous process of individual growth and development which facilitated the emergence of new and positive health patterns. Within the process of empowering potential, individuals use a variety of strategies, which guide the initiation and maintenance of health-related change. The process of empowering potential consists of three stages: appraising readiness, changing, and integrating change." (Fleury, 1991a)

A limitation of the application of Fleury's (1996) empowering potential theoretical framework is that even though participants shared some concerns and

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[13] Health Belief Model (Lewin & Cols, 1944; Maimen & Becker, 1974); Health Promotion Model (Pender, 1987); Theory of Reasoned Action (Ajzen & Fishbein, 1980) / Planned Behavior (Ajzen, 1985; Ajzen & Timko, 1983); and Self-Efficacy Theory / Social Cognitive Theory (Bandura, 1986)

[14] "*Tell me about some of the ways that you take care of yourself*"

experiences in relation to self-care practices and relationships, both the discussion and presentation of findings primarily focused on the stages that compose the empowering potential framework. Themes or categories that fell outside the categories in the framework were not revealed to the reader.

In this study, the wellness motivation was expanded to appraise how health behavior change takes place within a cultural context that comprises: health values, community orientation, and health beliefs as motivational factors in behavior modification. Findings suggest that personal beliefs about illness and treatments, presence or absence of symptoms, and health care provider level of understanding of older adults' difficulties interfered with wellness motivation, that is, intention to initiate and sustain both preventive and secondary health behavior. However, even though participants' accounts made reference to flair-ups of chronic conditions, qualitative distinctions between difficulty to initiate and difficulty to maintain health care behaviors were not discussed.

Motivation and Relationships

Thralow & Watson (1974) studied motivation and relationships in a 20-week prospective study on "*remotivation*"[15] of chronically ill older adults who lived in any one of the three buildings of a U.S. hospital geriatric unit. The trial was intended to test the applicability of Smith's remotivation technique (Robinson & Winnik, 1970) in therapeutic remotivation programs that used elementary school students rather than non-professional staff[16]. Robinson & Winnik (1970) describe the technique as 30 minute patient group discussions led by a non-professional staff member that involved four steps:

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[15] Term used by the authors, with no definition presented in the description of the study.

first, developing a "climate of acceptance" (informal conversation); second, "bridge to the real world" (songs or poetry related to the day's discussion topic); third, "sharing the world we live in" (development and utilization of visual aids on the day's discussion topic); and fourth, "climate of appreciation" (expression of feelings and anticipation for the following encounter).

Older participants (N=72) were divided into experimental (N=36, mean age 69.4 years) and control (N=36, mean age 65.2 years) groups. Participants' mean number of months in the psychiatric hospital were 106.8 and 124.9 respectively. Sixth grade students (N=36) were paired with older adults in the experimental group. Patients were selected by a staff nurse observing pre-set eligibility criteria for older adults: be a resident of one of the three buildings, be exempt from participation in other activities, be able to provide adequate responses to questions, not eligible for discharge in a near future, and not deaf or blind. Students were selected upon both school and parents proposal acceptance and schedule and curriculum compatibility to older adults' hospital activities. The experience was integrated as a practical activity in social studies aimed at helping students to develop social consciousness and positive attitudes towards aging and psychiatric institutions. Young participants also attended orientation sessions with hospital staff, orientation to Smith's remotivation philosophy, a gerontology lecture, meetings with several geriatric patients and a brief meeting with their older partner.

Instruments used in the study included: 1) the 6-item Nurses Observation Scale for Inpatient Evaluation - NOSIE[17] (Honigfeld & Klett, 1965). This toll was used to pair

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[16] Term used by the authors

[17] Measures social competence, interest, neatness, irritability, psychosis and level of retardation.

participants based on their paired scores[18] and to assess change in participant characteristics after the intervention. Participants were then randomly assigned either to the control or to the experimental group; 2) the 7-item Remotivation Self-Evaluation Scale[19]; and the 35-question Morale Self-Evaluation[20] scale developed by Thralow[21]. These tools were completed by the older adults and used by the researchers as support in the evaluation of changes in participants' attitudes, interests, and values. Patients were rated on all 3 scales before the program started, eleven weeks after it started and four weeks after its completion. The experimental program with two 40-50 minutes weekly meetings lasted 16 weeks and was completed by 23 pairs. Patients who died or were discharged were dropped from the study. No drop out of students was reported.

At eleven weeks, T-tests resulted in statistically significant differences at 0.05 level in the variables: neatness, total positive, and overall total score of the NOSIE tool. For the same tool, there was some improvement at 20 weeks from baseline but not statistically significant at 0.05. Even though results at 20 weeks on travel, relationships and hospital life of the 7-item Remotivation Scale were reported as significant at 0.05 level, these items were only partially described, which did not permit adequate understanding of the findings. The 35-question Morale Self-Evaluation scale did not show significant results at the 0.05 level. Overall, the quantitative data presented did not provide sufficient evidence of the applicability of Smith's (in Robinson, 1970)

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[18] On the basis of their NOSIE total scores, with one participant of each pair being randomly assigned to the experimental group, the other to a control group.

[19] Consisted of questions on reading, travel, walks, interest in getting off the ward, desire for visitors, interpretations on how people felt about them, interest in events, feelings about staff and desire to participate in hospital activities

[20] Questions on happiness, loneliness, feelings of self-worth and friendships

[21] No date or publication were specified

remotivation technique in therapeutic remotivation programs with participation of elementary school students rather than of non-professional staff. Another limitation is that the study does not make reference to any qualitative component or to how the qualitative data that were presented were collected. However, even though the study could not demonstrate a statistically significant effect, the results reported are of clinical significance because the discussion section reported that parents, students, patients, hospital staff and administrators involved in the study had enjoyed the original program and as a result, three more programs were developed between 1973 and 1974. Reports by ward personnel indicated that older participants prepared themselves and looked forward to meeting the students, and after the end of the 20-week period they missed the students. Staff described their perception of students as being enthusiastic, friendly and interested in their partners as well as being good "remotivational therapists" and that in some cases students developed meaningful relationships with older adults with whom hospital staff had failed.

Thralow's & Watson's (1974) implementation of an integrated, intergenerational study on motivation provided experiences from which both younger and older participants as well as staff and families appear to have found useful. Despite the study limitations, Thralow's & Watson's (1974) findings indicate that regardless of duration, relationships can influence older adults' motivation in getting started with "non-prescribed" self-care practices (e.g., neatness). Even though the study would benefit from methodological refinement and from replacing the term remotivation (which may give rise to various interpretations of the authors' theoretical perspective[22]) with motivation, the program would benefit from design improvement, however, it still holds potential for fostering knowledge development on how relationships and motivation interact. Systematic collection, analysis and presentation of qualitative contributions made by staff, older adults, students, parents and teachers would have refined the study, bringing to light different, meaningful perspectives at least on lived experiences, relationships and their influence on motivation not only for getting started with, but also for maintaining self-care practices in the long course of chronic diseases. Findings cannot be generalized because the sample was composed of mostly older adults living in an institution.

O'Connor's (1995) prospective study to investigate family and friends relationships among older and younger adults had a three fold purpose: first, to investigate life satisfaction as related to both qualitative and quantitative parts of involvement with friends and family; second, to test the belief that relationships with friends are more positive than relationships with family members and that interactions with the latter are based on obligation (non-self-determined motivation), while interactions with friends are more spontaneous (intrinsically motivated); and third, to test the hypothesis that for the most part intrusion and criticism are delicate issues and occur more often in older adults' family relationships. The study was initially intended to compare older adults' responses with those of their adult children. Nevertheless, very few older adults agreed to have their children contacted to participate, so other younger adults

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[22] For example: Older adults had no motivation at all before the intervention? If older adults were re-motivated, what was the baseline of motivation before the intervention?

were contacted by phone and invited to participate in a “survey on satisfaction with relationships”.

After pilot testing 21 older adults for the measures, excluding those who either had none or only one child, and excluding those who had missing data, a total of 82 older adults took part in the study. Participants were 64 women and 18 men, mean age 70 years and had on average 9.3 years of education. All older adults were tenants from senior citizen apartment complexes in Canada, eight of whom lived with their spouse and 74 lived alone. All older adults had at least two children. Younger adult participants (N=91) were 57 women and 34 men, age range between 25 and 55 years and mean age of 41 years. Two of them were single[23], 78 were married, and 11 were either separated or divorced. Both older and younger participant groups provided demographic information, rated their present health on a five-point scale with range between 1 (very poor) and 5 (very good), and specified how often they spoke on the telephone and saw the described persons (parent / children / friends).

The tools used for data collection were the general Life Satisfaction (Lee & Ellithorpe, 1982); Norton’s (1983) five-item Quality of Marriage Index (having the word “marriage” replaced by the word “relationship” in the items); typical feelings when with each of the persons (not clearly presented) described in an adjective scales of happy-sad, cheerful-irritable, friendly-angry, sociable-lonely, energetic-tired, excited-bored (Larson, Mannell, & Zuzanek, 1986); motivation for interaction with the persons described on

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[23] The author does not indicate the sex in the text of the publication

five-point scales[24]; degree of perceived similarity with the described persons on two five-point scales for attitude and interest similarity (Henry & Cumming, 1992); criticism and intrusion in the described relationships on two questions (first, "*When people get together they occasionally ask each other questions about things that are going on in their lives. When your _____ asks you questions about your own life and affairs, do these questions sometimes feel like criticisms?*" and second, "*Do these questions sometimes feel like intrusions into your personal freedom?*"), which were rated in five point-scales ranging from "never" to "very often". Older adults were also interviewed and asked to describe aspects of their relationships with one child with whom they got along well[25], with one child with whom they got along less well[26] and with friends.

Results report internal consistency on all multi-measures with alpha coefficients varying between .85 and .97 for both older and younger participants. In the demographic data collected, only general health was a significant predictor of life satisfaction for both groups at a .05 level.

Contrary to the author's predictions, older adults reported relationships with their positive children as being better than with their friends. In relation to motivation, the interaction with friends and negative children was more non-self-determined extrinsically motivated and the interaction with positive children was more intrinsically motivated. With respect to relationship quality, criticism and intrusion were significantly correlated with children, but not with friends. Because relationships with children were rated as

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[24] *"I interact with ________ because I am supposed to, or because I feel obliged to" (non-self-determined extrinsic motivation), and "I interact with ________ because I enjoy interacting with them" (intrinsic motivation).*

[25] Author classified these as "*positive children*"

[26] Author classified these as "*negative children*"

better than with friends, older adults were less critical of questions into their personal issues when asked by their children in general, but experienced inquiries as being less invasive if made by positive children.

For younger adults, quality relationships, rather than frequency of contacts with parents, were consistently more important for life satisfaction, whereas frequency of contacts with friends was not significant. They also described their relationships with friends as being better than with their parents, suggesting that older adults perceive family relationships more positively than younger adults.

Although the study had a complex design, involving multiple tools[27] and variables, its methodological implementation was mostly sound and provided enough detail to track/follow the statistical tests and analyses performed in the preliminary analysis: 1) all of the multi-item measures were analyzed for internal consistency for both older and younger adults; 2) demographic variables (age, gender, general health, income, education and marital status) were entered in a regression predicting life satisfaction, in which only general health was a significant predictor (older adults $\beta=.32, p>.05$ and younger adults $\beta=.26, p>.05\beta$). General health was also the only demographic variable with a significant Pearson correlation with life satisfaction (older adults $r=.26, p=.02$ and younger adults $r=.32, p=.02$). Demographic variables were not clearly associated with the relationship variables.

Additional statistical procedures were: zero-order correlation (involvement with friends and children); and multiple regression controlling for health (first entering health,

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[27] If considered that use of some and not all items of certain scales were used is acceptable

then second entering relationship variables). Different regression equations were used for positive children, negative children and friends. For older adults, relationship quality was a significant predictor of life satisfaction in all three kinds of relationship.

On relationship quality, mood and motivation, ANOVAs and also a pairwise comparison using the Bonferoni adjustment procedure were performed. Older adults reported considerably better relationships with their positive children than with their friends and with their negative children. For interaction motivation, there was a smaller non-self-determined extrinsic motivation for interactions with positive children than with friends. There was a greater intrinsic motivation for interactions with positive children.

On determinants of relationship quality, correlations were mostly significant for family relationships and were non-significant for relationships with friends. Older adults took questions asked on personal issues by positive children as less critical than when asked by negative children or friends.

Overall, the hypothesis that life satisfaction was related to both qualitative and quantitative aspects of involvement with friends and family was supported. Not only were these forms of involvement important to older adults, but also the quality of involvement was more valued than contact frequency. The quality of relationship with friends was the most significant aspect that influenced their life satisfaction. However, contrary to initial predictions, relationships with friends were not rated as more positive than with family members. Thus, the second hypothesis on motivation was not supported, since interaction with friends was more non-self-determined extrinsically motivated whereas the interaction with positive children was more intrinsically motivated. Finally, the last hypothesis confirmed intrusion and criticism as delicate issues, not regarding to frequency but to how they are perceived, i.e., as being less intrusive if asked first by positive children, followed by negative children and then by friends.

Though participants rated their present health as "average" (M=3.1), values for each group were not stated, leading the reader to believe that both older and younger adults had similar values. The author adequately recommends caution in the interpretation on the study's multigenerational comparisons, since individuals were not related. This study cannot be generalized because it was composed of mostly women, self-evaluated as healthy and that lived in older adult apartment complexes, on which there was no description in terms of facilities and levels of independent living.

In health and social sciences, formal and informal relationships and networks are found to work as both empowering (Paterson, 2001) and as social support resources (Steketee et al., 1997; Reynolds & Scott, 1999; Parchman, Pugh, Noel, & Larme, 2002) in older adults' lives. Thus, in spite of the design, site, health status, and the differences that existed in social and policy issues between the time in which Thralow & Watson (1974) and O'Connor (1995) conducted their studies, both works indicate that intrinsically and extrinsically motivated relationships may affect self-care.

Motivation and Self-Efficacy

In recent years Bandura's self-efficacy theory was supported by a number of studies. For example: Lachman, Weaver, Bandura, Elliott, & Lewkowicz (1992) on evaluating methods for improving memory performance and beliefs about memory ability and control; Mendes de Leon et al.,(1996) on the interaction effect between self-efficacy and change in physical performance; McAuley et al. (1994) on a randomized control design in an effort to examine the effects of an efficacy-based intervention in enhancing exercise adherence in a large sample of formerly sedentary middle-aged males and females; Senecal, Nouwen, & White (2000) on a motivational model of diabetes dietary self-care, which postulates direct links between self-efficacy/autonomous self-regulation, and adherence/ life satisfaction; Lang (2001) on the relationship between perceived control over development (PCD) and subjective well-being (SWB) across adulthood; and Lorig et al., (1999) on the effectiveness of a self-management program for chronic disease designed for use with a heterogeneous group of chronic disease patients and (2001) on participants' experience of improvements or less deterioration than expected in health status and reductions in health care utilization. Yet, most research articles resulting from a search of PubMed and PsyInfo entries for the group of keywords self-efficacy, motivation, self-care and older adults refer to the word motivation but do not present its definition and features, assuming that the reader has extensive knowledge of the construct or demanding that the reader to further research to better understand the theoretical background of the studies. This is a potential limiting difficulty for readers who are assumed to know the definition and perspective of motivation under social cognitive theory. As stated in Bandura's work (1991, 1997) motivation is:

> *"A general construct that encompasses a system of self-regulatory mechanisms. Attempts to explain the motivational sources of behavior must specify the determinants and interviewing mechanisms that govern the three main features of motivation: selection, activation, and sustained behavior towards certain goals"* (1997, p. 228).

From a self-efficacy perspective, people motivate themselves by the kinds of goals, aspirations and challenges they set, outcomes they expect, their behavior to produce desired effects, the costs and benefits involved in the task at hand, and what they perceive as causes of their successes and failures. For example, if older adults cannot perform given self-care practices and they attribute the cause to not having worked hard enough or having used the wrong strategy, then this would lead them to try to double their efforts, which would sustain motivation. But if they believe that their failure was due to basic deficiencies, then self-efficacy beliefs would become a dis-incentive, which is demotivating or may lead older adults to condemn themselves and to go into depressive modes/states.

In social cognitive and self-efficacy theories, human motivation and acts are regulated by forethought (Bandura, 1997) and influenced by three motivators that stimulate individuals by the kinds of goals and aspirations they set. The first is how people attribute their successes (e.g., success based on the efforts of others) or failures, i.e., to deficient capabilities or to insufficient effort, strategies or adverse conditions. The second relates to expectancy value theories, which assume that motivation is a function of one's expectation, and that a certain pattern of behavior will produce a given result in relation to the value placed on those outcomes. The third category of motivators is goal properties (i.e., specificity, challenge and proximity) and self-motivation (Bandura, 1997). Under these latter conditions, goals do not motivate behavior directly. They motivate behavior only to the extent that they create self-investment, investing one's own energy in that goal attainment. So in order to get that motivating effect, people have to have a goal and need some kind of challenge at some standard (intrinsic or extrinsic) by which they are going to evaluate themselves. They also need feedback on how they are doing relative to that goal. Thus, in social cognitive theory, besides having a goal, older adults need to believe that they can pursue the specific goal, what Bandura calls self-efficacy.

Intrinsic and extrinsic factors related to self-efficacy, such as mastery, encouragement from a credible source, and vicarious experience (i.e. see individuals of a similar cohort or situation perform a specific activity) and physiological and affective states influence the adoption and maintenance of health behaviors. This is demonstrated in Resnick's (2001) and McAuley et al.'s (1994; 2000a; 2000b) research on exercise in older adults.

Because self-efficacy will be described in detail in the Methods chapter and a full review of research focused on self-efficacy is beyond the scope of this section, Lorig et al.'s (2001) longitudinal study on self-efficacy and patients' self-management was selected for this section. Based on Bandura's social cognitive theory and using self-efficacy training as an intervention to enhance motivation for health behaviors, the longitudinal study was designed as a follow-up of a randomized clinical trial in a community-based, peer-led Chronic Disease Self-Management Program (CDSMP)[28] and aimed to assist persons with chronic disease develop self-management skills. The main hypothesis tested in this study was that over a 2-year period individuals who participated in the CDSMP would experience gain or less deterioration in health status and a decrease in utilization of health care services.

The self-efficacy based intervention of the CDSMP was administered at community sites by a pair of peer leaders[29] who had received a 20-hour training on the

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[28] Which is based on the generic principles of the Arthritis Self-Management Program (Lorig, 1985, 1993; and Stanford Patient Education Research Center, 1997).

[29] Seventy-one percent of the leaders had one or more chronic diseases.

program. The intervention was delivered over a period of seven weekly 2½ hour sessions. Participant groups were composed of 10 to 15 adults of different ages and diagnoses. Family members were welcome. The content of the program ranged from adoption of cognitive self-management techniques, nutrition and social support, to communication skills, problem solving and decision-making strategies[30].

Over a 4½ year period, a total of 1,140 community-dwelling adults who were 40 years or older and had a diagnosis of heart disease, lung disease, stroke or arthritis were recruited to participate in a randomized trial, through announcements, talks and notices. However, since data was collected right after joining the program, at 6 months, at 1 and 2 years, only 831 participants were eligible for the follow-up because participants who joined the program after the first 30 months could not complete the required 2-year data and participants who joined the program after the first 36 months could not complete the required 1-year data required for the follow-up. Data collection ended 4 ½ years after the first group entered the study (Appendix B).

Participants who attended at least one out of seven CDSMP sessions (Mean attendance = 5.7) and completed the 1-year questionnaire were included in the study. All participants completed informed consent and questionnaires in the initial 6-month period. Upon returning the initial tools / questionnaires, which comprised 1) the self-rated health scale used in the National Health Interview Survey; 2) a modified version of the Health Assessment Questionnaire (HAQ) physical disability scale; 3) the Medical Outcomes Study (MOS) energy fatigue subscale; 4) a "slightly" modified version of the distress

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[30] Full content published in "*Living a Healthy Life with Chronic Conditions*" (Lorig, 1993) - A copy was given to each participant, which worked as a guide.

scale from the long-form MOS health distress scale; 5) the Social/Role Activity Limitation Scale (Lorig, et al., 1996); 6) two combined scales for self-efficacy (Lorig et al., 1996); 7) participants' self reports of health care utilization during the prior 6 months; and 8) a Self-Efficacy scale, which combined two other scales developed and validated for the CDSMP (Lorig, et al., 1996). Participants were randomized to receive the CDSMP at the beginning of the program or half a year later. Six months later participants assigned to wait received the CDMP. Seventy per cent of the wait group participated in the CDSMP.

In the data analysis, t-tests were used for differences in baseline demographics, health status, utilization, and self-efficacy variables between those who were eligible for the 1-year program and those who were eligible for the 2-year program. Contingency tables (X^2) were used for three dichotomous variables (gender, non-Hispanic whites and married). Baseline characteristics of participants who completed the study and of those non-completers were compared through *t*-tests. Matched pair *t*-tests were used for testing changes in health status, utilization and self-efficacy at baseline and 1 and 2 years. The authors describe that a series of multiple regressions were done only for the 1-year data for purposes of maintaining enough statistical power. Variables controlled for were age, gender, education, ethnicity and marital status. In order to verify the effects of self-efficacy on utilization, the authors – controlling for baseline utilization - predicted 1-year levels of utilization as a function of changes in self-efficacy during the initial 6 months and baseline levels of self-efficacy.

In comparison to their baseline status, participants showed a significant increase in perceived self-efficacy, reduction in health distress, and a reduction in the number of visits to physicians/ERs at 6 months, 1 and 2 years. Even though an increase in disability was observed in the first year, no significant deterioration was observed between 1 and 2 years. Based on the reduction in health care utilization, i.e., visits to physician/ER at 1 and 2 years, the authors examined the relation between self-efficacy and utilization of services. At 1 year, a decrease in utilization was associated with higher self-efficacy at baseline ($P<0.0001$), and the greater the 6-month self-efficacy improvement ($P=0.02$), the lower the utilization at 1 year.

The main hypothesis tested that over a 2-year period CDSMP participants would experience gain or less deterioration in health status and a decrease in utilization of health care services; this hypothesis was partially confirmed. Despite increased disability over time, patients' pain remained below baseline, their self-efficacy increased and their outpatient visits declined substantially.

The CDSMP design was comprehensive, including: 1) exercise; 2) cognitive symptom management techniques; 3) nutrition; fatigue, sleep, emotions (fear, anger, depression) management; 4) medication and community resource use; 5) training in communication with health care providers and others; 6) health-relate problem-solving; and 7) decision making strategies. However, similar to other studies using social cognitive theory as a theoretical foundation and having development of self-efficacy used as an intervention to improve health outcomes, the discussion section does not refer to motivation as facilitating or hindering participation in the CDSMP as well as achievement of the desired outcomes.

The authors acknowledged that results should be interpreted with prudence due to the existence of drop outs and non-completers - who attended a smaller number of sessions and were worse off than completers in all health status variables. Except for those participants who were too ill to complete the study (1-year = 45 and 2-year = 60) and those who died (1-year = 18 and 2-year = 40), the study would benefit from asking participants what helped and what hindered them from continuing to attend the program and to perform self-care practices as conceptualized by the CDSMP.

Thus, from older adults with chronic disease lived experience perspective, the question of what it is that helps or makes it more difficult to maintain self-care practices in the long run remains unanswered.

Conclusion

Even though not all chronic diseases are life threatening, they impact the quality of life, health and economic status of older adults, both at the social and individual levels For the society, heart disease and diabetes as chronic diseases stand among leading causes of morbidity and death in older women (United States Department of Health and Human Services, 1999) and represent a major concern. For the individual, the management of chronic diseases is challenging and involves comprehending the many interrelationships between mind and body, between cognition and emotions, and between social expectations of health behaviors while trying to live within a given circumstance (Paterson, 2001).

In addition, although health care practitioners may have specific procedures by which to examine and watch a person's physiological status, it is only the person her or himself who has to comprehend all the information and decide whether that information is adequate for her/his treatment (Thorne et al., 2002). Furthermore, besides being long lasting, chronic diseases require motivation for care practices, most of which are to be performed by the community dwelling older person her/himself (Hampson, Glasgow & Toobert, 1990).

The importance of motivation and how it is a current social and research interest is supported by the proliferation in the use of the term in the literature over the past twenty years (Murphy & Alexander, 2000). In addition, studies discussed in this section indicate the complexity of the construct as well as its association with specific terms: levels / ratings (high, low), types (intrinsic, extrinsic), outcomes (adherence, compliance), resources of the self (coping, self-efficacy, health behaviors) and relationships.

In health and behavioral sciences, a number of studies have been designed to provide a better understanding of motivation have tested strategies to get older adults started with self-care practices. However, current research has not been able to capture the full domain of motivation yet, and thus our understanding is still incomplete (Pastorino & Dickey, 1990; Rosenbaun, 1990; Frenn, 1996; Zauszniewski, Chung & Krafcik, 2001; Loeb, O'Neil & Gueldner, 2001).

As indicated earlier in this section, much of the empirical literature on motivation related to self-care practices and to chronic disease lacks any description of the theoretical background upon which the studies are based. Often research reports give the name of the theory but do not provide readers with the principles or foundations on which the theory was formulated. This fact poses significant difficulties to readers who often need to refer to primary or other references in order to follow the researcher's rationale for both study design and interpretation of findings.

The study designs on motivation in older adults have been mostly descriptive, of a quantitative nature, and seeking and testing reliable measures of motivation. These studies have been predominantly carried out with either younger community-dwelling adults or older adults living at nursing homes and / or assisted living facilities.

The research topics referred to as sections in this chapter reflect the empirical focus and findings that have been published in recent years, i.e., intrinsic motivation, adherence, coping, health behaviors, relationships and self-efficacy. However, because older adults living at community settings still have had a modest participation in motivation research, it cannot be assumed that these findings provide an extensive understanding on how motivation is experienced by older adults because: 1) the majority of community-dwelling older adults are women who care for themselves and have one or more chronic conditions (United States Department of Health and Human Services, 1999); 2) quantitative, standardized measures may leave out aspects of motivation that can be better understood from a qualitative perspective e.g., meanings, emotions; 3) motivation needs to be defined and described by those who do or do not experience it; and 4) motivation not only for initiating, but for maintaining, self-care practices in the long run is much desired by health care providers, but continues to be poorly understood at this point in time.

Furthermore, current motivation research seems to suggest that types of motivation (e.g., intrinsic, non-self-determined extrinsic, self-determined extrinsic and amotivation) are differentially effective in promoting specific behaviors, although Cox & Wachs (1985), Cox (1985), Cox et al. (1987), O'Connor & Vallerand (1994, 1998), Vallerand et al. (1995), Guay, Vallerand & Losier (1996), Williams et al. (1998), Murphy et al. (2001) and Wang (2001) do not try to look at different domains of life in terms of this effectiveness. Others (Tharlow & Watson, 1974; O'Connor, 1995; Brillhard &

Johnson, 1997; Williams et al, 1998) look at what actually promotes certain types of motivation (e.g., a supportive environment, autonomy support), which might increase intrinsic or self-determined motivation.

Given this context, a current challenge is to understand qualitative distinctions on how motivation happens in older adults' lives in the long process of a chronic disease. Older women are the majority of older adults who face the challenge of not only acquiring and processing information on the disease before getting started with health care practices: they are expected to maintain self-care practices over long periods of time.

Because a full program of research on motivation is beyond the scope of this dissertation, decisions had to be made in favor of collecting data on motivation for self-care from a more homogeneous group. The intent was to minimize confounding factors (such as differences in culture, ethnicity, gender, age cohort) evidenced in the pilot study, and to focus on 1) how motivation for self-care is experienced by women; 2) chronic diseases that involve medication regimens, constant monitoring and changes (lifestyle, behavior); and 3) chronic diseases that are the leading causes of morbidity and mortality in older women: diabetes and heart disease.

Study Aims

This study seeks to provide a better understanding of motivation, voicing community-dwelling older women's perspectives and lived experiences, on what helps and what hinders them from maintaining self-care practices over time.

Hence, for the outset of this project, motivation was defined as what moves older women towards engaging in and sustaining self-care practices over time. Based on this working definition, this study's aims were:

- To gain a better understanding of factors that influence motivation through perspectives and descriptions of experiences of community-dwelling older women, on what helps and what makes it more difficult for them to maintain self-care practices in the long course of a chronic disease.

- To learn how motivation is described or perceived by older women through accounts of their experiences in maintaining self-care in the long run.

The following chapters present a descriptive theoretical background review on how interrelated motivation systems and theories have developed under different perspectives, and why and how the grounded theory approach will be used to analyze the phenomenon of interest.

CHAPTER II: MOTIVATION, COGNITION, EMOTIONS

Introduction

Chapter one focused on how motivation for self-care in chronic disease has been researched. Approaches have included explorations on how types, tools and associations with adherence, coping, health behaviors, relationships and self-efficacy. However, the physiological, social-cognitive and philosophical perspectives on motivation provide us with tools to explore and understand the complexity of interactions involved in sustaining self-care practices in the long course of a chronic disease.

Gollwitzer, Delius, & Oettingen (2000) describe motivation as what causes human beings to exhibit a combination of behaviors at different points in time, for example, eating, drinking, socializing, achievement seeking. These behaviors do not happen isolated from biological, cognitive, emotional and social aspects. For this reason, the purpose of this chapter is to explore the interface between bio-psych-sociological theories of motivation. It articulates how cognition and emotions are related to older peoples' motivation for self-care.

The first section briefly describes the bio-physiological foundations of needs and drives using the hypothalamus as an example of a reductionistic approach to the study of motivation. It reviews how the biological approach, which is founded on physiological processes, has proven to be widely applicable to studies on biological drives (e.g. thirst, hunger, sleep). Biological theories are described as providing an explanation of how motivation originates from integrated physiological processes (e.g., hormone secretion, neuronal activation, electric conduction, etc). The section concludes with Maslow's theory on human motivation, which is based on needs and drives as having a hierarchical order of importance. That is, people's lower order needs (e.g., physical and emotional well-being) must be satisfied before higher order needs (e.g., influence and personal development) can motivate people. However, this perspective overlooks social meanings and how "low order" needs may be shaped by social meanings and by "higher order" needs.

The second and most extensive section describes Bandura's social cognitive theory, which presents cognitive processes and self-efficacy beliefs as fundamental to human motivation. This theoretical framework is a comprehensive perspective that acknowledges multidirectional influences on motivation from cognitive, personal, behavioral, social and environmental factors. From this perspective, motivation is defined as a general construct and as a multidimensional system that involves interlinked processes. As a psychosocial theory of motivation, Bandura's theory proposes an explanation of motivation in terms of cognitive intentionality (e.g., behavior change, planning and achieving desired outcomes). This section also addresses issues that influence human motivation that are overlooked in social cognitive theory, a psychosocial approach, which is founded mainly on cognitive processes that appear to be applicable to studies of motives - believed to be predominantly human and strategic (e.g. power, control, success needs). The section concludes by indicating how emotions, relational and identity concerns as sources of motivation are left out of consideration in Bandura's cognitive perspective.

The third section describes, from both a cognitive and a philosophical perspective, how emotions are helpful in understanding human motivation and an individual's life-world.

This section concludes the chapter by indicating that despite the fact that the different theoretical approaches are presented as separate or even competing explanations of motivation, they are not mutually exclusive.

Even though the main focus of the proposed study is not biological motivation, the next section starts by briefly describing the relationship between biological and psychosocial theories of motivation, using the hypothalamus as an example of physiological processes influence on motivation. In addition, this section makes reference to Maslow's (1967, 1969, 1987) theory about a hierarchical relationship between physiological, psychological and social needs.

Motivation

Bio-physiological foundations, needs and drives

Biological motivation is studied in terms of physiological mechanisms such as neuronal activation, hormone secretion, and key anatomic-endocrine structures. Modern in vitro and in vivo research techniques provide evidence that the hypothalamus is one of the integrative links between mind and body (Vastag, 2001). The hypothalamus is an important center in the brain that is rich in ganglia, nerve fibers, and synaptic connections (Gupta & Gupta, 2000). It is composed of several sections called nuclei, each of which controls a specific function. For example, together with the septo-hippocampal region, the hypothalamus plays a role in memory, independence and affective behavior (Scherder, 1999; Scherder, Van Someren, Bouma, & V D Berg, 2000). The hypothalamus also is involved in the regulation of temperature, sex drive, blood pressure, heartbeat, metabolism of fats and carbohydrates, and blood sugar levels.

The inhibitory and the excitatory centers in the hypothalamus are influenced by different physiological and anatomical factors that can affect hypothalamic functions. For example, blood-borne hormones such as leptin (Satoh et al., 1999), an adipocyte-derived factor or its synthetic equivalents, are important in food intake and energy expenditure (Mantzoros, 1999), as well as in sensory information such as sight, smell and taste of food, and in fluid intake (Matsuda et al., 1999). The hypothalamus is also affected by environmental and genetic factors (Lupien, King, Meaney, & McEwen, 2000; Wand, Levine, Zweifel, Schwindinger, & Abel, 2001), by learning and experience (Simpson, Snyder, Gusnard, & Raichle, 2001), by emotional and motivational factors associated with cognitive performance (Mayberg, 1997), and is presumed to participate in the establishment of food and dietary preferences quite early in life (Toogood, 2000).

The participation of the hypothalamus in awareness of emotions and pain has been supported by clinical trials (Hsieh et al., 1996; Lentjes, Griep, Boersma, Romijn, & de Kloet, 1997; Blackburn, Cross, Hille, & Slater, 1988; Drolet et al., 2001). However, according to Moffet (1993) and Berne (1998), besides producing specific autonomic effects (e.g., rise in blood pressure, pupillary dilatation), the most distinct role of the hypothalamus is in the integration of effects (Toogood, 2000) into patterns of activity. For example, in a state of alertness and during changing levels of activity, physiological needs are raised and result in increased respiration and sweating. However, it must be noted that many of these hypothalamic influences may not function to restore homeostasis or balance (Berne, 1998), but rather work to integrate responses to heightened emotional states (e.g., fear, love, anxiety) in order to reorganize the body internally to deal with a new environmental demand or emotional changes (e.g., an older woman walking on her own in a deserted neighborhood at night; a student going though a final examination). Thus, the integrative role of the hypothalamus is believed to be one among many connecting levels between physiological and environmental aspects of motivation.

Hypothalamic functioning helps us to understand that from a physiological perspective, needs, drives and internal and external demands interact not only among themselves but also with and within the physical and social environments as underlying components of motivation. In this sense, reductionist approaches have been successful in elucidating the physiology of motivation (e.g., the hypothalamus) and the mechanistic or basic levels of functioning that explain biological needs and drives. These approaches focus on the description of systems and subsystems, which are part of a person. Nevertheless they overlook the multidirectional influences and relationships of bio-psych-social aspects of human motivation.

A comprehensive discussion of the studies on needs and drives conducted in genetics, anatomy, physiology, and biotechnology, which have added substantial knowledge to the physiological underpinnings of motivation, is beyond the scope of this chapter. Moreover, these studies overlook theoretical foundations encompassing cognition, social processes, relationships, values and experiences that are fundamental to a more extensive understanding of motivation as experienced and manifested in the person's world. Additionally, needs and drives rarely come as isolated processes but are rather almost always mixed with meanings and emotions. Therefore, human motivation cannot be explained purely as a result of physiological processes.

Maslow's Theoretical Model

Human motivation involves different aspects of physiological and psychosocial needs and drives. Early efforts to understand these relationships and influences stem from Cannon's (1932) work on the concept of homeostasis (referring to a state of equilibrium), and from Maslow's (1954a; 1971, 1987) work that suggested that physical and psych-social drives have a hierarchical order of importance or priority.

Historically Maslow's research on bio-psych-social needs and drives started on monkeys (1932), transitioned into more elaborate studies on both monkeys and humans (late 1930s early 1940s), progressed into the proposal of a theory of human motivation (Maslow, 1943a, 1943b, 1954b) and finally evolved into the development of a theory of meta-motivation (Maslow, 1967, 1969, 1987).

Maslow's late work on a theoretical model and its conceptualizations has made noteworthy contributions to nursing science and practice. In the twentieth century, nursing was highly influenced by his definition of the restoration of physiologic homeostasis as a basic need. These needs were further hierarchically differentiated between higher and lower needs on the basis of the principle of relative urgency and potency.

Needs are satisfied by forms of activities or dispositions defined as drives (Wagner, 1999; Gupta & Gupta, 2000; Gollwitzer et al., 2000). Wagner (1999) describes these needs as either primary (homeostatic) or secondary (non-homeostatic). Primary needs are defined as those physiological or psychological drives that consciously or subconsciously motivate behavior towards need satisfaction. For example, to eat (Campfield, Smith, Guisez, & Devos, 1995), to drink (Montain, Latzka, & Sawka, 2000), to have sex (Sarrel, Dobay, & Wiita, 1998), to avoid danger (Maslow, 1987). Secondary needs are those that most often become more important due to their connection or association with primary drives and thorough learning processes. For example: affection, socialization, sense of control, and dominance.

The studies cited above utilized Maslow's theoretical model and provided additional empirical evidence for its relevance. However, while Maslow's research was considered a benchmark work and a major step forward in the study of motivation at the time of its publication, it provides a relatively simplistic and schematic description in which internal needs originate from deficits that arouse a drive to satisfy initial need (s) and to restore homeostasis. Today the application of Maslow's findings to guide research on needs, drives and motivation is limited because it makes insufficient reference to other sources of influence an individual's motivation (e.g. cognition, society, environment, concerns, experiences, history, meanings, and emotions- See Figure 1). Although some physiological drives may influence some of our decisions, Maslow's hierarchy of needs cannot explain the human motivation for a hunger strike or a refusal to take liquids.

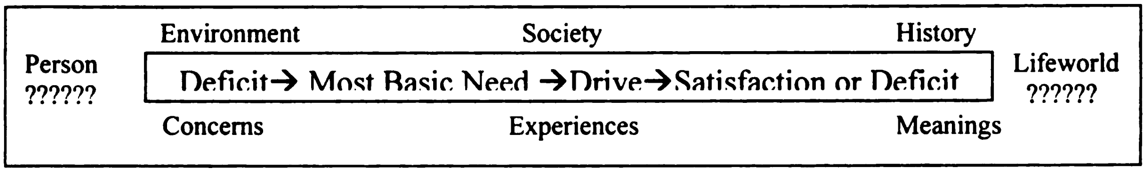

Figure I. Simplified schematic critique of Maslow's theoretical unidirectional view of motivation. The gray area represents aspects that are not addressed in his theory and the interrogation marks within it represent the unaccounted personal or social meanings, all of which are capable of modifying a person's hierarchy for need satisfaction. The white area represents Maslow's theoretical model.

Two further limitations with regard to basic needs in Maslow's research and theory are: 1) that they do not account for the fact that basic needs do not exist as uninterpreted atomistic elements devoid of their psychological and social meanings; and 2) physiological responses to motivation and emotion flow in many directions (e.g. a drive to protect oneself may block out hunger). Therefore, motivation is co-constructed and interactional, i.e., in addition to physiological systems, needs, and drives, human motivation is affected by cognition and emotion, as argued next in this paper.

This discussion is set off by the following section, which begins with a review of Bandura's Social Cognitive Theory and its importance as one of the theoretical foundations for the proposed study. It then discusses where this theory falls short in contributing to a more comprehensive understanding of what is involved in motivation for self-care in older adults.

Bandura's Social Cognitive Theory and Motivation

Social Cognitive Theory was derived from Miller and Dollard's (1941) Social Learning Theory. Even though Miller and Dollard (1941) formulated a theory of social learning and imitation that moved away from behaviorist concepts of associationism and favored drive reduction principles, it still did not take into consideration concepts that Bandura and colleagues felt were critical (Pajares, 2002). These included: 1) The possibility that individuals can construct totally new, innovative responses, and 2) The existence of processes of imitation[31], i.e., transferring behaviors from one situation to another, which can occur at a later time and without reinforcements.[32]

In the early 1960s, Bandura, Ross, & Ross' (1963) studies and subsequent publications expanded Miller and Dollard's (1941) Social Learning Theory by including observational learning and vicarious reinforcement, addressing issues of late, non-reinforced imitations. Then in the 1970s, Bandura introduced self-beliefs as a key element in his refined theory. In the mid-1980s Bandura's work expanded further in a more comprehensive view of human functioning through the publication of "*Social Foundations of Thought and Action: A Social Cognitive Theory*" (Bandura, 1986). In this conceptualization of a new social theory, Bandura replaced "learning" with the construct

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[31] Imitation of a specific action but in different contexts / situations / as opposed to Miller and Dollard's (1941) similar contexts / situations

[32] E.g.: A child receives a Bobo doll (doll that rolls back and forth) as a gift and learns/is taught to hit on it. As time goes by, besides hitting the Bobo doll or even other toys the child may hit people, who are neither objects nor toys. The child did not "learn" to hit people, but does it anyway.

cognitive in the name of the theory to underscore the importance of cognitive processes in the regulation of human agency, beliefs and behaviors in changing societies (Bandura, 1995).

In Bandura's social cognitive theory, sometimes referred to as self-efficacy theory, motivation is a multidimentional system, presented as having three different extensive categories (Bandura, 1986, 1991) that are part of people's lives and that interact continuously. The first category includes bio-physiological conditions that evolve from genetic, cellular and physiological responses to internal and external events. The second includes social incentives, which entail positive and negative experiences, basically in concurrence with an individual's perception[33] of other people's reactions of interest, approval, disapproval or censure. The third is cognition[34], in which by exercising forethought, people motivate themselves and anticipatorily guide their actions towards goal achievement. In Social Cognitive theory, these three different classes of motivators are aspects that influence the regulation of human agency.

Human Agency

Human agency reflects acts intentionally done (Bandura, 1997, 2000b; Beauchamp & Childress, 2001), with specific characteristics that work through consciousness (Bandura, 2000b). Hence, in a social system context, individuals function dynamically as sentient agents of experiences, rather than simply undergoers of experiences (Bandura, 1999). Thus, through a process of "*reciprocal determinism*"

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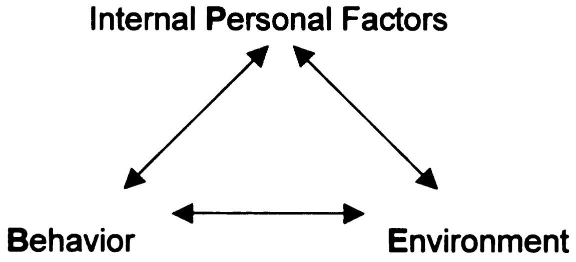
[33] OED (2003). The world experienced (otherwise called the 'field of consciousness') comes at all times with our body as its centre, centre of vision, centre of action, centre of interest; a situation regarded as a system of psychological forces with which an individual interacts; socially observed.

[34] OED (2003). 'Cognitive' is used to mean 'empirically verifiable or else analytic.'

(Bandura, 1986, p.23), behavior, internal personal factors (cognitive, affective and biological) and the environment constantly interact at varying strengths, and influence one another bidirectionally, as schematically represented below.



[35]*Figure II.* Schematization of the relationship among the three classes[36] of determinants in a triadic reciprocal causation (Bandura, 1997, p.6)[37]

In Social Cognitive Theory, human agency assumes an interactive model (Bandura, 1986, 1999), where thoughts exist in conjunction with neuro-physiological events, concurrent with the concrete, psychosocial aspects of motivation. For Bandura (1997) human agency has four main characteristics: intentionality, forethought, self-reactiveness[38], and self-reflectiveness. Intentionality is a deliberate resolution to do specific activities or "*to bring about a certain state of affairs*" (Bandura, 1986, p. 467). This entails planning towards a desired outcome but does not grant success in itself, since mistakes, biases or even unpredicted events may bring about unexpected or unwanted results. Considering older adults' life and health experiences in combination with the wide range of presentations of chronic diseases, intentionality as a deliberate resolution

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[35] Bandura, A. (1997). *Self-efficacy: The exercise of control.* New York, NY, US: W. H. Freeman & Co, Publishers.

[36] Because the determinants can be broken into: an individual's own behavior, which can vary; interpersonal factors such as biological, cognitive and affective; and the physical and/or social environments.

[37] These factors influence human agency at different strengths, at different points in time.

[38] Term used by Bandura (1986)

alone does not guarantee maintenance of self-care practices, given the difficulty of foreseeing all possible interactions and influences right at the outset.

Forethought is evidenced through prominent thoughts about desired outcomes. These thoughts are likely to facilitate adoption of attitudes and behaviors to succeed and are a step ahead in planning, working as self-motivators that channel actions towards an anticipated / desired result. As indicated in Bandura (1997), even though future health outcomes are not causes or motivators of actions at hand, they can be cognitively represented in the present and converted into current motivators for adoption of self-care practices. In cognitive motivation, "*people motivate themselves*" (Bandura, 1997, p.122) and the exercise of forethought works as an anticipatory guide for their actions.

Self-reactiveness involves taking specific sets of actions along with motivating and regulating their implementation (Bandura, 2000b). Self-reactiveness is a combination of five basic contributory functions that enable self-regulation of motivation (Bandura, 2000a; 2000b): "*self-monitoring, personal standards, evaluative judgment, self-appraisal and reaction*" (Bandura, 1991, p. 150). Once a set of actions is intentionally taken towards the achievement of a specific outcome, performance is continuously compared and judged based on one's personal standards. When people's self-evaluation matches their personal standards, their efforts are directed and sustained towards the achievement of the desired outcome / goal. Understanding how self-evaluation and personal standards operate in older adults' goal-setting requires further knowledge about individual and group backgrounds and beliefs because these beliefs contribute to motivation in determining goals people set for themselves, amount of effort they apply, how long they persevere in difficult times, and their resilience in the face of disappointments (Bandura, 1995). On the other hand, self-reactiveness and goal setting may be a poor fit for addressing motivation, relational concerns, existential meanings or even older adults' everyday life concerns (e.g., loneliness, comfort, belonging) because an individual's concerns and meanings can change over time.

Self-reflectiveness is a *metacognitive activity*[39] (Bandura, 1986, p. 20) that enables people not only to think critically about their attitudes and experiences but also to reflect upon their own thinking processes. In other words, it is people's evaluation of the motives, values, and meanings underpinning their objectives as well as their choices on what subsequent action to take to achieve desired outcomes. Improvements in education, information and knowledge socialization may provide more resources for self-reflectiveness, which in turn may influence older adults' motivation for maintaining self-care practices, reducing risky behaviors and living longer, healthier lives. Thus, self-reflectiveness may become the enabling factor supporting and being supported by social changes such as the health care shift from a disease model to a health model.

However, the four aspects of human agency above still do not account for factors such as emotions (e.g., sadness, love) that may interfere with helping and/or making it more difficult for individuals to sustain health practices in the long run. For example, even if an older adult with diabetes is able to overcome physiological needs and drives (e.g., polyphagia); plan, implement and reflect upon her/his self-care plan; and have

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[39] Awareness and understanding of one's own thought processes, esp. regarded as having a role in directing those processes. Examples of meta-cognition in memory are recollection and intentional learning. The two main aspects of metacognition are: 1) Description of the control process in which active learners engage as they perform various cognitive activities; and 2) A process that may underlie the very important processes of generalization and transfer of strategies learned (Marzano & Marzano 1988; OED, 1989)

positive reinforcers for keeping the diet, she/he may not choose to stay on the diet because over time an individual's order of priorities can change, such as observed in the critique to Maslow's work. Furthermore, the reason(s) for change in this order of priorities could be mistakenly perceived by health care providers as "lack of motivation" to keep on going with the diet, or even as the individual's "lack of agency." In fact, this is one more argument against standardized methods (e.g., scales such as the EMS and the HSDI presented in Chapter I) which are not capable of capturing the full domain of motivation and do not address multiple interactions that happen along the course of a chronic disease.

Modes: Personal, Proxi and Collective

Social Cognitive Theory makes a distinction among three types of human agency: personal, proxy and collective (Bandura, 2000b, 2002). In direct personal agency people manage their lives by acting individually and directly in order to influence themselves and their environment. In proxy-agency, which is dependent on the environment and on society, people seek to obtain desired outcomes by approaching other people who have the power to influence, the resources, or the expertise to act so that they benefit from these actions. Collective agency can only be exercised by means of group action, through inter-reliant effort by pooling together resources to accomplish the desired outcomes.

These agency modes do not exist in isolation but they are exercised every day, at different points in time, according to people's needs. However, in a meaningful lifeworld one or more of these modes may assume greater importance than the others at given moments, depending on the person's concerns, cultural background, social context.

To maintain a community-dwelling status, older adults with chronic diseases have to cope with changing personal needs for support and resources (Hampson et al., 1990, 1997; Mendes de Leon, Seeman, Baker, & Richardson, 1996; Ford et al., 1998; McAuley, Blissmer, Katula, Duncan, & Mihalko, 2000). Thus they need to skillfully manage and apply different agency modes to produce desired outcomes and to promote self-renewal and adaptation for sustaining self-care practices in an ever-changing, multifaceted life and in different social contexts.

Self-Efficacy

As discussed in the previous section, people are capable of self-reflection and are able to influence their own actions. In Social Cognitive Theory, perceived self-efficacy is a core issue that is described as *"the beliefs in one's capabilities to organize and execute the courses of action required to produce given attainments*" (Bandura, 1997, p.3). It is not the number of skills that people have, but what they believe they can do with whatever skills / resources they have under different circumstances (Bandura, 1997).

In Bandura's framework, self-efficacy beliefs are developed though different strategies or sources: mastery experience, vicarious experience, modeling, social persuasions, and physiological and emotional states. Mastery is based on people's lived experience of success and failure, on what skills and how much effort was required to persevere and to overcome obstacles. Vicarious experience is based on observational learning, and is regulated by attention, retention, reproduction/production of a response and motivation. Modeling is based on the assumed similarity of the model. The model's persuasion power is directly proportional to its similarity, in the event of either successes or failures. Model competence and aspirational modeling also promote incentives for self-development. Social persuasion is structured around the effects of evaluative feedback given to people based on their performance. In this sense, feedback highlighting personal capability promotes self-efficacy beliefs.

From a social-cognitive perspective, self-efficacy beliefs are fundamental for understanding motivation, personal accomplishment and well-being because if people do not believe that they can obtain desired outcomes there is reduced incentive to take action and to persevere in the face of adverse situations (Bandura, 1986, 1997; Pajares, 2002).

Furthermore, self-efficacy beliefs contribute to a person's psychosocial functioning, because beliefs about one's capacities operate as a group of determinants for behavior, thinking patterns and emotions experienced in challenging situations. Again, self-efficacy beliefs may change over time and so does what matters to people. For example, an older woman may have self-efficacy beliefs that she is able to initiate and maintain a physical activity program. However, after initially getting started, she not only interrupts the program but also reduces the number of times she walks to the grocery store because her husband has moved into an advanced stage of COPD and she decides that spending as much time as possible with him means much more to her. In other words, self-efficacy beliefs may play an important role in motivation for initiating and maintaining self-care practices towards goal achievement, but it is subject to modification by events that happen along the course of a chronic disease that change an individuals's order of priorities.

Health Care Practices

Social Cognitive Theory advocates using psychosocial methods in public health for promoting health behaviors. Bandura (1997) argues that the decrease in premature deaths and morbidity has been more the result of extensive implementation of healthier lifestyles than from health care technologies. Furthermore, the author suggests that community-wide endeavors lead to health benefits by reducing health-risky behaviors. From Bandura's perspective, perceived self-efficacy can be used in public health on the study of health and psychosocial determinants, acting at two key levels. At a basic level self-efficacy can be used to look into how biological systems, which act as mediators between health and disease, are affected by coping. At the next level, perceived self-efficacy can be used to investigate the use of direct control over modifiable behavioral, social and environmental determinants of general health conditions.

However to use self-efficacy in public health tools when attempting to identify how motivation is experienced by groups of people, one needs to understand how individual and collective beliefs interact within a given social context. Furthermore, how these beliefs influence implementation and maintenance of self-care practices in the long run cannot be seen apart from barriers (e.g., crisis situations; interactions among physiological, social and life events) that people have to deal with in order to change and sustain self-care practices. In Social Cognitive Theory these barriers are indicated as cognitive, situational or structural. At the same time, because competing incentives can be pleasurable (e.g., having cake and soda with church committee members), they can make adoption and/or maintenance of healthy behaviors difficult.

In addition to awareness of barriers, the management of chronic diseases in old age involves thorough understanding of treatment regimens, which frequently include multiple prescriptions and a number of self-care guidelines. In studying self-efficacy, Taal, Rasker, Seydel, & Wiegman's (1993) work on poor adherence to treatment indicated that, rather than incapacity, problems may be founded more on the clients' lack of self-efficacy to do what is "prescribed" to them. In addressing this sort of difficulty, Holman & Lorig (1992) and Lorig et al. (1999, 2001) applied Social Cognitive Theory as the methodological and theoretical foundations for their intervention studies. The researchers devised modules for self-management of chronic disease that include cognitive pain control techniques, self-relaxation, proximal goal-setting combined with self-incentives as motivators to increase physical activity levels, problem-solving, use of community resources location and medication management skills. The results indicated that clients can develop capabilities through modeling of skills, guided mastery practice and informative feedback. However, they made no reference to individuals not following prescribed treatment but truly believing they are able to follow them; what was helpful in the implementation of the skills learned in the training programs in the studies; nor how participants' meanings and emotions may have additional and unaccounted for interactions or even additive and cumulative effects on following or not following the recommended health practices.

Self-Efficacy in Old Age

"*Self-efficacy issues in older adults center on reappraisals and misappraisals of their capabilities*" (Bandura, 1997, p.198). Changes that occur with aging bring decreases in physical capacities, new patterns of intellectual and memory functioning and a different speed of cognitive processing, thus demanding reappraisals of older adults' self-efficacy.

The availability of support (Ford et al., 1998), physical health status (Resnick, 2001), and psychological health status may alter the level of trust posed by community-dwelling older adults regarding their capabilities and their ability to persevere to overcome a challenge and achieve a given goal achievement. In addition, psychological distress (e.g., depression) and psychological well-being may also influence self-efficacy beliefs and motivation for maintenance of self-care practices (McAuley, 1994; Stewart & King, 1991).

Based on the work of a number of researchers, including Baltes & Baltes (1990, p. 210), Bandura (1997) indicates that in spite of declines in physical and psychological capacities, a high sense of self-efficacy can be sustained in older adults through six processes: 1) Making social comparison of self capabilities with other older adults that are selected for comparative self-appraisal; 2) Changing standards of self-appraisal, 3) Practicing the skills that were developed over time; 4) Integrating comprehensive efficacy information – even though slower, to keep processing information and problem solving; 5) Making selective optimization with compensation by concentrating efforts on what is really important; and 6) Scaling down one's pursuits and/or adopting new roles (for example, continuing in the same field of activity / practice, but performing a different function).

Based on these six processes, reappraisal of self-efficacy and adoption of different strategies and cognitive aids may be a continuous process, with multiple strategies that can be used separately and/or in combination at different phases in life. However, reappraisal of self-efficacy still does not address the issue that older adults' lived time and experiences may also interact with current meanings and priorities for maintaining self-care practices in the long course of a chronic disease, regardless of self-efficacy beliefs.

Motivation in Social Cognitive Theory

According to Bandura (1997), in order to explain the motivational sources of behavior, it is essential to specify contingent and intervening mechanisms that regulate the three core aspects of human motivation in Social Cognitive Theory: selection, activation, and sustained direction of behavior towards specific goals (Bandura, 1991). In his 1997 publication, Bandura defines motivation as "a general construct that encompasses self-regulatory mechanisms." Because motivation involves a number of different interlinked processes as well as levels in terms of selecting courses of action and amount and diligence of effort, it can be understood that besides being a construct, motivation is also a multidimensional system.

As previously noted, in Bandura's (1997) work, human motivation is multidimensional and is mostly cognitively generated through people's exercise of forethought and beliefs in their efficacy, along with the three forms of cognitive motivators: causal attributions, outcome expectancies and cognized goals (Bandura, 1998, 2000a). Each of these motivators has its own corresponding theory.

Attribution theory, as described by Bandura (1997), is related to the motivational effect of retrospective judgments of the causes of people's actions. For example, successes, capabilities and failures may be credited to the amount of effort put in and persistence when things go wrong. It also relates to whether and how people ascribe their failures to poor ability or successes to situational factors (Bandura, 1988). For example, an older woman wants to lose weight, but instead she puts on a couple of pounds. She may think that she failed because she did not put enough effort into sticking to the diet or because she did not know which kinds of foods convert into sugar or even because it was pouring rain for two days in a row and she could not go to the grocery store to get the vegetables she needed.

In a case like the above it is not easy to raise motivation and accomplishments just by changing causal attributions from one type to another. The person can initially feel motivated, but if there are no successes motivation may fade away. In addition, telling people that they did not succeed in self-care practices due to insufficient effort may be demoralizing (Bandura, 1997). On the other hand, telling people they did fine while they are having repeated failures, can harm the reputation / credibility of the attributer (e.g., the health care provider). It may be true that in some cases feedback works as an alternative, an additional strategy to the effect of retrospective judgments of the causes of people's successes and failures. Nonetheless, one cannot assume that this as the prime way to raise motivation in older adults. Because of lack of successes as well as different meanings and interests, there is still the possibility that feedback alone will not sustain motivation for maintaining self-care practices in the long run.

Expectancy-value theory relates to how people motivate themselves and guide their actions by thinking of the outcomes they want to achieve. For Bandura (1986, 1997) this type of motivation is influenced by personal self-standards of values and priorities. In other words, the higher the value of the desired outcome and the higher the expectancy that a specific behavior can secure it, the higher the motivating potential.

The downside of expectancy models is that actions and consequences are both multidetermined and underdetermined by more than intent alone. Emotions may lead people to not consider alternative ways of achieving the desired outcome or to not consider likely consequences of their actions for achieving the desired outcome.

For example, an older woman who has diabetes wants to lose weight before the commencement ceremony of the granddaughter's graduation. This weight loss will have two potential beneficial effects: it will allow her to fit into her favorite dress and it will help lower her high blood pressure. Even though she is rationally aware of how harmful crash diets can be, she decides to take up a weight loss program she saw on TV instead of following the prescribed combination of diet and exercise that was recommended by her health care provider, because she wants to lose weight in a short period of time. However, if we continue with this woman's story: she manages to lose quite a lot of weight, lowers her blood pressure, fits in the dress and feels really accomplished. So far we could say that the expectancy model worked towards achievement of the weight loss. However, the woman could not make it to the graduation ceremony because she fell, due to hypoglycemia, and broke her hip. Thus, an additional critique on expectancy-value theory in relation to motivation for self-care is that it does not account for unexpected interactions (e.g., physiological, social), events and for non-rationality or competing concerns.

Goal theory is related to personal challenge and the evaluation of one's own accomplishments, providing an important *cognitive mechanism of motivation and self-directedness* (Bandura, 1988). This theory is based on standards and also involves comparisons. In addition, goal intentions are mediated by affective self-evaluation, perceived self-efficacy to achieve the established goal/outcome and adjustment of personal standards (Bandura, 1996). In goal motivation, important aspects are: self-influence, feedback from valued individuals or groups and goal properties (i.e., specificity, challenge, proximity) (Bandura, 1997).

For example, a Spanish-speaking older adult receives the diagnosis of diabetes but she is asymptomatic. Every appointment her health care provider says that her lab results can be improved. In one of the brochures she gets at the facility she goes to there is a chart, which becomes her guide towards achievement of her goal: get adequate values for her lab results. She starts following the recommendations but the next appointment is in three months and after her travel to Nicaragua to visit her brother. Even though her self blood test readings show improvement, she wants to be sure she is doing it right[40]. She calls the facility and gets to the computerized triage of calls. There are so many options before she gets to talk to someone that she gives up half way though the call. Thus, from a goal motivation perspective, having access to her health care provider would be an opportunity to get feedback on how she has been doing self-care / health wise and to ask questions she may have.

Even though standards such as the chart can be helpful, having goals without knowing how one is doing does not help one stay motivated over the long run (Bandura & Cervone, 1986; Bandura, 1997). There is the goal challenge, but without feedback on one's performance, there is no reinforcement towards goal achievement. Moreover, there are competing incentives such as the planned, expensive trip to Nicaragua. Another critical aspect of goal achievement and motivation in chronic disease is that it is a long life process, which very often requires a great deal of maintenance and readjustment of personal standards.

As indicated above, in social cognitive theory, causal attributions, outcome expectancies and cognized goals are permeated not only by forethought and self-efficacy

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[40] She wants to double check, be reassured / become more confident

beliefs but also by external factors or motivators that may help or make self care practices more difficult to maintain in the long run. However, Bandura's (1986, 1997) social cognitive theory works for strategic, clearly articulated goals; for goals that can be broken into smaller, easier ones; and for thinking about a goal at a time. Furthermore, people have multiple interests and goals and these are permeated by emotions, many of which may be meaningful or relational oriented, rather than explicit, strategic or instrumental.

Even though Bandura's theory has been successfully applied to studies on clinical trials on health behaviors in older adults with chronic disease (Holman, & Lorig, 1992; Taal, Rasker, Seydel, & Wiegman, 1993; Mendes de Leon, Seeman, Baker, & Richardson, 1996; McAuley, Blissmer, Katula, Duncan, & Mihalko, 2000; and Lorig, Ritter, Stewart, et al., 2001), this theoretical approach on motivation is still rationally oriented, based on the premise that behavior can be controlled, planned, and modeled through self-efficacy beliefs.

In spite of the limitations discussed in this chapter, Bandura's perspective on social cognitive theory was chosen for this section because it brings together the different aspects of motivation which are dealt with in separate theories of human motivation, for example, goal, attribution, and self-determination theories. However, in order to expand the theoretical foundations needed for studying motivation, the next section further discusses emotion and motivation from Nussbaum's cognitive perspective. The section concludes and transitions into the philosophic approach on motivation as related to emotions and to the lifeworld of a person.

Emotion and Motivation

Besides motivational processes, affective states are considered another mediating process in Social Cognitive Theory. Bandura (1997) indicates that emotional experiences are involved with self-efficacy beliefs in a sense that "efficacy beliefs affect the nature and the intensity of emotional experiences through the exercise of personal control over *thought, action* and *affect"* (Bandura, 1997, p.137). In this model, beliefs come first, whereas emotions are thought of as impediments or requiring control rather than as "*movers*" or sources of motivation. In a sense, it's the opposite path from Maslow's theory. In Social Cognitive Theory, cognition may affect biological reactions. For example: anxiety and fear may suppress hunger, thirst, etc. In Maslow's theory, biological reactions may affect cognition, since the theorist considers needs and drives as hierarchic and unidirectional motivators. In either case, both theories overlook what matters to the person.

Toates' (1988) extensive review on motivation and emotion from a biological perspective (1961 to mid-1980s), suggests that motivation and emotion should be integrated in the same publications. Even though his work is primarily based on publications in experimental psychology, Young's (1961) characterization of motivation as "*goal direction,*" and emotion as an "*affective state,*" is a good basis on which to understand how these two constructs may operate together, influencing one another as recommended by Toates (1988). Motivation in social cognitive theory is predominantly a cognitive process, influencing and influenced by the environment and society. In Young's theory, motivation is an "appetite," which can be distinguished from emotion by the physiological, organic nature of its origin, since we do not refer to the "emotions" of tiredness, sleepiness, thirst, or pain. According to Young (1961) and Toates (1988), biologically originated feelings are affective but not authentic emotions and what really differentiates motivation from emotion is "*emotions' psychological origin*" (Toates, 1988, p.4) and interaction with environmental factors. In his conclusion Toates (1988) presents his argument in favor of studying motivation and emotions from a more inclusive, holistic perspective by stating that motivation is influenced by combined physiological, cognitive, social systems and emotions. Also in favor of an integrated perspective on motivation and emotion, Khul and Kazen-Saad (1988) indicate that a reductionist approach to motivation provides limited understanding of the experience. According to the authors, a theoretical issue is that people do not always "*perform the action alternative having the highest value even if they are perfectly capable of doing so*" (Kuhl & Kazen-Saad, 1988, p.63). If one considered Khul and Kazen-Saad's (1988) perspective as an approach and applied it to health care, it would suggest that although an individual's preference and observed self-care practices seem to be equivalent, they are not. Based on three empirical studies these authors indicate that volitional efficiency (making of an efficacious, definite choice or decision with regard to a course of action) can only be evaluated in relation to a specific intention the person is focusing on. Even though Khul & Kazen-Saad (1988) do not underscore the importance of environmental and social factors as Bandura (1986, 1997) does, they make a theoretical advance by indicating the need for conducting studies with different levels of analysis on the interplay among volition, motivation and emotion.

For a better understanding of how motivation and emotions interact, one needs to examine what emotions entail. Nussbaum (2001) points out that emotions involve judgments about things that are important to a person. In these judgments, when people consider something important for their own being, they recognize their own sense of need and of being incomplete in a world that does not offer people the possibility of being in total control of internal or external events. Nussbaum (2001) develops her argument on the research of Seligman (1975), Lazarus (1991a, 1991b) and on Ortony, Clore, & Collins' (1988) work on theories of emotion.

The author initiates her argument by describing Seligman's (1975) experimental studies with dogs to investigate depression in both humans and animals and the association of depression with the belief that one is helpless to control the environment one is in. Based on the described experiment, one of Seligman's arguments is that optimism about one's possibilities to achieve significant goals is a major factor in maintaining successful agency – a view very similar to Bandura's (1986, 1997) Social Cognitive Theory argument on personal agency, in which beliefs about one's capabilities constitutes a basic factor in the process of how cognitive motivation for maintenance of self-care practices is regulated.

Nussbaum (2001) then introduces her perspective on emotions through a review of Lazarus's (1991a, 1991b) work on emotions and on Ortony, Clore, & Collins (1988) classification of emotion domains. First Nussbaum describes "appraisals" as when an animal identifies that something he wants is at stake in relation to what is happening in the environment in which he is dwelling. In this case, emotions are ways of concentrated attention and interaction, in which "*the world is appraised in its relation to the self*" (Nussbaum, 2001, p. 106) at a given time. Though Nussbaum asserts that these appraisals are propositions based on beliefs, from a philosophical perspective these "appraisals" are often perceptual and might be considered as meaningful even though they remain tacit and the person may not be able to articulate specific beliefs (Benner & Wrubel, 1989).

Second, Nussbaum describes different domains of emotions as proposed by Ortony, Clore, & Collins (1988): 1) temporal reference (direction in relation to a situation or episode or action past, present or future); 2) self-other distinction, i.e., event evaluation as good/bad for himself or for others; and 3) good-bad distinction, i.e., moral value / above all. Based on the review of Lazarus' work and on Ortony, Clore, & Collins' (1988) classification, Nussbaum (2001) expands the second domain and indicates that there are also four additional categories for emotions that need to be observed: emotions that perceive an occurrence that is good for another person as a good thing (e.g., happiness for a neighbor's grandchild's graduation); emotions that perceive an occurrence that is good for another person may be experienced as a bad thing for another (e.g., envy about the travel ticket and hotel voucher for thirty days in Florida his neighbor got from his daughter – the person hopes he cannot make it); emotions that perceive an occurrence that is bad for another person as a bad thing (e.g., feeling genuinely sorry for your senior girlfriend's loss of her spouse); and emotions that perceive an occurrence that is bad for another person as a good thing (e.g., the person who got the ticket cannot make it to Florida and will stay around for company because he has to go through a surgical procedure and will not have enough time to recover). Thus, considering Seligman's (1975), Lazarus' (1991a, 1991b) and Ortony, Clore, & Collins' (1998) works, similar events may trigger diverse emotional perceptions and cause a number of possible responses and, depending on the processes, meanings and interactions that one experiences at a given moment in life.

Nussbaum adds that in Lazarus' (1991a, 1991b) work emotions are highly salient transactions, which entail an elevated, concentrated attention to the world in which one is dwelling. For Lazarus, this heightened attention usually goes along with an elevated degree of concentrated sensory attention that accounts, in part, for motivational and adaptative importance. In addition, Lazarus (1991a, 1991b) calls attention to the fact that expression of an emotional reaction reveals meanings or what is at stake for the person in the encounter with the physical or social environment.

In summary, as previously indicated in this chapter, Toates (1988) and Bandura (1997, 2002) agree that motivation is goal-directed, and may be influenced by the environment. In order to sustain motivation for self-care practices that are not always pleasurable, one's goal needs to be a priority. Nonetheless, not all goals sustain priority status over time. For example, an older woman with a chronic disease may have the goal to be physically fit for as long as possible so that she can care for her frail, diabetic husband. However, she may not go for her own exercise consistently so that she can stay home with him – also for as long as possible. From a social cognitive perspective, staying at home to care for her frail husband is a competing incentive for pursuing the goal to be physically fit for as long as possible. Thus far, a competing incentive has been identified and acknowledged but it does not account for emotions, salience, meanings, and social interactions in this woman's life.

Considering that one's emotions are intense, salient transactions (Lazarus, 1991a, 1991b) that involve things that are important to a person (Nussbaum, 2001), that have different domains (Ortony, Clore, & Collins, 1998; Nussbaum, 2001), and that are influenced by the physical (e.g., sidewalk) and social (e.g., community) environment, seeking to maintain a self-care practice may be conceptualized as being important to maintain one's physical fitness and to live longer but not necessarily be intense enough to become one's priority. In other words, because emotions may interact / interfere with one's order of priorities, cognition (e.g., self-efficacy beliefs), the identification of beliefs or emotional experiences alone does not account for all aspects involved in motivation for maintaining self-care practices throughout the long course of a chronic disease.

Furthermore, in order to be able to understand what helped or challenged the older woman's motivation for sustaining self-care practices, one needs to reflect upon her lived experience and look back for interactions, meanings, and what is salient in her lifeworld (Merleau-Ponty, 1962).

Grounded theory, the guiding approach for data collection and analysis of this study will be discussed in the next chapter. However, in order to facilitate the understanding of Merleau Ponty's standpoint in relation to a person's lifeworld and motivation, at least one philosophical perspective needs to be included in the current chapter. The following section presents an overview of phenomenology as a philosophical movement, which had an extensive influence on 20th-century thought (Van Manen, 1990, 2001), and presents Merleau-Ponty's perspective on motivation.

Philosophic Thought and Motivation

It was with Husserl's (1859-1938) interpretation that phenomenology became a scientific movement based on the idea that forms of reflection were at the core of human science and philosophic thought (Van Manen, 1990, 2001). As a discipline, phenomenology became a method that sought to describe how the world is composed and experienced through conscious acts. For Husserl, the narrative is supposed to describe -

without pre-conceptions or theoretical notions - what is given to people in immediate experience. In the book "*The Crisis of European Sciences and Transcendental Phenomenology*" (Husserl, 1936/1970 in Van Manen, 1990, 2001), the notion of the lifeworld is articulated *(lebenswelt)* as meaning the everyday world in which people live with an innate, taken-for-granted attitude. In phenomenology, this notion of the lifeworld became fundamental to the development of a more existentially oriented approach, in which the intention is to describe how a phenomenon presents itself in lived experience and human existence (Van Manen, 1990). In other words, Husserl emphasizes that the relationship between perception and its objects is interactive, in the sense that people's consciousness dynamically composes objects of experience, where it is always consciousness-of something (Gubrium & Holstein, 2000).

Even though Heidegger (1927/1962) took a different direction, he carried on Husserl's work. In the book "*Being in Time*" (1962) Heidegger indicates that the study of people's forms of "*being in the world*" is what matters. That is, to let the things of the world speak for themselves. His fundamental questions are: What is the nature (*Being*) of this being? What lets this being be what it is? (Van Manen, 2001). Heidegger points out that: "beings are in themselves the kinds of entities they are, and in the way they are, even if... Dasein[41] does not exist, but it is Dasein that makes beings show up, apparent."

In re-opening the ontological questions of being, Heidegger (1927/1962) considers how entities show up for people in particular lifeworlds. Heidegger describes spatiality as an important characteristic of the life world i.e., that things are either far or

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[41] Dasein is a term used by Heidegger to refer to the entity or aspect of people's humanness which is capable of wondering about its own existence and inquiring into its own Being (Heidegger, 1927/1962)

close, but not necessarily in geometric-spatial terms. An example of Heidegger's notion of distance in the lifeworld is when an older woman asks for information on whether the nearest accessible public restroom is within walking distance, and is told that it is. However, it is also necessary to think of her personal limitations and the obstacles she has to surmount before getting to the restroom (e.g., incontinence, disability, pain, architectural barriers). In this example, the lifeworld has meaning in relation to on how difficult it is to get to the restroom, but not in relation to the scientific, physical world, if understood as the geometrical dimensions of the restroom location.

Another issue is that a great deal of what people know about the lifeworld is experiential, and not easily voiced because it is not noticed or is taken for granted. For example, if we are asked to explain how we are able to swallow food, we experience difficulty in coming up with a fully articulated answer for something we live everyday that we do not need to think about. These actions happen in a pre-theoretical, not fully conscious mode. In phenomenology, the knowledge on these actions is called "*tacit* or *unarticulated*" knowledge (Dreyfus, 1991).

For Heiddeger (1927/1962), entities of the world of science, of the physical world result from a theoretical stance (Dreyfus, 1991), explained by decontextualized normal properties. For instance, if we take a computer keyboard as a gadget that we use to write a paper: A) primarily for indicating word processing commands and B) secondarily as a physical object. Then the keyboard has a meaning: it refers to what tasks or commands it can execute. To comprehend the meaning of a keyboard is to know its applications and how to make use of it. This meaning is not an additional quality to the keyboard being a physical object. To type a qualifying paper in Microsoft Word® we not only need a good keyboard but also we need to know how to handle it in a skilled way. If the keyboard is bad (e.g., a broken letter key) or if we are keyboard-incompetent, the work will be bad as well. But as a tool the keyboard's quality can be evaluated and it is evaluated in relation to the function it was made to execute. To consider this gadget as a merely physical or theoretical object, we do not need to think of it as a tool.

Because people take for granted their everyday lives, it is easy to fail to notice their lifeworld. We know what a keyboard looks like and how to make use of it. As a result, we do not really think much of it unless it does not work the way it should (e.g., the space and the return keys do not attend to the typing commands). Older adults may face similar experiences when a chronic disease that has been "controlled/stable" for a longtime presents a flair-up. Then the life-world needs to be interpreted. Self-care practices need to be reviewed and reorganized in particular lifeworlds, constituted by the older person's concerns, relationships and activities in ways that allow things to stand out for them as more or less important.

From Merleau-Ponty's perspective, we are required to re-view how to look at the world as we encounter it in immediate experience. For this reason, it is not enough to look at and see, but also to become aware of and to have the perceptual acuity to get hold of "*the meaning of the world as that meaning comes into being*" (Merleau-Ponty, 1962, p. xxi).

Merleau-Ponty's (1962) describes motivation as:

> "*one of those 'fluid' concepts which have to be formed if we want to get back to phenomena. One phenomenon releases another, not by means of some objective efficient cause, like those which link together natural events, but by the meaning which it holds out – there is a raison d'être for a thing which guides the flow of phenomena without being explicitly laid down in any one of them, a sort of operative reason.*" (pp. 49-50).

For example, we look to the right and see that a car is parked. As we turn, there is an illusion of movement of the car "*to the extent that the motivated phenomenon comes into being, an internal relation to the motivating phenomenon appears*" (p.50). Rather than one phenomenon simply succeeding the other, the motivated phenomenon makes the motivating phenomenon evident and understandable and consequently seems to have occurred prior to its own motive. In consequence the distant parked car and its physical projection on the retina elucidate the difference of images, and, through a retrospective illusion we make reference to a natural geometry of perception. In a sense, we bring what happened second to the first place, thus losing sight of the original relationship of motivation, in which the distance between us and the car launches itself into existence "*ahead of any science, not from a judgment of 'the two images,' for these are not numerically distinct, but from the phenomenon of the 'shift'*" (Merleau-Ponty, 1962, p.50).

From this perspective, what we think motivated the phenomena may not have. We can only know what really motivated the phenomena after one has experienced the situation, when emotions, meanings, processes, and interactions in the lifeworld of an older person become more evident. Then, when reflecting upon the phenomena, one is more likely to find what motivated it. Furthermore, according to Benner and Wrubel (1989), emotions open up the possibility of reinterpretations in the light of present situations. That is, motivation for maintaining self-care practices over time is dynamic and related to the lifeworld, which is also dynamic, where things are close or remote (Fjelland & Gjengedal, 1994) based on what is needed to and may interfere with overcoming the remoteness. For example, to better understand how difficult it is for older adults to sustain self-care practices, one needs to reflect upon what were the physiological drives, cognitive decisions, social interactions, and emotional experiences in situations when self-care practices were sustained and in situations when they were not sustained.

This philosophical perspective reiterates that physiology, cognition, and emotion, while aspects of what a person may experience as motivation, are meaning-related - in a lifeworld of significance, concerns and interactions with the environment and the society where one dwells.

Conclusion

Earlier sections of this chapter described that Biological Theories, Maslow's metacognition theory, Bandura's work on social cognitive theory, Nussbaum's cognitive work on emotions and Merleau Ponty's philosophical perspective on motivation augment one another as a theoretical foundation for this study. The conclusion of this chapter presents a brief summary on characteristics of the theories discussed above and points out issues related to motivation that were overlooked.

Reductionist approaches have been successful in elucidating the physiology of motivation and have added to the body of knowledge on basic levels of functioning to explain biological needs and drives. However, human motivation comprises more than physiological needs and drives. Maslow's (1967, 1969, 1987) research on bio-psych-social needs evolved into the development on a theory of metamotivation, which still falls short in providing a comprehensive understanding of motivation because it does not account for two facts: 1) that basic needs are not devoid from psycho-social meanings; and 2) physiological responses to motivation and emotions flow in many different directions.

Bandura's social cognitive theory acknowledges and integrates both the biophysiological and psycho-social aspects of motivation. As previously discussed in this chapter, from Bandura's perspective the core issue of social cognitive theory, self-efficacy, is fundamental to understanding of motivation. As a multidimentional system, motivation involves 3 different classes of motivators (biophysiological conditions, social incentives and cognition) that influence the regulation of human agency. Adding to the theory's complexity, besides having 4 main characteristics such as intentionality, forethought, self-reactiveness and self-reflexiveness, human agency also has 3 modes to accomplish desired outcomes: personal, proxi and collective. Bandura notes that these agency modes do not exist in isolation; rather they are exercised everyday, at different points in time, according to people's needs.

Furthermore, in terms of older adults' health functioning issues, despite the decline in capacities a high sense of self-efficacy can be sustained in old age through 6 processes: 1) Making social comparison with other older adults; 2) Changing of standards in self-appraisal; 3) Practicing skills developed over time; 4) Integrating comprehensive efficacy information; 5) Making selective optimization; and 6) Scaling down one's pursuits and/or adopting new roles. From a social cognitive perspective, these 6 processes enable older adults to reappraise their self-efficacy and to adopt different cognitive aids and strategies.

However, social cognitive theory still does not provide a comprehensive understanding of issues that may influence / interfere with maintenance of self-care practices in the long course of a chronic disease such as: 1) in a meaningful lifeworld, and depending on the person's concerns, one or more human agency modes may become more important than the others and interfere with or facilitate maintenance of self-care practices; 2) albeit self-efficacy can be developed through mastery, vicarious experience and modeling, social cognitive theory does not account for the possibility that self-efficacy beliefs may change over time, as does what matters to people; and 3) changes in capacities may also interact with current meanings and priorities - regardless of self-efficacy beliefs' reappraisals.

Moreover, this theoretical approach works mainly through strategies to achieve goals that are clearly articulated or can be broken into smaller ones, and for thinking about a goal at a time. Also, it is not applicable to situations in which behaviors cannot be controlled, planned, modeled and sometimes predicted through self-efficacy beliefs.

Considering the above unaccounted issues in biological and cognitive theories of motivation, i.e., despite needs, drives and high self-efficacy beliefs people may not feel motivated and choose not to sustain self-care practices even if: 1) they know the reasons why certain self-care practices should be continued; and 2) they believe they are able to perform those practices to achieve the desired outcomes.

Thus, because older adults' priorities may change as they face their experiences, possibilities in the social and physical environments in which they dwell, and in relation to what matters to them, seeking to maintain a self-care practice may be thought to be important but may not be intense enough to become one's priority.

Nussbaum's cognitive perspective acknowledges emotions as involving salient transactions and things that are important to a person. However, her work falls short because it does not account for older adults' lived experience. In this sense, Merleau-Ponty's philosophical perspective on motivation is a "fluid" concept that accounts for the lived experience, and that the individual needs to reflect on the issue that motivated the phenomenon and makes the motivating phenomenon evident and understandable, rather than on the se/quence of one phenomenon succeeding the other. From this perspective, motivation can only be understood in looking back after the experience in search for salience and for possible interactions.

Albeit further investigation from both quantitative and qualitative approaches is required for better measurements and understanding of motivation in older adults, qualitative studies that also address overlooked theoretical issues are needed.

It is necessary to further explore qualitative distinctions in the lived experiences and perceptions of older adults in the maintenance of self-care practices in the long run of a chronic disease. The full range of symptoms, experiences and expressions must be considered from distressing symptoms to ones that do not cause uncomfortable bodily sensations or changes. Application of Nussbaum's (2001) theoretical and philosophical exploration of the intelligence of emotions can provide resources and new possibilities for a better understanding of motivation in older adults by addressing concerns that may lack a purely cognitive, rational explanation but may interfere with the maintenance of self-care practices for long periods of time.

However, because both physiological needs and cognition exist in a meaningful world - they are almost always intimately blended with meanings and emotion. For this reason this theory chapter attempted to integrate the physiological, cognitive, and philosophical perspectives on motivation. As previously noted, Toates (1988) has indicated the critical need for bringing together empirical and theoretical content on these topics. In this sense the attempt to combine Social Cognitive Theory, which studies cognitive aspects of motivation but that overlooks emotions as related to motivation, and Nussbaum's (2001) perspective on the intelligence of emotions offers the possibility of an integrative approach to studying motivation, cognition and emotion.

The theoretical perspectives discussed in this chapter provide an interpretive dialogue to explore how the physiological, the psychosocial, the cognitive and the philosophical components of motivation complete one another through mutual interaction and influence. However, it is important to emphasize that these components are not devoid from a social context, with mutual influences and interactions.

Given the nature of both the aspects that were overlooked by empirical and theoretical perspectives, and of the research question posed, a qualitative approach was selected for this study.

In refining the research question, grounded theory proved to be the most suited methodological approach to guide this study, which seeks to understand older adults' experiences and motivation for sustaining self-care practices that are or become visible within and interact with the social context in which they dwell.

CHAPTER III: METHODS

Introduction

As indicated in Chapter I, the primary aim of this study was to qualitatively describe what helps or makes it more difficult to maintain, over time, self-care practices for a chronic disease – based on older adults' accounts of their own experiences and possibilities. As reviewed in Chapter I, studies using quantitative research methods with standardized measures were not able to capture older adults' lived experience and meanings the way this author sought to understand.

According to Gergen & Gergen (2000) and supported by researchers in grounded theory (Strauss & Corbin, 1990, 1994), phenomenology (Georgi, 1994; Moustokas, 1994), and feminist theory (Miler & Stiver, 1997; Im & Meleis, 2000), qualitative methods value the human experience. Thus, the qualitative approach offered more resources to better capture the essence of the experience of motivation in older adults.

The following section broadly dicusses qualitative methods and specifically describes grounded theory techniques, which were used to analyze the data.

Qualitative Method

Strauss & Corbin (1990) and Denzin & Lincoln (2000a, 2000b) indicate that qualitative research is a broad methodological area that refers to qualities of entities, processes and meanings, which are not ideally understood or described through experimental assessments regarding quantity, intensity, or frequency (Denzin & Lincoln, 1998, 2000). Rather, in current qualitative research there is a demand for further description of the relationships within the social environment that shape the investigation of motivation and the sources of influence of both participants, i.e. the researcher and the older adults. While re-visiting the nature of the research question posed for this study, this author's own assumptions and theoretical orientation, qualitative methodology was selected as the most powerful approach.

From a psycho-sociological perspective qualitative methods opened up possibilities for better understanding the phenomenon of motivation. They provided strategies for discussing what it means to be an older human being in terms of everyday life, presenting general structures of how people interpret their own way of being as incorporated into the research methodology. The qualitative approach to study motivation helped this author to understand how older adults' intersubjective world and reality are constructed (Sahwandt, 2000), and how their everyday practices exist in conversation through meanings, emotions, actions and interactions. In addition, qualitative methods opened up the possibility of reinterpretations of the participants' text (Benner & Wrubel, 1989) in the light of contextualized, present situations.

Many strategies can be used for data collection. In order to voice older adults' perspectives, interviews – here described as encounters – were the primary data source. What both participants – older adult and interviewer – shared in the construction of the text was critical in building the most accurate description possible of how things figured in rational thoughts, everyday experience, and emotions.

Dwelling in the texts produced in these encounters raised new questions for the researcher participant who did not live a similar experience of being old and having a chronic disease that involves motivation for life-long self-care practices. In order to get the best description and understanding of the participants' lived experience it was necessary to begin to know and understand these women through interviews in which not only words but also actions, the physical and social contexts, and emotions spoke for themselves. For example, decorations; photo displays; the feeling, the smell and the sight of the location; the looks in the older participants' eyes; and the influence of the encounter on the life of both interviewer and interviewee. These were all elements of the text and were part of the context where most self-care practices happened: in the community, a dwelling space and a stage with a multiplicity of meanings, possibilities and social processes that influenced one another as well as older adults' motivation in the long run.

Grounded Theory

In refining the research question, the complexity of the construct (Bandura, 1991b, 1997; Ellingson & Yarber, 1997; and Maclean & Pound, 2000), and this author's background and theoretical orientation, grounded theory proved to be the most suited approach to conduct this research.

Historically, grounded theory has its theoretical underpinnings in the pragmatism and symbolic interactionism movements and is described as concerned with comprehending action from the perspective of the research participant. As indicated by Blumer (1969), symbolic interactionism has three core principles: 1) that people act toward things based on the meanings that these have for them; 2) that the meanings of such things come from the social interaction that people have; and 3) that these meanings are dealt with and changed through an interpretive process that people use in managing the things encountered or events faced.

Based on these principles, grounded theory is described by Strauss and Corbin (1990, 1998a, 1998b) as a theoretical approach concerned with the generation, elaboration, and validation of social science theory. However, Strauss and Corbin (1990) indicate that the value of grounded theory methods is broader than their own research focus on theory development. They note that this approach can be used for theme analysis, concept development, and to explore different ways of thinking about a phenomena. Thus grounded theory techniques can be used to gain a better understanding of a phenomenon when the primary goal for research is not necessarily the development of a theory.

Grounded theory techniques

In designing semi-structured interviews for a study using grounded theory techniques, Strauss and Corbin (1990) and Wilson and Hutchinson (1991) recommend that questions move from the general to the specific, seeking to bring forth important information such as dimensions, phases, properties, strategies, consequences and contexts.

Data collection began with this researcher's intent and immersion in the study topic. Awareness of interactions, personal values, feelings and beliefs constituted the basis for the development of this study. Observations, field notes, and interviews served the purpose of shedding light on meanings participants attributed to specific situations and helped this author to answer the research question through the perspective of older women with chronic disease.

Validity and Reliability

Given the descriptive nature of qualitative research, both internal and external validity must render credibility (Janesick, 1998) and trustwothiness (Kincheloe & McLaren, 1998). Internal validity was supported by accurate descriptions in text construction, observations and measurements. External validity was sought by comparing findings from this study with those from other groups of older women with chronic disease. Grounded theory techniques were chosen for this study because they answer some of the positivist demands for validity and reliability (Charmaz, 2000). In this study, reliability and validity were sought through: 1) formulation and rejection of this researcher's hypotheses; 2) searching for and investigating atypical situations, events or episodes, and distortions; 3) comparing and contrasting data; and 4) use of multiple data collection strategies, field notes, observations, interviews. Grounded theory techniques also served purposes of increasing the amount of data collected for clarification and identification of excessive bias, given that it is unrealistic to say that any interpretation can be free of the researcher's biases.

Research Study

Design and Sample Characteristics

This dissertation research was a cross-sectional, descriptive, qualitative study that used grounded theory techniques to explore older women's motivation for maintaining self-care practices in the long run of a chronic disease. The convenience sample was selected from community dwelling, English-speaking, white women residing in the Bay Area who were willing to participate and who met the inclusion criteria.

Inclusion Criteria

Participants were required to be women 65-84 years of age, self-evaluated as cognitively fit and willing to participate in a set of two interviews. In order to assure satisfactory levels of ability to discuss participants' experiences, their cognitive status was also evaluated during the first interview through the 10-question Kahn and Goldfarb

Mental Status Questionnaire -MSQ (Kahn et al., 1960a, 1960b) (see Appendix E). The MSQ has a reported re-test reliability of .8, a Cronbach's alpha of .84, and a recommended cut off point of 5 (Kahn et al., 1960a, 1960b; Kane & Kane, 1981).

In view of the fact that this study sought to learn about motivation over the long run of chronic diseases, participants had been diagnosed with diabetes and/or heart disease for at least one year, so that they would have moved beyond initial phases of the diagnosis of a chronic disease (Thorne, 1990; Thorne & Patterson, 2001; Thorne et al, 2002). The intent was to recruit participants who had one or both chronic diseases because these conditions are highly prevalent in old age, are long-standing, and involve more than one of the following self- care practices: constant watchfulness, monitoring across time, following medication regimens, and implementing and maintaining life style changes (e.g., diet, exercise).

Exclusion Criteria

This study is aimed at listening to the voices of community-dwelling older women who live alone or with another older adult in the same household. Therefore, older women living with and depending upon younger adults, and residents of fully assisted living facilities for retired citizens or of nursing homes were not eligible. Older women who had not received a formal diagnosis of either diabetes or heart disease could not participate in the study.

Methods of Access

Older adults were invited to participate through fliers (Appendix F) posted in ambulatory care settings, clubs, leisure areas, associations, churches and community facilities, and through researcher's participation in explanatory meetings / invitation sessions at the same locations above mentioned. The snowball procedure was adopted, whereby participants were asked if they knew others who might be willing to participate. Each participant was provided with the researcher's contact information to share with friends and acquaintances.

Fourteen community-dwelling older women were contacted for a set of two interviews each. This author did all 28 interviews with the study participants. The number of participants was determined by increased density and saturation of recurring categories of the data gathered. Women were not paid for the interviews.

Procedures

Signed consent was obtained just prior to the first interview. The procedures were two informal in-person interviews, with an estimated interval between the first and the second encounter varying from one to four weeks. Each of these interviews lasted from forty-five minutes to an hour and a half. Interviews were audiotape-recorded upon participants' agreement, and were conducted at a time and place of their convenience. Detailed field notes were taken regarding the interviews themselves, the environment, and the social space that the participant chose for each encounter.

The first interview started a conversation with participants in which each woman was given the right to choose her own pseudonym. This author recommended women chose a name that nobody else – including family and friends - would be able to connect them with. Participants enjoyed the possibility of selecting a "secret" name for themselves and all women selected names that had special meanings to them. The interview followed with socio-demographic questions (Appendix D), and questions and probes on chronic disease, motivation and self-care. The questions this author used are listed in Appendix C. As previously indicated, during the first interview the MSQ (Appendix E) was also administered.

The second interview included questions and probes based on preliminary data analysis of each participant's first account and were aimed at achieving more depth, better description, more information, and clarification of data. Both interviews were combined with thorough written and recorded field notes in order to make room for richer descriptions of stories, images, spoken words and silences that were contrasted and compared throughout the data collection and analysis processes.

To illustrate the Strauss & Corbin (1990, 1998a, 1998b) and Charmaz (2000) recommendations, the paragraphs below schematically present how data collection and analysis from multiple sources were conducted.

Data Collection, Method and Risks

Audiotaped-recorded interviews may have been uncomfortable for some participants. Older women were able to withdraw or to refuse the recording prior to or at any time during the interviews. Participants were free to decline to answer any questions they did not wish to answer or stop the interviews at any time. The author explained the confidentiality procedures when obtaining informed consent before initiating the first interview. Interviews were audiotaped-recorded and transcribed with permission only. All transcriptions used a pseudonym chosen by each participant, rather than their actual names. The interview tapes will be destroyed after the analysis is completed. Tapes, transcriptions and documents were kept in a separate, metal, locked box, available only to the author. In the future, small transcribed segments may be used for educational, scientific and publication purposes, without respondent identification. Transcribed segments and paradigm cases may be translated into Portuguese for educational, scientific and publication purposes, without any identification of respondents aside from their pseudonyms.

Data Analysis

Throughout the study grounded theory techniques for data collection guided data collection and analysis. Descriptive statistics were used to present the demographic profile of participants. Information collected using a demographic tool designed for this study (Appendix D) and the Kahn and Goldfarb Mental Status Questionnaire -MSQ (Kahn et al., 1960a, 1960b) (Appendix E) was entered into a computer file using the Statistical Package for Social Sciences software for accurate description of the sample.

Two teams of transcriptionists were hired and all interview data were transcribed into Microsoft Word for Windows® documents. Quality and accuracy of transcriptions were controlled for by the researcher each time one of the tapes was turned in by listening to the tape and by checking it against its corresponding Word document. Field observations on participants' pauses, changes in tone of voice, physical reactions and external events to the interview were added to the transcribed text at that time. After verification, all word documents were converted into Adobe PDF files for document organization, memoing, data coding and analysis.

To be consistent with grounded theory inquiry (Strauss & Corbin, 1998; Charmaz, 2000), interviews were analyzed in levels. Right at the outset of interview transcripts were coded line by line in search of sensitizing concepts while examining the data and delineating actions and events. In this phase, further development of this author's analytic process took place through the use of background ideas and concepts (Charmaz, 2000), which informed the research in question. Based on this preliminary analysis, properties were divided into dimensions. The use of axial coding guided the study of connections between each category and its subcategories.

Next, constant comparisons and contrasts between categories and interviews were done, followed by initial development of category profiles. Then data were separated and grouped together in different ways so that categories could be reexamined under different lenses and a better description of their subcategories and connections could be provided. To validate relationships and refine concepts, the core category was compared with each of the other smaller categories.

During the whole research process, data were analyzed through constant comparison and contrast among different participants; within each individual's account at different moments of the interviews; and among events, incidents and categories (Strauss & Corbin, 1990, 1998a, 1998b; Charmaz, 2000). Data were constructed into text and reflected upon for building of thematic and conceptual analysis. This researcher's developing ideas were also refined through data sampling.

In order to assure the best possible analysis and gain an awareness of any bias, the author discussed her data and findings over the course of five months in weekly meetings with her academic advisor and weekly sessions with members of her independent qualitative research study group. Monthly meetings of the Disability Interest Group at UCSF were also attended for sensitization on invisible difficulties, challenges, and barriers that individuals experience. To help the researcher to get "*analytical distance from materials*" (Straus and Corbin, 1990, p.199), several tape-recorded and written memos and graphic schemes were produced.

Consent Process and Documentation

Informed consent was obtained prior to conducting an interview with each participant. Each participant received a copy of the informed consent form. Given the new regulations were implemented by the Committee on Human Research at UCSF, participants who joined the study after April 14th, 2003 also signed the Health Insurance Portability and Accountability Act (HIPPA)[42] form (Appendix F). The consent forms are kept in a separate, metal, locked box, which is separate from tapes and transcriptions, at a location known only by this author. Only designated study personnel have access to these documents. Chapter IV presents the findings of the study, which are discussed in Chapter V.

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[42] http://www.ucsf.edu/hipaa/
http://www.ucsf.edu/hipaa/whatis.html
http://www.ucsf.edu/hipaa/education_index.html
http://www.universityofcalifornia.edu/hipaa/welcome.html

CHAPTER IV: FINDINGS

Introduction

As indicated in previous chapters, motivation is a complex construct that has been studied though several perspectives. This chapter describes the most significant findings from 28 interviews with 14 older women focused on the continuation of self-care practices, which can only be sustained if there is some degree of motivation. It is important to note that the interviews used self-care practices as a basic strategy to gain access to participants' experiences on sustaining motivation.

Demographics of the Sample

Participants were thirteen white women from a variety of backgrounds and lived in Northern California at the time of the interviews. They ranged in age from 67 to 84 years, with a mean age of 77.2 (SD5.19). Seven women were married (35%) and five were widowed (30%). Six women (30%) had heart disease, two had diabetes (10%) and five (25%) had both diabetes and heart disease. The number of persons in the household ranged from one to three, with five households composed of the participant (25%), six households of participant and spouse (30%), one household with a daughter who sleeps in (5%) and a household with an employee who spends the day in (5%). Mean income of women who lived with a spouse was higher (range of $30,000-40,000) than those women living alone (range of $20,000-30,00). One participant who lived alone declined to share her income. Nine women had attended college (45%), two had attended graduate school (10%) and two high school (10%). At the time of the interviews, the current occupation of seven women were housewives (35%), two were active church committee members (10%), two were active community committee members (10%) and two were writers (10%). Six women were Presbiterian (30%), six Unitarian (30%) and one Catholic (5%). All women attended Sunday services and took part in at least one social activity in their churches. Hobbies declared were card games, writing, embroidery, volunteer activities, study groups, gardening, bowling and bocci ball. The following chart presents a summary of participants' demographic information.

Women	Alberta	Andrea	Ann	Anna	Betty	Bogey	Carol	Cissie	Ellen	Lou	Melissa	Red	Rose	Tarzan
Age	70	79	78	67	76	82	79	80	82	84	70	80	70	77
Marital Status & Length (Yrs)	W = 10	W = 8	M = 31	W = 17	W = 12	W = 3	W = 45	W = 18	M = 58	W = 10	M = 49	M = 55	M = 46	M = 52
Education	C	C	C	C	HS	C	GS	C	C	HS	C	C	C	GS
Former Occupation	sales	RN	secretary	PT	sales	job interviewer	social worker	Sec. for American Cancer	teacher	sales	teacher	RN	secretary	teacher
Religion	P	P	U	P	P	U	P	U	U	Catholic	P	U	U	P
Non-Income Occupation	CCM	writer	HW	HW	CCM	HW	CCM	writer	HW	CCM	CCM	HW	HW	HW
Favorite Activity or Hobby	CCM	photography	garden	needle work	garden	play cards	SV	writing	study group on dreams	bowling & bocci	SV	play cards	-	-
Living Arrangement	child	alone	spouse	child	alone	employee	alone	alone	spouse	alone	spouse	spouse	spouse	spouse
Income (US $)	10,000-20,000	10,000-20,000	30,000-40,000	30,000-40,000	30,000-40,000	30,000-40,000	20,000-30,000	20,000-30,000	Over 40,000	Declined to answer	Over 40,000	30,000-40,000	Over 40,000	20,000-30,000
Main Source of Income	SS	SS	I	I	I	I	pension	I	I	SS	I	I	HE	SS
Health Condition & Duration (Yrs)	HD = 2 D = 44	HD = 3	HD = 25	HD = 40	HD = 17 D = 3	HD = 31	HD = 5	HD = 3.5 D = 11	HD = 3	HD = 3 D = < 1	D = 20	HD = 3 D = 41	HD = 17	HD = 2 D = 8

Legend:

W = Widowed
M = Married
P = Presbiterian
U = Unitarian Universalist

HS = High School
C = College
GS = Graduate School

RN = Registered Nurse
PT = Physical Therapist
CCM = Church Committee Member
HW = Housewife
SV = School Volunteer

SS = Social Security
I = Investments
HE = Husband's Employment
HD = Heart Disease
D = Diabetes

Figure 2. Summary chart on participants' demographic information

Motivation: A Constant Re-Negotiated Process

This research tried to capture, in two hours of interviews with each of the 14 participants and countless hours of data analysis, these women's voices on sustaining self-care across years of experiences and life history of living with chronic disease. To achieve depth and provide a better understanding of everyday life examples in their accounts, self-care domains - medication, diet, and exercise – were used to bring up concrete examples of participants' voices and experiences.

Studying these accounts using the grounded theory techniques of constant comparison and contrast between and across the women's life histories, experiences, and health care providers' recommendations for health practices, assisted this researcher to come closer to these women's lifeworlds[43]. Grounded theory principles also helped in making distinctions on how self-care practices were analyzed, negotiated and then dropped or sustained by the participants. The procedure of constant comparison and contrast brought the issue of balance as a dialectic to the center of the women's actions - a balanced health and/versus a balanced life. This dialectic became core to the understanding of an individual's continuous re-negotiation process towards sustaining motivation for self-care practices in the long course of a chronic disease. Thus, the story about what motivates older women with heart disease and diabetes to sustain self-care practices is a story of negotiation – a process of balancing life and health.

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[43] The idea of the lifeworld *(Lebenswelt),* as the world of lived experience, derives from Husserl's last and largely posthumously published text *The Crisis of European Sciences and Transcendental Phenomenology* .He described the lifeworld as the "world of immediate experience," the world as "already there," "pregiven," the world as experienced in the "natural, primordial attitude," that of "original natural life." http://www.atl.ualberta.ca/po/glossary

The story of this negotiation and renegotiation was told through information shared on what mattered to these women, people and events in their lives, and the physical, social and emotional spaces in which they dwell. These women's negotiations towards sustaining or maintaining balance were affected by their values, meanings, emotions and priorities, which were often different for these older women than for their health care providers. Findings on what was clinically important in participants' lifeworlds indicate that there was constant tension between personal and social values that called for re-negotiation in order to achieve balance.

Balancing Life and Heath

As observed through these women's description of self-care practices, quality of life and good health can have different weights on a constantly fluctuating balance-scale. As indicated by Lou, how these women learn about their bodies and how they feel on a daily basis influences motivation for self-care:

Lou: *"You know yourself how you feel from one day to another. Some days you feel real spunky and others days you feel what the heck. (Laughs) That's it."*

When recounting their life stories of living with chronic disease and lessons learned from their bodies, women talked beyond objective symptoms and chronic disease treatment: they described an on-going course of self-exploration, learning, knowing, and negotiating with different people (self, health care providers, family members, friends and institutions) who recommended, helped or hindered maintenance of self-care practices at different points in time. Furthermore, participants brought an existing divergence to the foreground: that older women, health care providers, family and friends may have distinct or even conflicting health priorities. In making an analogy to a balance scale, the scale will oscillate between quality life and good physical health - depending on what negotiations are made and on the weight had by each aspect involved. Examples of these aspects are presented in this Chapter and will be discussed in Chapter five.

Clinical Importance and Participants Lifeworld

A major element that entered into the negotiation processes was what these women deemed clinically important and felt self-efficacious about. However, clinical importance and priorities can have different meanings for older adults than for health care providers. From a health care provider's perspective, health conditions that are clinically significant are those that may be life threatening: these need to be taken care of first. From participants' perspective the clinically significant condition may become secondary - depending on the meaning it holds for the individual. Differences in the order of priorities affect investments in negotiated practices and maintenance. For Cissie, a writer by nature who now has heart disease, vision took precedent.

Cissie: "*I think what has, ah, really depressed me more than anything is the vision. And, I just don't think, you know. I just think, why, why, bother?* [Laughs]. *But I guess it could be worse. The vision depresses me. But, I, the heart business doesn't."* [On learning a voice recognition software] *"But I have confidence that I will learn this program. Other people do and there is no reason that I can't do that." " But I get, when I start having to dictate and say comma, ah, ah, period, and all these things. I get a little confused. So, but I do well in reading it. If there is too much punctuation, you know, it takes a long time to do it. So, I will get it done. I think I'm going to bring it in here, though, so that I have, take away that lamp* *over there and put my computer and my magnifier over there so I can do it. Because that is, that is, a part of my life."*

[When asked about physical activity] *"I went on my walks, made friends on the walks and all this. So, ah, I think that's what I really should start is the walking. And, going to L's exercises in the morning."*

To better understand how these women came to consider things as important in their lives, the following section describes sub-categories related to the individual and how what mattered to them could shift in order of priorities.

Individual Experiences

Participants' combined biological, personal, and social identities influenced negotiations within the self and the interpretation of lessons their bodies and society had taught them over the years. Factors involved in determining what was clinically meaningful and how this determination influenced these women's setting of priorities were described through participants' lifelong habits, preferences, meanings, body lessons, fears, test results, and goals.

Meaningful activities.

Self-care practices that were recommended by health care providers were maintained over time if the participant truly "wanted" to do the recommended activity, the practices were in association with activities of daily living; the practices were important for regaining or maintaining function that would enable the participant to do favorite activities; participants looked forward to an achievement [e.g., complete the cross-stitch pattern], and if they helped to sustain participation in participants' social groups. Thus, the self-care practices had potential to or made a shift toward becoming meaningful. For example, in Anna's experience, embroidery moved from being a self-care practice into something interesting.

Anna: *"I took up the counted cross-stitch to exercise my hands and arms because of the rheumatoid. And so — and then I got interested in it"*

Lifelong habits, preferences and meanings.

Participants' narratives related to their identity were permeated by what mattered to them, their lifelong habits, preferences, and meanings. Modification of long time habits was a major challenge. For example, when talking about favorite eating habits a woman pictures not only the time in her life when she remembers eating red meat, but also with whom and how meat became a meaningful part of her biological, personal, and social identity as someone who was born and raised on a ranch. As Betty indicated:

Betty: *"But, ah, oh, I eat a lot of protein. Somehow or another, I was raised on a ranch where my father raised beef and... Man: "I have to have meat." You know, all these people that are into pasta and stuff. So, I am a nut on meat. Sometimes, I'll eat turkey and chicken because I know it's better for me than beef but...and eggs. I eat lots of eggs. I know they are, I have been told not to but I eat about 4 eggs a week."*

Body lessons.

The physical and the emotional body was a reference for these women. These lessons brought the chronic condition to the forefront, highlighting its clinical significance and emphasizing the limits of when and how much of "sticking to recommended practices" was needed. In describing lessons learned from their bodies, Ann, Anna, Ellen and Betty noted:

Anna: *"If I do feel like I am beginning to feel sluggish or if my feet are beginning to swell or any of those symptoms that show that you have too much salt in your system or you're retaining fluids or what have you, then I check it* [blood pressure] *more frequently."*

Ann: *"You have to get up all by yourself without a little boost* [coffee]. *But that really made a big difference in the number of irregular beats that I threw."*

"I noticed even losing a couple pounds made a difference in my breathing. You know, when you think – 'What is it?' – Every pound you gain you put on a mile of blood vessels. That's a stress on the heart, it's more oxygen you need..."

Ellen: *"And I'm wondering if my exercise program is right now. I come away very tired from that hour of exercise and I'm wondering if that's right, that if I should be doing something different. And I don't really know whether I am doing too much or not."*

"I'd like to have a physical. I'm due in July to have one and I'm just thinking maybe I should move that date up a little bit and see her sooner. I've also thought of going outside of [HMO] *and seeing another doctor, seeing if I can get some ideas on how to take care of myself. But I haven't done it."*

Betty: *"I did notice something was wrong. And, like I was saying when I sat for long periods of time, I would have, I would have these tingles in my legs. Really, you know, it really disturbed me and I think that was because I had high blood sugar."*

"And, she told me to eat only 45 carbohydrates at a meal and 15 carbohydrates at my 2 snacks during the day. That's about my limit. It's what my insulin, ah, my

metabolism can take care evidently. 'Cause when I go over that, I just feel so lousy."

Fears.

In addition to body lessons, lived experiences such as witnessing, observing, and helping other people with the same diagnosis to go through difficult experiences brought awareness and fear of ways that these older women did not want to live or die. Thoughts of other people's difficult times functioned as an incentive and helped participants work towards the maintenance of self-care practices and prevention of complications.

Anna: [Helped Anna to keep on going with exercise] *"When I was a child I knew someone that had rheumatoid arthritis so badly that her fingers went that way. And she was really in very bad shape. And mentally I thought, "Lord, I hope I never get rheumatoid arthritis." And I knew someone else that had a stroke and they were in a wheelchair for the rest of their lives. And I thought, "Oh, Lord." And that's the two things I've had."*

"*I don't really take all of it* [medication] *but I knew that exercise was the best bet for coming back from either of those two things. And just — I have such fear of being crippled to the point of being incapacitated"*

Ann: [Helped Ann to keep intellectually active and to stick to her diet] *"I thoroughly expect to be doing the same thing if I don't lose all my marbles. My father had Alzheimer's. Ph.D." "That's a pretty strong hereditary link and that's probably my greatest fear, because I can see that my forgetting is getting..."*

"But when - word-finding. You know, I'll know what I want to say but I can't think of the word, so that's really scary."

Betty: [Helped Betty to maintain continue performing self-physical exam, exercising, and avoiding some foods] *"But I know other people who have diabetes who have had ...My girlfriend had it so bad she went to the hospital and got a bedsore on her leg in November and she died in May. And she still had that sore. It never healed. Even though they were sending a nurse to dress it and everything. Well, she had it really bad. She was young too. She died about 65."*

"*Once I found 8lbs of* [Gourmet chocolate brand] *candies in her house. And, she was blind and was on dialysis. So, I got my experience the hard way* [Laughs]. *I don't want to end up like that." "I think that's a major motivator."*

Betty: *"I want to try and maintain my own health and physical ability as long as possible because I hate* [emphasis on hate] *seeing the way those people needed someone to care for them."*

"I've gone on cruises and trips where people have to go in wheelchairs and they're on crutches. You know, one, the husband and wife will go and maybe the wife will be on crutches and I, I want to see everything before that happens to me. If I don't take care of myself, how am I going to do it? [Pause] *You know, I'd like to, there are some trips I liked to do, like there are hikes in the* [Name of Area] *Alps, special walks, you know. I'd like to do that. How can you do that if I can't walk? I have to do it now before I get...* [Pause]*"*

Test Results.

Test results information seemed to be powerful alerts and worked as an indicator-incentive of how badly participants needed to intensify or sustain self-care practices. Ann and Red relate experiences they had when they got results that surprised them:

Ann: [In not smoking and intensify exercise program] *"Well, I had had a vital capacity test and it was low and I thought well, I'd better do something about this."*

[In sustaining exercise, medication taking and diet] "*The osteoporosis, that's a* <u>*shock*</u>*, that was a real shock because here I'd been doing the walking, the pounding, I'd been doing exercises."*

Red: [When she stopped trying to control her blood glucose herself] *"It seemed to get higher every day and I kept taking more and more insulin. It didn't help a bit. That was frightening. I don't know whether the high sugar was from the bladder infection or whether it was the heart surgery."*

Health protection and recovery goals.

Due to the importance of the outcome, participants restrained themselves from doing anything that would compromise their recovery. For example, for Lou, who was a bowling and bocci league player, adequate knee recovery was essential because it would enable her to go back to these activities. Thus, the wait and pain of the exercise practices were bearable. As she noted:

Lou: [Bowling and bocci senior league player to sustain exercise practices] "You have to have a goal. You have to have something to go for"

"I do all the ones [exercises] that physical therapy has showed me. And, then when I've gone down to the place where they do physical therapy, they showed me some more. So, I do those. And so, I try to do that every day because, on account, of my knees."

"That's my incentive. I want, I want to be able to walk like I want to walk. I want to be able to do things that I've been doing before. I don't want to be like this, just sitting and doing nothing. I cannot do that."

"You have to have incentives to want to do want you want to do. If you don't have that incentive, you're not going to do it."

Flair-ups and new health conditions

A new health problem or flair-up of an old condition can interfere with possibilities and continuity of recommended self-care practices, as experienced by Melissa. Interrupting one self-care practice to favor healing of a recent condition hindered maintenance of self-care practices recommended for another chronic health problem. As Melissa narrates her ordeal with the cellulitis on her leg:

Melissa: *"I should be doing and I did it for a long time until I had this cellulitis, was going twice a week for aquatic exercises. And that I really need to get back to 'cause I need to do more exercise. I know that and I – that's just – you know, the doctor said don't go in the water with the cellulitis so I couldn't go, and I can't do much exercise without being in the water because of my weight. So it's a vicious circle, trying to lose weight, trying to... I have to diet to not gain weight and that's the struggle, so – because I know it makes a big difference in diabetes if I could just lose the weight, but I can't. Haven't been able to."*

Self-Care Practices – Coping Strategies

Motivation for sustaining self-care practices in the long run was also influenced by a variety of strategies that helped with maintaining or regaining balance. However, participants' narratives required a deeper look into what they described as self-care. The result of breaking down the code "self-care practices" or "strategies" made it possible to discriminate between "plain" self-care practice that does not make adaptative demands and a self-care coping practice that requires notable demands or challenges. For example, a "plain" self-care practice would be brushing one's teeth daily for the sake of an individual's health. In order to facilitate the understanding of self-care coping strategies - which will be seen in excerpts of participants' accounts discussed in this chapter – this author will use Ellen's situation as an exemplar.

Ellen bought mostly pre-cooked food for her household at restaurants. This woman had heart disease and was the primary caregiver of her frail husband and a disabled older child. All people in her household (participant, husband and son) had different diets, appointments, and needs, all of which were to be coordinated to taken care of by the participant. Ellen's buying food to go could be seen as a coping strategy if one does not consider that by acting this way Ellen could free some time for relief of her caregiver activities, for attending her exercise classes, and to do other things she needed to do for her own health. As Ellen noted:

Ellen: "*It's hard. And the shopping. But we manage.*"

> *"I do the cooking but I do buy a lot of – I go out and buy things at restaurants or at the store that are already cooked. And we…* [Chuckles] *I used to be a pretty good cook but I'm not such a good cook anymore because it's too hard to find things for all of us. I'll give my husband* [who has recurrent diverticulitis] *one thing and me another and son* [had had a stroke] *another."*
>
> [When asked for an example] *"Well, yesterday I went to a Japanese place and we had a very nice chicken dish, a very Japanese chicken dish, and sometimes I'll*

buy sushi because that's something my son and I can eat. And my husband doesn't like that and he can't manage it very well so I'll fix him soup or something else. And I've found places that make very good rice dishes that we can eat, we can all eat, and I do a lot of buying at – I'm always looking for places where I can buy ready-made food."

"We can all eat salmon."

A number of other self-care coping strategies (e.g., letter, list, notebook/binder) were in these women's narratives. For example, when going for appointments or keeping their own health records in order, Andrea, Ellen and Anna use strategies that fit coping if analyzed under the light that appointments get shorter each time. On the other hand, they are articulating a way to get the health information they need to sustain their self-care practices in the long and complex course of single or multiple chronic diseases. Andrea, Ellen and Ann mentioned:

Andrea*: "10 minutes is a long* [appointment duration]. *"How do I? I write him a letter."*

"I have a letter. I make a copy for myself and I tell him what's working, what's not working.... You know, symptoms that I'm concerned about, reports on all the other specialists, you know, what the heart guy did, I had the mammogram, everything turned out okay, um, and, um, you know, this test, the bone density, they sent him a copy, was it all right?"

Ellen: [Referring to her primary health care provider] *"I make a list of things that I need to ask her, you know, any physical problems. I just make a list."*

"In fact, I keep a little notebook of the things that I want to ask her."

"I think she's very busy and you feel like you don't want to take any more time. But she always answers all my questions."

Ann: *"I bring my notebook, yeah. And some of the doctors remember... Well, now the primary doctor, by the time you get into MediCare you don't have to do that."*

"Too much in a hurry. The doctors have to be in hurry. They haven't got the time."

"*Well, your doctor takes records but they don't read them* [change in voice on but they don't read them] *and they don't compare one to another. You know, I think you're your own health advocate."*

The Balancing Act: Self-Care Domains

Descriptions of women's experiences were exemplified and organized around the major three self-care domains: medication, diet and exercise.

Medication

As a self-care domain, medication taking issues were shared across all interviews, by participants who had either/or both heart disease and diabetes. Women shared that some discomforts could be endured and others could not. Overall, gastrointestinal side effects caused by medication were especially difficult to tolerate. Based on each participant's perception of her body's lessons or symptoms, and her priorities and interpretation of the purpose and effects of the medication, each woman established her own strategies for taking it; evaluation of its side effects; trial period; and criteria for continuing or stopping it.

Strategies

Taking medications first thing in the morning and in a specific location helped these participants remember to take them. As Red, Rose and Betty noted when referring to a morning routine:

Red: *"Well, the first thing I do is get all those pills I want out, take all those. I test my sugar, see what it is, take my insulin. Then we eat breakfast."*

Rose: *"I take medication in the morning at breakfast time and then in the evening at dinnertime."*

Betty: *"I make sure I take all the vitamins the doctor told me to. The first thing in the morning. I do that."*

Side effects

Taking pills in the morning was referred to the easiest self-care practice to sustain. However, participants indicated that medications that required dealing with / tolerating uncomfortable side effects hindered motivation for sustaining correct and continuous pill-taking. As Ann remarked,

Ann: *"Now with pills, I don't see that as being a big problem unless you have lots of side effects that aren't good."*

Other times however, side effects became a significant barrier to everyday activities and even a threat. Andrea, who was more sensitive to medication observed:

Andrea: *"I have fallen a few times. I've sort of fainted once or twice. Um, one was on Procardia® and I could have told him that's a killer. They had to find that out later. That's a blood pressure medicine that they've taken off the market. And* *now, what happens, I get dizzy or I start perspiring or something, I don't know which medicine is causing it."*

[When talking about knee surgery] "Well I either use ice or heat or rest or prayer, or, um… Advil, because heavy painkillers I just, I can't handle them. You know, my eyes get cross-eyed or I get terrible stomach upsets."

"I take less medication than he [physician] *prescribes." "Well, like with the tranquilizer. If I get so tired it's dangerous for me to drive. So I just cut it in half and don't take it quite so often. Try to do meditation instead of a tranquilizer, or take the herbal drops instead of, you know, some other, you know, pain killer that upsets my stomach."*

Trial Period

Besides drug side-effects, sustaining correct pill-taking was subject to a "trial period" with self-established criteria through which participants assessed and decided if the medication was worth continuing or not. Participants' own criteria were used to both drop or sustain medication regimens. For example, Anna described her decision-making in situations when no health improvement was felt, and Andrea described her decision to sustain medication use after a fall in which she did not have any fractures:

Anna: *"I will take it for a while… and then I will judge whether it's helping, harming, or what – or nothing. And if it's harming or nothing, it's dropped* [Chuckle] *And I don't always tell the doctor."*

"I have had a lot of prescriptions that I take some of and then I decided they were more harm than good. And I have narrowed it down to Fosamax® now. And I do take Ibuprofen at times or if — if I walk a lot — like we go to San Francisco and

walk around there, I will probably have leg cramps, which is another old age jolly. And I will take Ibuprofen® for that and that sort of thing but like one doctor gave me another medication; I didn't feel like it was doing me any good and couldn't see any point in keeping on taking it."

Andrea: *"I felt, you know, the Premarin® I've taken for so long and they now advise against it and yet, um,* [Sigh] *if I hadn't been on Premarin® I would have broke my hip last year when I fell in the drugstore."*

Diet

Findings indicate that motivation to sustain diet and exercise self-care practices were more difficult. When talking about diet at the outset of the interviews, participants were able to accurately explain in detail the diet they were expected to follow. Challenges for sustaining continuous diet practices and self-care coping strategies came to the foreground later in the interviews, when a better rapport had been established. Diet recommendations, stage in life, food participants really enjoyed - described as "sinful" foods - and how they balance recommendations were described through accounts on challenges, strategies, successes and failures.

Challenges and Strategies

A challenge to dieting was to have "sinful" food items at home. That was an invitation for ritualized trips to the refrigerator or cabinet; that is, making trips to the refrigerator to get "sinful food" without thinking about them. As described by Ann,

Ann: "*It depends. I've never noticed. Sometimes I'll beat a track back and forth to the refrigerator at night several times and, you know, you have to figure out how to stop yourself when you're on that trail."*

Having a taste was described as a strategy to avoid eating much of what was not recommended but still being able to enjoy foods they liked. As Red indicated about balancing things out and not having a "*miserable life*":

Red: "*Well, if you watch out in your diet for everything they tell you, you'd have a miserable life. And hell, I'd rather die young. My book says that you shouldn't drink much alcohol and I used to have plenty around here.* [Now] *If we have a party I might take about this much* [less than half of an inch] *in my glass.*"

Spacing out was a strategy to balance what was and what was not recommended. As Ann, Betty, Ellen and Rose shared in their experiences:

Ann: '*You know, you can guard your back and now guard my knee and you can eat well. I mean, it's too bad when you finally retire you have enough money to go out and eat, and you can't eat because everything is bad for you. But you can space some of the sinful things like prime rib.* [Laughter]"

"*Lunch very often is a salad with turkey or ham and cheese. Try to stay away from the dark cheeses. Every once in a while you have to have a toasted cheese sandwich.*"

Betty: "*I drink lots of water. I'm very conscientious about, you know, drinking a lot of water and then I watch what I eat. Except every once in a while, I have to have one of these hot dogs which I know is probably full of cholesterol.*" [Laughs] [Betty was having a big hotdog and salad as we talked]

Ellen: "*Well, I believe in moderation in all things so I don't go overboard on it. If there's something I want to eat and it's not on my diet, I'll usually have a small portion of it anyway.*"

"I love cheese and I don't eat a lot of cheese. Sometimes I have some but I don't eat a lot of it. And oh, I love desserts and I'm pretty careful about eating desserts. I have some once in a while."

"Well, I don't resist desserts when I go out, which I probably should do, but I enjoy them so I just figure that why not? I mean, I don't believe in being – I believe in moderation in all things and even desserts." [Laughter]

Rose: *"Actually I'm, I'm rather fortunate that um, that, my, ah, I have just a balanced approach to eating. I don't—I mean I like my sweets on occasion but I just know I should eat well and part of it was—I think raising children and you know, as they say, "children need models more than they need critics." So eat well all through your life and that pretty much stays with me."*

Having an indulgence schedule, for example, when Anna, Red and Cissie described times of the day in which they women would excuse themselves from following the recommended diet for them:

Anna: *"And by eating her* [daughter] *diet with her for meals —for breakfast, which we very seldom eat together, I could eat my hot breads and — I like the scones and I like the orange-cranberry hot bread mix and that sort of thing. I can indulge my breakfast like that and then eat very healthy foods for lunch and dinner and I don't gain weight* [Chuckle]*."*

Red: *"My first doctor I had, I haven't seen him for years, put me on a diet that sounds sort of like the Atkin's diet. He told me I couldn't have cereal and milk for breakfast, that I should have egg and yogurt, but I got sick of that so I started eating more cereal for breakfast. And then for lunch he said protein and fat.*

Well, that only leads to heart problems so I cut back on that. So now I'm just sort of – what do they say? – playing it by ear. Whatever works."

Cissie: "*Well, it watches, it makes me watch out what I eat, only I'm a Hershey® bar addict. And I'm just delighted that some people think it good for the heart.*

[Laughs] *So, that's the way I, ah, solve my conscience."*

[Amount of chocolate] "*May be 2 to 3 a week. Little ones."*

Women who were married described sharing with husband as a strategy to split foods that were of high caloric value. However, when there were differences in cooking styles preferences, there was no sharing but taking leftovers home. For instance, Ann described what she and her husband did not split:

Ann: "*And my husband and I go out to lunch every – maybe once a week but we split what we get. We always split, except prime rib. He likes it well-done and I like it raw."*

"But then we'll bring it home and have two more meals so that you consciously, when your metabolism starts slowing down, you consciously have to eat less and so you just drink more water."

Exercise

Along with diet, exercises were difficult to sustain. In all interviews, participants made some sort of reference to the importance of exercise. However, continued attendance at classes depended mostly upon driving (as discussed later) and the "clima[44]"

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[44] To best describe this category and its properties I needed to look for a word that would attempt to indicate the incommensurability of participants' accounts. I discussed it in a peer study group and with my advisor, and neither climate nor environment translated it adequately.

of the group or class. "Clima," a word used in spoken Brazilian Portuguese, describes a combination of good emotions felt in the air, of flow of positive energy, of people – not necessarily with smiley faces - but happy, with an inviting, deep attitude welcoming to participation and sharing each time one enters a specific physical, social or emotional space. The continuous participation in group exercise activities took place when there was a good "clima," peer participation and also paid membership (most of the women did not have significant financial limitations). Friends were important in getting participation started for these specific group practices, but not always in continuing them. However, having a routine and friend's or spouse's company helped participants to sustain walking or doing exercise at home. Reminders such as the interview about motivation helped them to get back to "forgotten" exercise practices. Ellen's account is an exemplar of "clima" at the same time it talks about how the exercise group shifts from a exercise class into a more significant event:

Ellen: [With a happy expression on her face] *"I like going to the YMCA. It's fun. There's a lot of nice people and they're all people with heart problems so we have a lot in common."*

> *"It's fun. There's a lot of teasing and joking and sharing, in spite of the fact that we're moving all the time. And I like going there. It's sort of a social event really, because I'm becoming friends with people there. I've been going for about two and a half years and so that keeps me going."*
>
> *"Well, it has to be – it can't be boring. It has to be diverse enough so it keeps your interest. And they do a pretty good job of that at the Y. They have different instructors each of the three days so that you have a different approach. And it*

could get very boring, just exercising for an hour. So I think you need diversity and exercise should be fun. I'd like to find something I could do now that's more fun in exercise. I don't know what it would be but..."

Melissa and Bogey's accounts made reference to peers in similar situation and the enjoyment aspect of the classes:

Melissa: [Aquatic exercises] *"They're great and I really enjoy it so I don't care if I look fat. I go in anyway. And always I'm not the only fat lady there.* [Laughter]"

"It's in [city name], *it's a public pool, and they offer a class for people with disabilities."*

Bogey: "*It's two years last July I started. The people are very nice there. The staff and the people who go there are all retired mainly men and women but they tend to be a nice group of people so it's kind of a social, as well."*

Routine also helped women to sustain exercise practices. For instance, Ann's and Lou's accounts exemplify exercise routines or rituals that occupied a specific section of most of their days. However, there were incidental (Lou's narrative) and recurrent (Ann's narrative) days in which exercise could be skipped. As Lou and Ann noted:

Lou: "*You get up in the morning and this is whatcha do. You put it in your mind. I've got to take my exercises this morning, so you do it. You don't, you don't try, may be one day might skip it but then you go right back and start over again.*"

[Situations Lou would skip the exercise session] *"If you are going somewhere. And you had to be there at a certain time. Like tomorrow morning, I'm going in for my mammogram. So, I will probably skip it unless I get up real early. This* *morning, I got up real early to do it, which was 6:30,* [Laughs]. *But tomorrow morning, I might get up early too and do part of it, you know."*

Ann: *"When I first injured my back I had to do the exercises twice a day and it took about 20 minutes each time. I got it down to once a day after a year or two. Now I do it five days a week and take the weekend off for good behavior."*

Participants indicated that the research interview, along with talks, magazines, appointments, and readings worked as reminders that exercise self-care practices could or should be sustained or resumed if they had been interrupted. Rose's account was an exemplar of these experiences:

Rose: *"A reminder of exercise. I think the latest magazine of some sort, you know, talked about strengthening exercises and so I went out and got my little exercise bands and I just always have my antennae up for..."*

"*So, um, I don't know, you know. I did join* [Local Facility] *to do some swimming and water exercise a few years ago, that was after my heart surgery; I was a little more motivated then. But, um, you know you're giving me some food for thought and this may be the importance to get me out to take, to get involved in those exercises."*

The Balancing Act: Cross Players

The previous section of this chapter focused on describing these women's experiences of balancing life and health through medication, diet and exercise. However, a number of enablers such as driving, health information (e.g., written and electronic sources), people (e.g., health care providers) and institutions (e.g., HMO) played a central role to the understanding of motivation for each self care practice but yet were global and spanned across self-care domains.

Enablers

Women's narratives indicated that there were some conditions that promoted motivation to sustain self-care practices. In other words, these conditions made it possible or helped these women to sustain self-care practices. For example, the most important enablers that were referred to across interviews were daytime schedules and a current driver's license. Transportation systems and services for people with special needs also worked as enablers for some of the participants to get to or to continue getting to their appointments, exercise classes and leisure. In addition, field notes on conversations away from the tape recorder also report that women referred to the periodic renewals of their drivers' licenses as occasions of great anxiety and fear of having the permit taken away from them. Tarzan, Rose, Cissie, and Andrea's accounts described how time of the day and traffic issues had an impact on whether they were able to sustain participation:

Tarzan: *"We got together at* [Name] *Hospital, diabetics, and it was—no doctor made you go or told you had to go, you just knew about it and you went, and there they would discuss meals and things to have for parties or whatever, or they would have a speaker. And that was very helpful—that continuing program that we did with them. Now, since we've become, most of us, not wanting to be out late in the night or anything, that won't—that isn't going to work, we don't want to do that."*

Rose: *"It was the series of classes was, was over, it, it got to be a little hard fighting the traffic in the morning to go to relax at a place and exercise at that particular place." "Yeah, it just was not a good, good time."*

Cissie: *"There is, there is an organization in the County called "Mended Hearts" and they meet, I think, once a month. They meet at night; I have no way of getting there. I have no way of getting there."*

Andrea: *"I go occasionally to social affairs at the church when it's in the daytime. I don't drive at night anymore."*

Driving

Driving was the strongest subcategry of enablers that totally surprised this researcher. Findings indicated that driving was fundamental in sustaining self-care practices in most of these women's lives because it enabled them to access health clinics, hospitals, exercise and health education classes, churches, associations and clubs they attended. The comparison of the type of license (with or without restrictions to drive on highways and at night) across interviews did not show it to be more or less helpful for sustaining participation. However, having a valid license and being able to drive enabled participants to continue attending a number of activities that they would not be able to should they lose their licenses. "The driving test" for license renewal is essentially one of the disturbing issues for these women who have their "own time" when they can drive where they choose to at the time they want. Accounts sounded like their possibility for freedom of movement, choices and decisions on their own time and direction was threatened. It is important to note that public transportation was widely available only for two participants who lived in a more populated city. Even though alternative options for transportation for seniors and people with special needs were available in some cities, these had limits such as set pick-up and drop-off times at the time one requests the service and they do not operate after certain hours. As Andrea, Lou, Tarzan and Ellen shared:

Andrea: *"I go to* [supermarket chain store]. *Yeah, oh yeah. I can drive down there; it's no problem. I drive to church. I get myself to the doctor's. Lately it's just been one doctor's appointment after another."*

Lou: *"Well, we've gone to the Doctor's Hospital [a series of health-related talks that is advertised on the local newspaper] if other people go and then they drive. I don't drive that far away. I like to drive around town but no further than that. I'm not that much of a driver. I don't like to drive, that's my problem. But I do go do my shopping and stuff like that."*

Tarzan: *"And people would come and they would get a blood check that day and she'd just talk about diabetes and you'd share it with each other. Those were good groups, but it doesn't really fit for us to go to much anymore, so...it takes too much* time*... it's a little harder. We're not, we're not... free to come and go with our car as we like, that makes a difference."*

Ellen: [Ellen's husband and son have disabilities] *"And then we have a lot of doctors' appointments between the three of us, so I spend a lot of time driving one or the other of us to a doctor's appointment."*

Health Information and Education

Health education / promotion classes and groups were a source of health information and participation that was sustained when they were required by the HMO for obtaining equipment / medication; there was personal interest on the topic; and there were quality classes as assessed by these women. The two most important categories that emerged from the data were classes and written and electronic sources.

Classes

Friends and not just company were important in planning together, getting started and in socially keeping up with these specific group practices and among them, classes, talks and support groups. Learning new things, content, and strategies helped participants to sustain interest and to continue. Betty's, Lou's and Cissie's accounts illustrate how they got to classes and what helped to sustain participation:

Betty: *"Because I went to those, the diabetic classes at* [Health Care Institution]. *I think there was something with Medicare that if you don't, if you go to those classes, Medicare will pay for your, ah, diabetic supplies and things. And, ah, she told me to eat only 45 carbohydrates at a meal and 15 carbohydrates at my 2 snacks during the day."*

"He [physician] *told me, "Betty you have to lose weight, you* <u>*have to*</u> *watch what you eat and you have to go to those classes." And it was 10 hours, 10 hours of classes. I had to go like 2 days, 3½ days and 1 hour with a dietitian over at* [Name] *Medical Center".*

"They were the one; that was where he recommended that I go. And, then they send a bill to Medicare. And, they were able to give me my blood monitor, you know. Oh, that, another thing I do for my health, I take my, my, I monitor my blood. Ah, every once in a while, not <u>*every*</u> *day. And sometimes not even every week."*

Lou: [In referring to a series of talks on health issues] *"They have it advertised in the paper at the Doctor's Hospital. They have different classes."*

"And then we try to get together if anybody is interested in going, then we go. Otherwise, we don't."

[When asked about the last talk she attended] *"Was to the knee, the knee and hip, yeah."*

"Before I was having surgery. My knees were getting bad, anyhow."

"It was in the paper. Another friend of my and I, we decided, she had the hip problem and I had the knee problem. [Laugh] *So, we decided to go. That's how we went."*

Cissie: *"I have been going here at the* [Area Name]. *I've been going to one on Wednesday morning at 9:00 where we get weighed-in. And, we read something from a medical journal or something like that all the time. And it's about nutrition. And, one of the nutritionist here at the* [Area Name] *is the teacher of the class. And I have always been very much interested in nutrition and I've taken nutrition at* [College Name] *of* [Name], *Nutrition I, Nutrition II and Nutrition III.* [Laughs]"

"I think it's, it's because you go once a week and it renews you about nutrition and you have a thought that, you know. It's not like just losing it and not thinking about, it keeps us thinking about nutrition, I go once a week."

Written and electronic sources

Although deprived of the aspect social group participation, women's additional sources of health information were mostly in written and some in electronic forms, such as medical journals in waiting rooms, books, HMO brochures and clinics newsletters, health-related magazines and family member's Internet search results/choice. At the same time these sources were informative, and helped women to keep self-care issues in mind, they also brought doubts about what self-care practices to continue. It was not quite a barrier but a confounding factor in these women's decision-making. For example, Lou's and Red's accounts refer to conflicting information that may cause confusion and make it more difficult for them to sustain long-term self-care practices.

Lou: *"You hope and pray it's a good book. You read it, you know, and kinda get an idea. But so many different, you know, so many authors have different ideas of foods and whatnot have you. One day it's this and one day it isn't this."*

"Because, you'll, you'll, they just con, you know, contradicting one another. And so, who do you believe? So, you go on doing whatcha been doing to begin with."

Anna: *"If I can get my hands on a medical journal I will read it and that was where the Fosamax® was over prescribed. That it was not necessary to take as much as is prescribed. It's very expensive."*

Red: *"I used to get a Mayo Clinic newsletter but they rarely had anything about diabetes so I just quit that. You know, you can get all kinds of things on the Internet now"*

"I check, you know, diabetes, any source for diabetes. There's so much stuff, you don't know what to look at."

Participants referred to their own experiences and encounters with health care providers, friends and family as facilitating or hindering their efforts to sustain self-care practices over time. Most detail was provided by participants on health care providers, about encounters, unfortunate events, negotiating treatment, relationship types and communication styles/strategies.

Health Care Providers

Encounters with health care providers that were perceived negatively as well as unfortunate events, comments, and inadequate attitudes by health care providers hindered maintenance of self-care practices. However, fortunate encounters in situations of poor health and frailty - in which participants were helped by a health care provider - were recounted as a source of motivation to trust their providers and to sustain practices recommended by them.

Unfortunate events.

Ann: *"And then I didn't particularly care for that doctor that had done the sigmoidoscopy the first time. No sense of humor. He was doing the sigmoidoscopy and I said to him, "Is your theme song 'On a Clear Day You Can See Forever'?"* [Chuckle] *He said, "Don't talk if you don't have anything important to say."* [Laughter]*"*

"I was trying to make it a little bit lighter. But he was just, he was brutal. But Mussolini, Hitler, little short man. So anyway, I found a different doctor and he was wonderful"

Anna: *"I had been having little strokes and I'd been shoved from doctor to doctor to doctor because nobody could find anything – my blood pressure at that time was 90 over 60 so they would not believe when I — I had classic symptoms of stroke except for high blood pressure. I did not have high blood pressure."*

Andrea: *"So I saw my doctor and he never even checked the x-ray. He never—nothing! He just said, "Oh just grandmotherly overexcitement. So that's when I changed doctors."*

"So I get a lady doctor temporarily until they find somebody else to, um, you know, um, take over Dr. M's practice and I'm now with Dr. B, who is wonderful! But he's over scheduled, he's over worked, he's underpaid. I'm one of his favorite patients and he can't figure me out."

Red: *"Well, they didn't take very good care of me. I say that because they assumed that I had adult onset diabetes and they gave me some pills and that didn't control the blood sugar at all. But they kept doing that for three weeks. Each week they'd increase -- a different doctor would increase the pills. And then I – the night before Christmas I ended up in the hospital with ketoacidosis."*

Fortunate events.

Andrea: *"It's really strange. When I came back after my husband drowned, he* [physician] *ordered every test under the sun, you know, blood tests and a, and I said, "Why are you doing that? This is not—I'm not normal right now. I've just had a shock and I'm taking all these things to calm me down and this is not the way I usually am, you know," and he said, "I want to see how your body reacts under such stress." In other words he* <u>*really*</u> *cared. I thought it was a waste of testing but I figured he ordered it - go ahead do all the tests you want. I don't know. You know we had better rapport with explaining things."*

Rose: [When got the recommendation of valve replacement] *"First, my own, my own, cardiologist referred me to someone because he understood that "yes" I wanted* *to have, you know, more confirmation and he was very good about it and then from there I went through my daughter to other sources at different medical centers And they, you know, checked me out so it was an actual physical check-up."*

[After having seen different health care providers] *'I think what it came back to was my own cardiologist, who was always available, who understood that I needed more confirmation from someone* [another physician] *outside of it, who accepted it very well that that's what I wanted to do, and is still available, you know, personally to me. And so I think a physician being open to a patient's need for further confirmation beyond what he or she provides is a good, good thing to have."*

Negotiated treatment.

Health care provider – patient negotiated treatment plans and shared decisions seemed to foster trust, imply compromise and help participants to continue with their self-care practices.

Ann: *"Well, the orthopedist – the knee - I said to him instead of having a meniscus repair can we just wait and see what happens? I know the blood supply isn't terrific when it comes to bones and cartilage and things like that but can we just see? And he said sure. I mean, he knows I'm up there at this point, and he said but you're not to work on your knee.* [Laughter] *I said do you really think I can do that? But I didn't. And after six months or so he said go ahead. You can start stretching."*

Ann: *"And the cardiologist said that he could put me on beta blockers or something like this if it bothered me a whole bunch. And he said, you know, "What do you do?" And I said, "Well, when it really stalls, you know, I just hit my sternum and we're off to the races again". So he left it up to me whether I wanted to take something. I said, "No, I don't want to take anything.""*

Ann: *"So anyway, I found a different doctor and he was wonderful and his treatment was fine except he wanted me to stay on the – what is it, acical or ascical? – acical, I think, I don't know – for the rest of my life type thing. And I said, "C'mon now. We haven't had any trouble for" -- you know. So all right. So he let me go off of it. And then when I'd have a problem I'd call him and go back on it. That seemed to work just fine."*

Meaningfulness of recommendations.

Association/Contextualization of exercises and recommendations with some sort of meaningful activity was described as helpful in maintaining interest in sustaining long-term self-care practices as opposed to isolated movements demonstrated by a health care provider or learned from a video tape.

Anna: *"And this one doctor told me* [Chuckle] — *he'd get a ball and place it on the floor in front of me, lean down and pick it up; and place it on the right, stand up, lean down and pick it up; and place it on the left, stand up…* [Anna demonstrated the movements as she spoke]. *I said, "Oh, I do that all the time. I dump all the dirty clothes on the floor, I put these over here, these over here, these over here* [Anna demonstrated the activity as she spoke]. [Chuckle] *Then I have a washing* *machine* [Chuckle] *and I just — I do that all the time.* [Laughter] *So he wasn't very happy with me."*

"He doesn't know much of a life of a woman."

Characteristics.

Style/personal qualities (e.g., thorough examiner, friendly) and length (e.g. knowing one another year or more) in relationship with health care providers helped participants to feel more willing to perform and maintain recommended self-care activities. Participants indicated that health care providers' characteristics / personal qualities that motivated them to sustain self-care practices were "healer" "comfortable making" "competent, knowledgeable but not an engineer," "mentor" and someone who answers questions and returns phone calls.

Thorough examiner and good listener

Andrea: *"The only person who took a really good medical history on me was my acupuncturist. That was a 6-week trial thing. She's great!* [Her acupuncturist is a nurse]

Red: *"I think the healthcare providers should absolutely talk to the patients because you get in trouble too quickly to solve your* [own] *problems. But, you know, when you're talking about long range kind of help so that you feel comfortable with this marriage and this doctor, you don't get too much of that."*

Friendly

Andrea: *"I mean we were friends, not just doctor and patient and uh.* [Deep sigh]"

[The physician she really liked] *"Well for one thing his family belonged to our congregation. His children went to Sunday school with mine. He lived around the* *corner [Name of street]. He, ah, I don't know he, he touched you, he talked. We had sessions of 45 minutes. We talked about the family and the Sunday school and his wife was, um, in a, with a nurse round the clock."*

Knowledgeable but not an engineer

Bogey: "*Some of the male interns — they're just like engineers or scientists. But — well, I think it's true in any relationship. Some people you get along with better than others. But — well, she was just — just a nice friendly person. I think she knew what she was doing. But for some reason she's left adult medicine and gone into infectious diseases over at the* [HMO] *Hospital over here."*

Ann: *"Because nowadays you're lucky if a doctor looks at the front page* [of the patient's file]*."*

Someone who returns calls

Lou: "*Like I said they take their time to talk to you. And if you have a question, they will answer it. And I can call him up. And he will get back to me. It might be in evening but he will get back to me. Some doctors won't do that."*

Ellen: *"We've adjusted the medicines from time to time. I was on a different cholesterol medicine and they changed it at one time 'cause I was having some reactions that we thought might be from the medicine."*

"I'd phone and leave a message and the doctor would call me back and say well, let's try this one. And I have a – they have a pharmacist at [HMO] *who just tends to cholesterol patients and he monitors my – I have my blood sample taken every three months and he monitors that and he'll call me and tell me we need to*

increase the medicine or cut back or it's not working and I want you to talk to your doctor, things like that."

Healer

Cissie: *"My special doctor there that I like so much started working in the hospital. And, he was, ah, he was a healer from way back. I mean, he could walk in the office and my blood pressure went zoom down.* [Laughs] *He was just so relaxed and, ah, he just had that smoothing feeling. But, darn it, he left."*

Cissie: "*Well, he just walked in and he would give his full attention to you, you know, and he was, he wasn't flamboyant. He was relaxed himself.* [Laughs] *I don't how he got so relaxed. And he would listen and he would help you but he would not, he wouldn't take any sort of foolish talk about your family or anything like that. He stuck to the subject.* [Laughs] *And, he was just, and he had just a relaxing, almost hypnotic effect. And, I'm not the only person who said that.* [Laughs]"

"And, he had a special quality about him, a healing quality. I think we always realize some, that some people are healers. [Laughs]"

Rose: *"So maybe the personality of the doctor, the confidence that a doctor has in him or herself that - "Yes, I'm pretty sure that this is what needs to be done, but the patient needs to be sure that this is the right thing to do, so."*

Length of relationship

Lou: "*Doctor* N*? I would say it's been about nine years, cause we had another doctor before him. So, Dr. N has taken his place. So, I've been with him for quite a few years."*

Rose: *"He had not been my doctor for a long time. My own cardiologist to whom I was referred when they, you know, found out that I had—I went with this health plan and they found I had this leaky heart valve, then I was referred to the cardiologist, and I had him as my cardiologist for, you know, 15-20 years before he died. And, ah, so I was really without a cardiologist until I got referred or had to go to the hospital with this sub-acute, you know, bacterial endocarditis, which was in '96."*

Betty: *"I've known Dr. A since he first started to practice. And I, we figured it out before he retired I've been going to him since 1957, maybe 45 years."*

Ellen: *"I like her. I respect her. I think she's a very good doctor. I've gone to her for a long time. She's very busy so you don't get a lot of time and it's hard to get an appointment but she'll always see me when I have to see her."*

Communication

In addition to type and length of relationships, participant accounts suggest that communication styles and strategies can facilitate or hinder long-term maintenance of self-care practices. Variations on inadequate communication styles such as reported in Anna, Lou, Carol, Ann and Tarzan's experiences led participants to seek treatment alternatives, new strategies, or to change of health care providers:

Anna: *"I don't know whether it's* [hometown] *doctors or what but to pull a little information you need pliers almost, you know."*

Lou: *"It has to be the way you talked to that person."*

"Because some people have a very harsh way of talking to people. And, that's the worst thing you can do to a patient. So, you've go to see and then you have to

listen to them also. Just listen to them and try to coax them to do what they should be doing. For their good, not yours, but for theirs. You're doing it for yourself. That's the best I can describe it."

Carol: *"I was in the hospital and they realized that my heart – well, I said I don't like the label but they say heart failure. But I don't – I know I don't have a strong heart but I don't worry about it."*

Ann: *"In the sixties, at the end of the sixties, I was in the hospital with pneumonia and the doctor took me in my short little gown down in the elevator two floors to see a man who was dying of cancer. And he said, you know, if you don't stop* [smoking] *you're going to be a respiratory cripple by the time you're 50. And I said well I would stop but it took me ten years. Isn't that terrible?"*

Tarzan: *"They're going to tell me a lot on Monday. Today is —March 3rd, I think it is, that I have an appointment."*

"I'm going to go and get the rundown and they're going to slap me around a little bit mentally."

"Well I'll have to because I – look at me, you know. Well, I weigh 188 pounds I think, or 86 and I'm going to have to shape up because my doctor looked at me and said, "You're could to have a massive heart attack at any time, Tarzan."

Family

Because of the inclusion criteria most family members referred to in the interviews were husbands. Grandchildren were referred to as incentives and inspirations. Daughters who only came home to sleep or lived nearby their participant mothers were also mentioned. Husbands helped women with company, moral support and concrete actions/physical help, which facilitated maintenance of self-care practices. However, as a contrast case, Tarzan's husband makes it harder for her (who is his primary caregiver) to both initiate and sustain self-care practices.

Incentives

Andrea: [What helps you to go through difficulties] *"I guess the thought of my children and grandchildren." "And that my mother had the courage to put us on a plane with total strangers to save our lives when she knew she was probably never going to see us again"* [Sad tone of voice]. *"If she had those guts I shouldn't be* [pause] *a weakling."*

Company and Support

Ann: *"A typical day, we get up early and take a 2-mile walk before breakfast. I won't allow my husband to eat breakfast until he's done it. He won't allow me to eat breakfast until I've done it."*

Red: *"I've gone on walks and have to have my husband come and get me 'cause my sugar's suddenly dropped off. So my neighbor found out, you know, and we talked about it. And you tell your friends. If they offer you sweet stuff you have to say "oh, I can't eat that"."*

Rose: *"And then with my husband's medical condition, you know, certain nutrition and ways of eating are very important to him and we compliment each other on what is a good diet."*

"I have dinner with my husband usually around 5:30. We eat quite regularly, um, because he is diabetic and so eats quite regularly to control his diabetes."

Action / physical help

Rose: *"For me having a little schedule of some sort, and part of this we developed ourselves, my husband and I, but I think with encouragement health professionals to keep, you know, just do a little diagram of, of, of exercise."*

"After I was released from the hospital about keeping track of your—how many minutes a day you exercised or when you took your medication, just something to give you control over what needs to be done and, a, a good way to, you know, an easy way to keep track of, "yes, I took that medication," yes, I got my 10 minutes of exercise." I think for a healthcare person to help you with these little practical matters, so that you're not, "Oh, I have to do this; I have to do that; I must remember to do this," you know, have a little grid of some sort that could be made up and say, "Okay, now this is how you can keep track of your medications. This is how you can keep track of your weight, your pulse, you know, whatever it is that you're supposed to be keeping track of."

Melissa: "*Well, I have a gripper, you know, and I do that with the – fiddle with that or I yell at my husband to do it, so…"*

Red: "*Well, I'm getting sort of lazy. You know, your diet is so restrictive. So my husband's willing to eat what I fix."*

"He doesn't complain about what I fix."

[Referring to hiking trips in the neighborhood and trail mix bar that husband carries with him for Red] "*I take some kind of precaution, a little piece of candy to keep me going and he checks for that and I don't think of that. But that's happened sometimes."*

[Husband came into the room and talked about when Red does not feel well during their hike] *"She just weaves. Sometimes she'll hold on to me and we'll make it home. And other times I'll have her sit down on a wall somewhere"* [And he comes home to get the car].

[When asked if husband keeps her company when going to appointments] *"Yes, sometimes he does. He keeps track of these pills I've got. When I'm sick he'll lay them all out, you know. He knows what my doctor..."*

Rose: [Referring to the Internet as a source of health info] *"Through my own health plan I get information. A lot of it I must say I rely on my husband to, to pull it up because he knows so much more about researching than I do."*

"I relied more on what my daughter and my husband, you know, I'd have to check to see where they, they pulled that up. I have all that in a little file yet, that, you know, that I can pull out for you."

Anna: "*Well, my daughter makes me eat better food.* [Chuckle] *She's a health nut.* [Laughter]"

Challenges

Ellen: [Who has heart disease] "*I try to eat healthy food.'*

"Diet's very difficult in our family because all three of us have different needs and so it's really hard to keep it... balanced. My husband has diverticulitis and he can't eat a lot of the things that are good for me)."

"Well, he can't eat the beans and peas, the legumes that I can eat. He can't eat cabbage or any of the... He's very restricted on vegetables. He can eat peas and carrots – well, he can't actually eat peas. Well, he also has problems with his

teeth so there are things that he can't chew. So Brussels' sprouts and broccoli and – he can't eat at all, and onions he can't eat and those things are all good for me, so...[Laughter]

Tarzan: *"Uh, if he* [disabled husband] *was dead, I would have it* [bypass surgery]. *But I can see what he means. Because if I died he'd have to live with our daughter, and our daughter's a very sweet and nice person, but he's used to me and he doesn't want to have to get used to having* [Daughter's name] *as his boss.* [Laughs]*"*

"I do feel, well, it is possible, but I'm one of those ones that does [emphasis on does] *need it done, not one of those ones that's just.... Maybe yes, maybe no. So that's where we're at. It's not a real point of contention because I just don't do very much, on purpose, to make it a bigger problem."*

Friends

As indicated in self-care domains under exercise, friends were important in getting participation started for specific group practices, which could evolve to social practices. At a smaller arena / an individual level, friends' company helped participants to sustain activities such as walking and getting out of the house.

Rose: *"I go out for a morning walk, sometimes with a friend, um, or if I don't go in the morning I go in the afternoon, but I try to get a walk in every day of, you know, a half hour walk."*

Betty: "*Some days, especially when it was cold like in the winter, I would just want to get hunker down and go watch my TV. And so, I needed a little push to get out and do my exercise."* [Which was given by her friend – a friend twelve years older than Betty]

"You know some days it would be easy to stay home. In fact most of the times it's my 88-year-old girlfriend calling me and saying, "no, you've got to go and do that [the exercise]*".*

Cissie: *"This woman who just called me walks, walks her dog. There is a walking path that goes all the way from, ah, on past here, ah, to* [City]. *The scenery is beautiful and I walk with here and we walk 2 miles and I'm, um, not tired at all".*

Ellen: *"A friend of mine is a doctor and he highly recommended it and so I did it* [exercise] *partly because of him."*

"Well, I think friends really help me. I have some good friends and that makes me feel good and keeps me going."

Institutions

Health system and institutional changes in the time allocated for appointments in the context of the health system were critiqued by participants and were a barrier for sustaining self-care practices. Reduction of the time health care providers had to spend with participants was reported as a major barrier – for them to have their files properly reviewed, be examined, resolve doubts and have questions answered. Furthermore, this time reduction influenced participants' adoption of coping self-care practices (e.g., letters, lists, notebook, journals) for obtaining health information and education. As Ann, Rose and Lou indicate about insufficient time:

Ann: *"I think it is why. I'm responsible for my health because they... they don't. I've had the same primary, if you want to call it that, doctor since 1985 and she has gone from being nice, likeable, taking time, to looking at her watch because she was scheduled, you know, so closely. And you don't expect to get good care out* *of a doctor that's every 15 minutes is seeing a patient or something. Terrible. Terrible. They went with a managed care firm that ran that office. They have since gotten out of it but it was terrible."*

"But I expected *__them__* *to keep the records. But then you began to see that they weren't looking back at any of the records or they'd stand during these shorter appointments and they'd be paging through and wouldn't find and stuff"*

Rose: *"I think that's almost a given, unfortunately, that there isn't as much time as I would like to have, ah, you know, it's not a—the professional with a hand on the door going out almost as soon as, as he or she is coming in. In fact it* *__really__* *helps, you know, if a professional takes the time to just sit down instead of standing there with the charts or whatever, but just sit down or lean and give, give that impression at least that you're going to stay there for a little while* [Chuckles] *to listen even though the time may be not* *__be__* *that much more, but just take the manner of the professional, ah, can make you feel like you're, you're getting quality time, but now I know that there isn't the long, long visit that perhaps there used to be, but."*

Lou: "*Well, it's been that way* [limited time with health carte provider] *since our new health thing has been going on and everything. I mean, they haven't got no time. Medicare's not paying enough. Medicare only pays what* *__they__* *approve and the doctor's have to make a living, too. And they're not, you know, really. So sad, really."*

Trajectories

"Going off track" and "shoulds" were trajectories experienced by these older women. However, going off track was transitory and participants returned to performing recommended self-care practices. Participants acknowledged that "shoulds" indicated conflicts between cognitive health goals and social values. "Shoulds" were self-care practices never initiated; or initiated but dropped when participants priorities changed (see graphical representation in Appendix H).

Going Off Track

Going off track were situations that altered the clinical significance of a given condition in contrast to a social goal. Participants reported that specific dates, situations, and life events were more difficult for sustaining healthcare practices because they generate conflicts between physical health goals and social values.

Occasions that older women went off the recommended self-care track most often were Sundays, holidays and when traveling. Another aspect of going "off track" is the flair-up of one condition hindering continuation of a self-care practice for heart disease or diabetes.

Special Occasions.

Weekly social gatherings after Sunday service were the most frequent special occasions, in which the food served was for the most part sweet. As Red remarks:

Red: *"Because every time I go to a party, anything* [emphasis on anything], *down to church, they've just got sweet stuff, you know. Terrible, terrible. There's nothing there to eat, nothing there to eat, so that's really difficult."*

"Even go to a committee meeting they'll pass around something to eat, something. Boy, and one piece of candy will send my sugar up like a rocket plane, just like that. So I don't eat much candy."

Even though recognizing that to get back on track was more difficult, only one woman made reference to trying to avoid holiday food. Annual family and social gatherings, namely Thanksgiving, Christmas and Cruises were described as having a lot of the "*wrong stuff*" (food) and as being difficult not to go off the recommended diet track. As Ann, Andrea and Rose indicated:

Ann: *"October, November and December always seem to be an increase and I thought well, okay, Thanksgiving always throws me 'cause, you know, a lot of people... and the cooking, the planning."*

Andrea: *"I usually get depressed in January and June. January because of the, you know, the seasonal whatever... disorder, and too many expectations, Christmas presents and rushing and eating the wrong stuff and everything, and, and the bronchitis, which I know, you know, it just goes—zoom! And I thought, "Well, now you've got a collapsed lung. So I need to be careful."*

Rose: *"When we travel we both tend to overeat and a lot of it is because I'm not doing the cooking, and the large portions or whatever, I don't know, we tend to overeat so we're very conscious of that now, and when we come back from trips if we haven't put on more than a pound or two or—because it's so <u>much</u> harder to take it off, I find as I get older it's much harder to lose weight. Better to keep it off, or better to stay healthy to begin with than try to take it off afterward."*

Shoulds

At the beginning of interviews, participants could list self-care practices that had been recommended by their health care providers and in health-related literature that they had read. However, not all these practices were initiated and maintained. In situations that self-care practices did not pass the "trial bar," were interrupted, or were not even started, participants made references to practices they knew would be good for them. Most of the accounts used "I should…" to describe what was health-wise or socially "expected" from them but that they did not feel like initiating or could not sustain. Furthermore, these women's "shoulds" point to their major challenges and difficulties that they had to overcome as individuals - in terms of getting motivated to initiate and to sustain practices they "should" be doing to take care of themselves. The scope of "shoulds" found in the data set are demonstrated in Andrea's, Tarzan's, Carol's, Rose's, Cissie's, and Melissa's thoughts:

Andrea: [A writer] *"I have carpal tunnel in both of them* [wrists]. *So I've given up needlework, except I will not give up typing and I will not let them operate. Thirty-five years ago I should've had them both operated on."*

Tarzan: *"I probably shouldn't eat as much fruit as I do."*

Carol: *"I scold myself because friends go to exercise Tuesday and Thursday morning and probably I'll get ambition enough tomorrow to be my first day because I have my pad that I use here at home. But I thought if I make it a point to go to the exercise class I know I'll stay with it for a half hour because that's my biggest problem, of being consistent with – because to improve your health and keep feeling well, exercise is the primary thing that should be done."*

Rose: *"I really should do more of that* [referring to exercise], *that's an area of, where I think: 'oh, maybe I should join the Y' because I keep hearing that older people should do more, ah, resistance, you know, strengthening exercises for their, for osteoporosis. I, I, you know, I get my* <u>walk in</u> *but I probably should do more of that, and I, I—so that's an area, this is, this is good. The way I need to figure out what will motivate me to do more of that."*

Cissie: "*May be I should see if there is anybody here in the [Area Name] who goes to "Mended Hearts"*[talk/support group]*"*

"There are exercise programs here in the [Area Name] *every morning and I certainly should get up, even though I'm lazy in the mornings, and take one of them."*

"My next door neighbor does one and she keeps saying, "Cissie, why don't you come?" and I should. I really should."

Melissa: [At the time of this interview the cellulitis was completely healed] "*I should be doing and I did it for a long time until I had this cellulitis, was go twice a week for aquatic exercises*."

Conclusion

Through description of everyday life and self-care practices, participants' accounts revealed that they evolved strategies that allowed them to balance need of good health and the desire to enjoy what was meaningful and pleasurable to them. It is important to notice that while "balancing" health, life and other activities, good health was regarded as important by all women, since it is a key aspect of maintaining quality of life. Thus, the tension came in view when activities to maintain health in the long run of a chronic disease compromised quality of life.

Chapter 5 discusses the contributions, implications, and relevance for nursing practice of findings presented in this chapter and makes recommendations for future research.

CHAPTER V: DISCUSSION

Introduction

As indicated in Chapter I, in order to minimize confounding factors (such as differences in culture, ethnicity, gender, age cohort) evidenced in a pilot study, the primary focus of this study was on how motivation for self-care is experienced by older women with heart disease and diabetes. These two conditions are chronic in nature and involve medication regimens, constant monitoring, and changes in lifestyle. They are also the leading causes of morbidity and mortality in older women in the ages of 62-84 years.

This study sought to provide a better understanding of motivation by voicing older women's perspectives and lived experiences on what influenced their maintenance of self-care practices over time. As a working definition for this research, motivation was defined as what moved older women towards engaging in and sustaining self-care practices over time. Based on this working definition, this study's two initial aims were achieved, despite its limitations of having a small, convenience sample.

The first aim was achieved in the sense that findings give a better understanding of factors that influenced motivation and of what helped and what made it more difficult for these older women to maintain self-care practices. The second aim was partially achieved; these women's description of their practices informed us about how motivation in maintaining self-care in the long run was experienced by them. At the moment this dissertation is written a participant-constructed definition for motivation has not been generated yet, given the long-term analysis required to achieve this goal.

This chapter presents a brief review on findings' key aspects; discusses how current empirical and theoretical knowledge is supported by these findings; discusses how the findings contribute to nursing, social and behavioral sciences; and indicates the study's limitations and recommendations for future research.

Bringing it all together

The literature and theory chapters reviewed studies and current views regarding one or more factors influencing motivation such as hormones (Hsieh et al., 1996; Lentjes, Griep, Boersma, Romijn, & de Kloet, 1997; Blackburn, Cross, Hille, & Slater, 1988; Drolet et al., 2001), and needs (Maslow, 1954a; 1971, 1987), and the characteristics of motivation (Martin et al.,1987; Dietrich, 1996; Lukkarinen & Hentinen, 1997; Jayanti & Burns, 1998; Markland & Hardy, 1993; Maclean & Pound, 2000; O'Connor & Vallerand, 1994; Brillhart & Johnson, 1997; Williams, Freedman, & Deci, 1998). These various factors are often studied in isolation from one another. However, participants' accounts revealed that when it comes to lived experiences, motivation for sustaining self-care practices was influenced by how physiological, social-environmental factors, and the lifeworld of each individual were brought together, and by shifts in their order of importance. Thus, what was clinically relevant for the participants and how they negotiated decisions to maintain, interrupt or drop self-care practices was based on what mattered most to them at a particular time. Sometimes health was primary and sometimes social engagements or eating "sinful" food were primary.

Besides what mattered to these women, sustaining self-care was also influenced by extrinsic and intrinsic types of motivation (O'Connor & Vallerand, 1994; Brillhart & Johnson, 1997; Williams, Freedman, & Deci, 1998). Albeit the empirical literature on types of motivation suggest that the most desirable type is the intrinsic (Deci, & Ryan, 1987; 1990; 2003), this study's findings indicate that more extrinsic (Deci, & Ryan, 1987; 1990) types of motivation can evolve into intrinsic motivation over time. A good exemplar is Anna's description that she initially had taken up cross-stitch embroidery as a health care provider recommended practice for her rheumatoid arthritis but over time she developed appreciation for it and sustained this practice because she enjoyed it. At the time of the diagnosis the recommendation aspect of the embroidery was in the foreground, but at the time of the interviews the recommendation had shifted into a pleasure and the participant indicated this as the reason why she kept doing it. Anna's account is a good example of how extrinsic evolved into intrinsic motivation in sustaining a self-care practice. At the time Anna was interviewed, embroidery was not only her favorite activity, but it also filled up her day in a house where she stayed alone all days and evenings. It provided a sense of looking forward to having short, partial goals achieved along the way and a sense of accomplishment in the end.

From Bandura's social cognitive perspective, this can be interpreted as a larger goal broken into smaller ones that motivated behavior to the extent that it created self-investment. So, to get the motivation effect, Anna had the challenge of having the embroidery done and, an extrinsic standard (the picture) that she used to evaluate herself, but she also got feedback from family and friends who saw how she was doing relative to the goal by reproducing and perfecting the picture.

However, from theoretical-philosophical perspective, the meaning embroidery had in Anna's life was what really sustained the practice, in spite of the bothersome use of a brace on her finger. As recommended by Merleau-Ponty (1962), to better understand the motivation experience, one would need to look back and reflect upon what happened in context of an individual's lifeworld for an extrinsic recommendation to become an intrinsic motivation. Furthermore, still using Anna's account as an example, she also recounted that after a trial period if she could not tolerate gastrointestinal side effects of a medication, that is, if she did not feel any objective improvement for taking it, she would drop the medication: "*And I got indigestion from it so bad that I just quit taking it*". Thus, findings suggest that discomforts and side effects alone do not account for all motivation difficulties in sustaining self-care practices (e.g., the embroidery entailed tolerating pain and discomfort): they were similarly felt by older women's bodies but differently interpreted for the value or impact they had in these women's lives.

Yet, findings also indicate that external factors such as "clima," reminders, people, and input were critical when extrinsic motivation did not become intrinsic: they helped these women to sustain self-care practices. Thus, study findings confirm that extrinsic types of motivation (Deci, & Ryan, 1987; 1990) and support (Bandura, 1997) helped women to initiate self-care practices such as attending their first health education, support or exercise groups. At the same time, this study's findings expand Deci and Ryan (1987; 1990); Vallerand, O'Connor and Hamel (1995); and Bandura's (1997, 2000) works by addressing how new possibilities and shifts that happened in the lives of these women influenced and were influenced by self-care practices. An example of this shift was Bogey's description of the new property of the group indicating that besides keeping its original property of being an health exercise group, the class became "*kind of a social as well.*" In other words, the initial (extrinsic) recommendation to get started with exercise was sustained by the group (extrinsic) that became a health care practice (exercise) that fostered a social practice (meeting peers) that fostered a health care practice (exercise). Yet, regardless of the type, connections, shifts and amount of extrinsic motivation, self-care practices were always subject to re-negotiation in the light of what mattered to these women at different points in time / moments in their lives.

The Balancing Act: What Matters

Negotiations and creative strategies to balance exercise, diet and medication were central in these women's attempts to sustain long-term practices as indicated by the terms "*try,*" "*balance,*" and "*moderation*" frequently used by them. Participants' following of all recommendations was a hard task considering that chronic diseases are not curable, and that "*forever is a long time.*" Furthermore, negotiations with the self, and with other people (health care providers, family and friends) to balance life and health priorities and to sustain health care practices as much as possible took place throughout the course of their health conditions. Enablers and challenges in trying to balance women's life and health were body lessons, fears, people (health care providers, family, friends) and the health system.

Tension existed in negotiating and having to re-negotiate priorities with self, others, and social and physical environments depending on how women's life and health events impacted what mattered to them. Thus, shifts were an on-going possibility in these women's motivation to sustain self-care practices. Empirical and theoretical studies reviewed in Chapters I and II in which Deci and Ryan (1985, 1990) and Vallerand et al. (1995) acknowledged changes from one type of motivation to another were expanded by Cox's (1985b, 1987) contribution that these changes are non-sequential. This study's findings add to the body of knowledge two more distinctive aspects of motivation: 1) motivation is unsteady/unstable, given the constant need for re-negotiation and reorganization of priorities; and 2) types of motivation (e.g., extrinsic, intrinsic) have permeable boundaries, which allow multiple possibilities of evolving from type into another.

Each woman's lifeworld, meanings and shifts in priorities were critical in the negotiation processes that were continuous from the diagnosis of the health condition up to the moment of the second interview. Findings on women's preferences and priorities indicate that what was clinically important for these women was not necessarily the severity of a health condition, but the influence it would have on what was important in their lives. Seeking to balance what mattered in these women's lives and health prompted shifts in their order of priorities, self-care and coping strategies. As indicated by Brillhart and Johnson (1997), and Zauszniewski, Chng, and Krafcik (2001), motivation facilitates people's choices of coping strategies in the face of difficult situations. However, this study's findings indicate that what mattered in participants' lives at the moment of the difficulty had an impact on their motivation to sustain self-care practices. Therefore, what facilitated or hindered their making choices in terms of coping strategies and self-care practices was not necessarily motivation, but women's meanings and priorities, which influenced motivation. In other words, meanings can predict motivation for sustaining self-care practices - as long as individuals' experiences are known and understood before interventions to boost or sustain motivation are all implemented.

The Individual

In participants' accounts, life events were used as memory markers to describe the "discovery" of the chronic disease and what was going on in their lives at that specific moment. Older women learned and described their body history, actions and reactions as indicators of when health was fine and when something was not quite right. Even though symptoms were "alarm clocks" which set off immediate action, the recognition of these manifestations went beyond the objectivity of symptoms because these experiences were described in terms of the everyday life of an historical, sentient body dwelling in the society in which each of these women was a part.

In sustaining or withdrawing long-term self-care practices, participants described memories of previous experiences that were accumulated and an extensive library of possible alternatives and explanations for causes and effects and that brought awareness of how much they believed they could or should do and fostered actions and decisions based on the lessons learned form their bodies. Symptom description such as number irregular heartbeats, poor breathing capacity, and sleepiness were described through messages gotten from the body's lived experiences in situations such as travels, favorite drinks, or foods (coffee as a boost; evening popcorn), and expressed through sentences such as "I noticed something was wrong"; "the time I get loggy" or "when I feel sluggish". These markers suggested recognition and the set off of renegotiation processes/experiences in selecting self-care practices that were to be maintained, intensified or withdrawn.

Fear and knowledge of other people's and of one's own difficult experiences with chronic health problems – diabetes, heart disease and Alzheimer's – helped participants to sustain self-care practices, mainly in not wanting to be like the "role models" they knew, helped or heard of. Women described what they would like to avoid if they could. From a social cognitive perspective, fear of developing complications or severe limitations was an incentive to keep these women working towards a health goal. However, one can only know what really motivated the phenomena after having experienced it and knowing the meanings that these "fears" had to them. These older women did not fear "the disability entity" itself, but the impact of disability on the lives they led, in the things they could do, enjoyed doing, or chose not to do. Thoughts of this impact seemed to be what really helped them to sustain self-care practices over time.

Besides meanings, priorities and impact, enablers such as driving, which was the most important but unforeseen enabler, fostered continuous attendance to classes or groups. It was a finding that has not been reported as such in the literature and was extremely important for these older women, for being a condition that made it possible for them to sustain a number of social and self-care activities. However, findings indicate that beliefs of how much these older women could do, that is, self-efficacy beliefs as described by Bandura (1986, 1997), were important enablers instead of motivators. Self-efficacy beliefs facilitated the process of initiation and maintenance of self-care practices, but they did not guarantee that motivation for self-care practices would be sustained.

Incentives

Incentives as described in Bandura's (1986, 1997) social cognitive theory were important in sustaining participation in exercise classes. Incentives such as a positive experience (class "clima," fun, variety, instructor, peers with similar health conditions), coercing (paid membership, condition to get blood monitoring supplies) or even negative past experiences (memories of people who became disabled due to diabetes) helped participants in sustaining recommended self-care practices. Making a shift from initial predominately extrinsic types of motivation (Vallerand, O'Connor, & Blais, 1989; Vallerand, O'Connor, & Hamel, 1995) into an intrinsic type (Vallerand, O'Connor, & Blais, 1989; Vallerand, O'Connor, & Hamel, 1995) as time progressed was associated with the impact and the meaning each of these incentives came to have in each woman's life. For example, accounts about going for the first time with friends to an exercise class indicate that, overall, friends were important in starting to attend classes, but sustained motivation for consistent participation happened when there was "clima", which provided these women with possibilities for developing shared and meaningful relationships with the class participants, instructors and institution.

Bandura's (1996) social cognitive theory's indication that incentives are key for individuals to keep focused on a specific goal was supported by this study. For example, a woman participated in walks organized by an association in which she was a member. Her incentive was also a cumulative goal was to get collectible pins to be used on her cap in future walks. The pins would show the community she belonged to how many walks she had taken part in. Other women referred to situations when an exercise was important to regain function or range of motion. Exercises that were related to performing meaningful activities (e.g., continue to be able to embroider despite arthritis; resume bowling after a knee surgery) kept participants motivated to sustain self-care practices regardless of pain (using a brace to keep her finger straight) and discomforts (of doing demanding knee exercises).

Trajectories: "Going Off Track" and " Shoulds"

Women's motivation to sustain self-care practices ups and downs were described through tough and sometimes competing health needs, priorities, values, emotions and meanings. The social importance of food (Sparks, 1993; Marshall, 2002) at weekly meetings (after Sunday service/mass) and on holidays (Thanksgiving and Christmas dinners) combined with each woman's life history, values, emotions and meanings were powerful challenges that resulted in women's going off track from their recommended diets. Accounts indicate that balancing diet alone (meaning only the diet, number of calories/types of food) was easier than balancing diet when combined with life events. For the latter situation women often interrupted or even abandoned their self-care routines for a couple of days.

Another major challenge for these women was the flare-up of a latent health problem or a new condition, which could interfere with sustaining self-care practices. A new status of health may require interruption of continuous self-care practices that were important to older women's health. For example, a woman who had diabetes and was overweight developed cellulitis in her leg. Swimming was comfortable for her because the group classes had "clima" that sustained her participation. Swimming was also recommended for both weight loss and reduction of glucose levels. However, due to the cellulitis, swimming was prohibited. Events such as this triggered the re-negotiation processes, which, depending on the significance of the moment or the event, evolved into women having to take new decisions to get back on or to continue off track for longer. Thus, motivation to sustain self-care practices has no stability over time since it is subject to personal priorities and physical changes.

Women learned about their own health condition from physical changes, body lessons, health care providers, classes and talks, institutional and informational brochures or newsletters, heath magazines, TV programs, friends, family and the Internet. Findings revealed that knowing most of the recommended self-care practices for diabetes and heart disease and cognitively valuing them did not ensure motivation to sustain them. The expression "*I should…*" acknowledges the importance of sustaining self-care practices but also admits that they are not being carried out at the time the expression is used. By comparing and contrasting different data points across the first and the second interviews, findings indicated that by the time women's meanings, priorities and clinical significance started to come up in the interviews, the expression "I should..." also began to be used. At this point in the interviews, participants brought into context an indication that some of the described practices that needed to be sustained were important, but not meaningful enough, at least at the time of the interview. The data suggest that women's going off track was transitory or unpredictable in contrast to "shoulds," which were long-lasting and more difficult to overcome (See Appendix H).

Even though the focus of this study is motivation for continued self-care practices, the research topic served as a "*reminder*" or brought to the foreground the memory that these actions were important. Thus the interviews were described by participants as prompting some degree of action. Five of the 14 participants did at least go back to home exercises with a stretcher; make long over-due appointments with optician / internist / dentist; or go to the mental health support group.

Relationships

Findings support in part O'Connor's (1995) study of relationships and motivation in older adults, adult children and friends in which the quality of involvement was more valued than the contact frequency. All fourteen women referred to qualitative aspects of relationships with their health care providers. Twelve women reported to have sustained self-care practices over time when they had been seen by the same health care provider for at least one year. Changes in health care provider and in the health care system over the years negatively influenced these older women's motivation to maintain self-care practices.

In support of Bandura's (1997) description of persuasory attributions, these women's descriptions indicated that several aspects served as additional "motivators" to mobilize efforts to start and to sustain self-care practices. These were: 1) fortunate and unfortunate encounters with health care providers, length of relationships; 2) personal qualities such as being open to listen before coaxing, friendly, caring, healer, self-confident, and knowing patients at an individual level; and 3) professional qualities such as taking a good medical history, returning patient phone calls, being a thorough assessor and file reviewer, knowledgeable "*but not an engineer*", and a good informer/educator.

Thus, in unfortunate encounters, when inadequate communication strategies were used or there was poor discussion about treatment plans and medication side effects took place, providers' verbal persuasion did not mobilize greater effort to start and to sustain self-care practices over time, but rather hindered them (e.g., Anna's accounts on reducing or even dropping prescription medication and Andrea's decision to change health care provider). In this context, participants' accounts did not reveal "verbal persuasion" as important as indicated in social cognitive theory (Bandura, 1997). Rather, when health care providers fostered discussion, participants described the situations as ones of dialogue and trust.

However, system and institutional time related changes for appointments in the context of the health system were critiqued by all fourteen participants and were perceived barriers for sustaining self-care practices. Reduction in the time health care providers had to spend with participants was reported as a major challenge – for them to have their files properly reviewed, be examined, solve doubts and have questions answered. Time reduction influenced participants' adoption of coping self-care practices (e.g., letters, lists, notebook, journals) for obtaining health information and education.

In relation to family relationships, husbands in good health helped women to maintain correct pill taking by keeping track of medication, organizing and printing appointment charts, and searching the Internet for health information. They were company in many ways and were incentives (e.g., Red's husband walked with her most days; Ann's husband did not allow her to eat breakfast before they walked) for women to exercise. A contrast case was Tarzan's disabled husband who was afraid of losing his wife during heart surgery and was also a devoted believer in a "guru" MD that wrote a book on how to cure most heart diseases with diet. Tarzan's husband managed to talk her into not going for the bypass surgery she badly needed. As time progressed, this woman's care giving activities, added to her husband's beliefs, seemed to confound what opinion belonged to whom in the dyad and had an impact in her life, making it more difficult for her not only to maintain self-care practices over time, but even to get them started.

History of people, preferences and joys - that were experienced before the diet - seem to influence how negotiation within partnerships (e.g., woman-health care provider; woman-husband) were carried out and how balance was sought. For example, a contrast case of someone who always followed the diet and other health recommendations is Rose, but even she shared that it was very hard not to open a bottle of champagne to celebrate when her long-time partner received an award for his work. She missed sharing this moment of joy. Rose's account confirms that there is a always tension in these on-going renegotiations and review of priorities. Like Rose, other women indicate that there are occasions in which possibilities of "going off the track" are greater. The most difficult days were Sunday gatherings after church, Thanksgiving and Christmas.

Husband-supported "going off track" strategies were described as exercising during the week and taking weekends off together "*for good behavior;*" when going out, both participants and husbands would order diet food for entrée but "*share the dessert;*" when "*sinful food*" portions were large or could not be shared because of different preferences, the couple would ask for a doggie bag to take home; and when going grocery shopping neither of them pick "sinful food" so that they do not have it at home and therefore preventing wife's ritualized trips to the refrigerator from happening.

Except for not buying the "*sinful*" food, which is a strategy to improve self-efficacy as an exercise of control (Bandura, 1997), all other strategies were exemplars of meanings that went beyond the diet itself. They showed women's everyday life episodes with attempts to "*try*" to maintain a balanced health and a balanced life without depriving themselves of attending places, being with people, and eating foods they enjoyed.

Friends' company was pursued to get started with in exercise classes and walking. However, their company was not fundamental for continued attendance at exercise classes. In other words, class drop out by a close friend was not reported as hindering sustained participation. Actions such as phone calls made by close friends were described as helpful in getting out of the house and going to exercise or health education classes, support groups, for a walk or a social activity. However, social activities were mostly described as important to be kept, and even when women did not feel like attending, they would end up going to them. Furthermore, keeping in touch and meeting with friends was a recommendation that 12 participants considered important and would make to other older women.

Accounts from women who sustained exercises that were done alone or with a partner indicated that a routine in terms of set times and days was helpful in keeping them doing it. Two women reported that "a reminder of exercise" such as a magazine or the interview itself were helpful in their getting their mats out of the closet, finding where the "stretchers" were and starting to exercise. When asked why they had stopped women could not pinpoint a specific reason.

Attendance in exercise classes was sustained when women used a number of examples to describe an existing "clima;" Having inviting social and physical environments and meeting other people who were regular members of the groups and with whom these women could share difficulties, become closer, care about and support one another also motivated women to continue and to work towards maintaining or improving health status.

Limitations of the Study

Findings need to be considered in the context of the limitations of the study. Interviews occurred with a small convenience sample, composed of white, well-educated women 65-84 years of age, without declared major financial limitations, and living in the United States. Therefore, the sample was not representative of the general older population. Participants could also be the most motivated because they agreed to participate in the study. Further, women tended to present a positive account of self-care practices and only after better rapport was developed began to share their greater challenges. Thus a longitudinal study would further facilitate an understanding of what sustains or hinders their motivation across time. However, given these limitations, the findings provide several challenges to current views of motivation and suggest areas for future research.

Conclusions

This study has described motivation to sustain self-care practices as a continuous re-negotiation process for balancing women's lives, what matters to them and recommended health self-care practices in heart disease and diabetes. The results are consistent with the literature for the most part, but add the concept of a renegotiated, tense process in which motivation is not a constant. The findings, by suggesting that older women's self-care priorities shift depending on what matters to them and not necessarily what could constitute a health or life threat, challenge nurses to develop expertise in identifying what older women's priorities and concerns at the moment of each professional encounter.

These findings suggests that nursing needs to focus on: 1) what matters to older women and how this facilitates or hinders motivation for continued self-care practices; 2) importance / awareness of enablers, strategies and challenges that influence motivation in community-dwelling older women; and 3) issues to be addressed in nursing education to help them to become better communicators and health care providers.

A future nursing research program direction is to conduct a longitudinal, multi-site study with a larger sample including male, gay and lesbian older adults from diverse ethnicities, levels of education, social economic status and living in various geographical locations. Cross-cultural comparisons could also be illuminating.

Further qualitative research on older adults' motivation for sustaining self-care practices is also recommended for a better understanding of motivation in older adults with different chronic diseases.

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APPENDIX A

Items and Response Scales of the Measure of Motivational Styles

Table 1. Items and Response Scales of the Measure of Motivational Styles[45]

01. In general, why do you perform the different activities to your health?
02. Why do you keep up with your diet/nutrition (watch your diet)?
03. Why do you see your doctor?
04. In general, why do you perform the different activities related to your biological needs?
05. Why do you eat?
06. Why do you sleep?
07. In general, why do you have relationships with other people?
08. Why do you have relationships with members of your immediate family?
09. Why do you have relationships with your friends?
10. In general, why do you practice religion?
11. Why do you attend (or listen to) church services?
12. Why do you pray (outside the church)?
13. In general, why do you have leisure activities?
14. Why you have leisure activities in groups (with one or more persons)?
15. Why do you have leisure activities alone (personal activities)?
16. In general, why do you follow the news?
17. Why do you follow the local news (of your center or neighborhood)?
18. Why do you follow the world news?

Response Scales:

I don't know; I don't see what it does for me. (Amotivation)

Because I am supposed to do it. (Nonself-Determined Extrinsic Motivation)

I choose to do it for my own good. (Self-determined Extrinsic Motivation)

For the pleasure of doing it. (Intrinsic Motivation)

Note: Responses are given on 7-point scales ranging from "strongly disagree" to "strongly agree."

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[45] Vallerand, R. J., O'Connor, B. P., & Hamel, M. (1995). Motivation in later life: Theory and assessment. *International Journal of Aging & Human Development, 41*(3), 221-238.

APPENDIX B

Eligibility Criteria for Lorig et al.'s Study

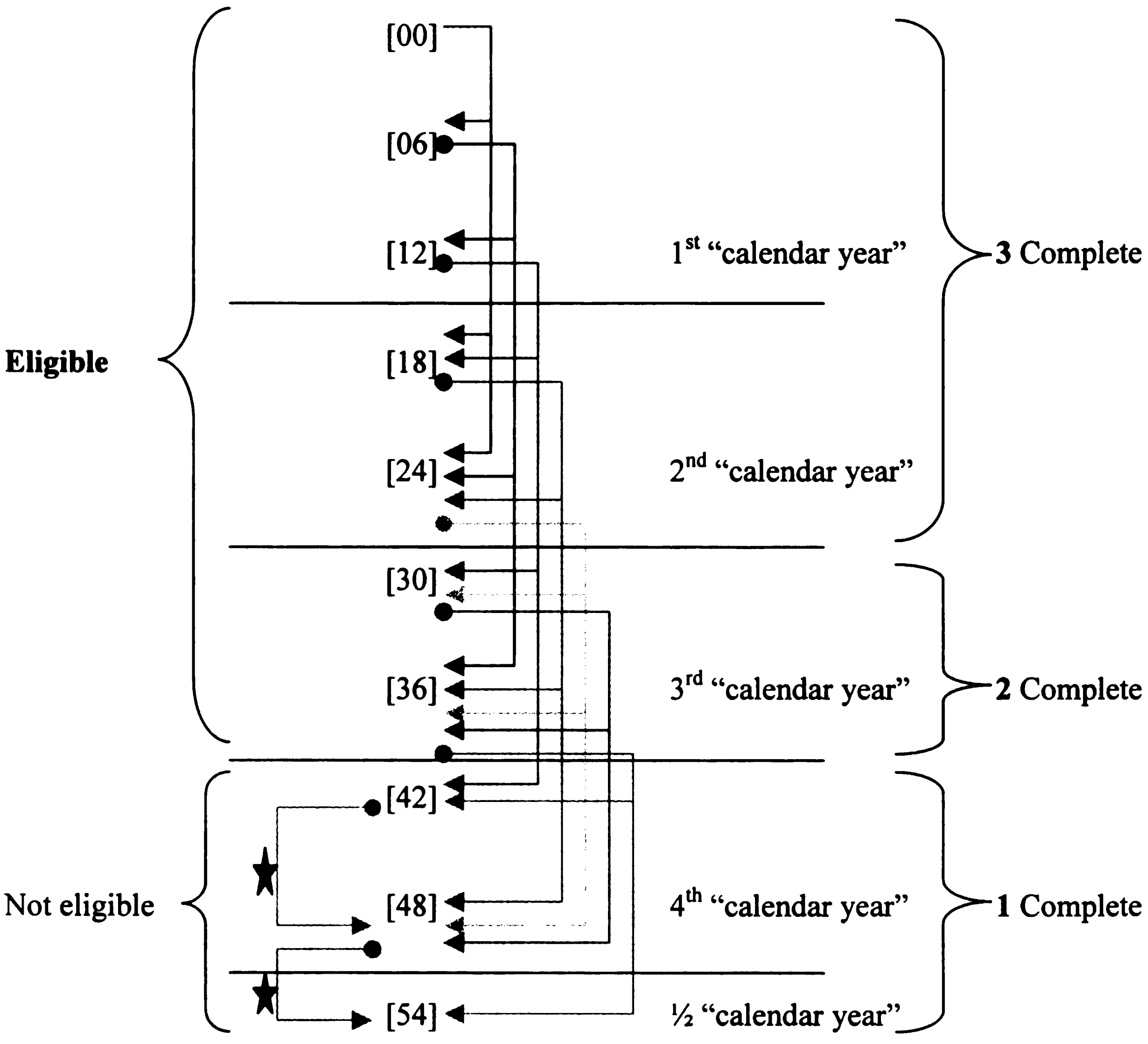
Tentative examples / explanation on why participants were eligible to join Lorig et al.'s (2001) study up to 30 and 36 months from its beginning:

1) A graphic explanation of Lorig et al.'s (2001) study design/data:

Time	"Entry in the Study"						
	0 month	6 months	12 months	18 months	24 months	30 months	36 months
I 6 mo	I at 06	I at 12	I at 18	I at 24	I at 30	I at 36	I at 42
II 1yr	II at 18	II at 24	II at 30	II at 36	II at 42	II at 48	II at 54
III 2yr	III at 30	III at 36	III at 42	III at 48	III at 54	✸	✸

2) An alternative way of graphically explaining the study design/data collection could be:

Number of Months



APPENDIX C

Interview Topics

The interviews were conducted in an open-ended fashion, giving the opportunity to participants to fully articulate their own experiences and perspectives. The questions / topics served primarily as a list of concerns of the researcher. Other related issues that emerged during the interviews were addressed.

01. Tell me a little about yourself, your health in a typical day.
02. What do you do to take care of yourself? Can you describe all the things you do to keep yourself as healthy as possible?
03. What has it been like for you since you were first diagnosed with (chronic condition)?
04. If it was a long time ago, did you feel any difference after a specific age or life event?
05. Can you tell me what you have been told by your health care providers (cause and treatment)? How did you feel about these recommendations?
06. Please tell me what else you have heard or read you should do to in relation to (chronic condition)? Where did you hear and/or read this?
07. How do you deal with these recommendations? How do you decide whether or not to take these recommendations? What makes it easier or more difficult for you to follow them?
08. What would help you to follow your health care provider's recommendations? / What helps you to follow the recommendations?
09. What hinders you or stops you from pursuing follow your health care provider's recommendations? / What hinders or stops you from following the recommendations?
10. When you feel things are not going well with your condition, what do you do to manage situation (i.e., chronic condition)?
11. Can you tell me whether these activities/procedures influence with your social life and/or leisure time?
12. When they do interfere with your social life and/or leisure time, what happens? What do you do you do? What do others do?
13. Can you tell me about a recent episode? How did it come about? What do you think caused that episode? What did you do?
14. What advice or suggestions do you have for health care providers who work with people with chronic conditions to help motivate them for self-care?
15. Is there anything else you want to tell me about?

APPENDIX D

Demographic Information Tool

Participant # ___________ Pseudonym: __________________ Age: _______________

1) Gender: A☐ female

2) Marital status: A☐ single B☐ married C☐ divorced D☐ widowed

If B / C / D, for how long? _______________________

3) Religion: ____

4) Education:

A☐ grade school B☐ high school C☐ technical training

D☐ college E☐ graduate school F☐ other_________________

5) Former occupation: ______________________ Age at retirement _________________

6) Current occupation: ____

7) Living arrangement

A☐ alone B☐ with spouse/partner C☐ with friend

D☐ with family E☐ with tenant F☐ other (specify)___________

8) Level of income

A☐ under $6,000 B☐ $6,000-$10,000 C☐ $10,000-$20,000

D☐ $20,000-$30,000 E☐ $30,000-$40,000 F☐ over $40,000

9) Sources of income

A☐ social security B☐ general assistance C☐ pension

D☐ investments E☐ employment F☐ family assistance

G☐ other ____

10) Health Conditions Duration

____

____

____

____

11) Medications in use

____

____

____

____

____

____

____

____

APPENDIX E

Kahn and Goldfarb Mental Status Questionnaire

Mental Status Questionnaire - MSQ

01) What is this place?

02) Where is this place located?

03) What day if the month is it today?

04) What day of the week is it?

05) What year is it?

06) How old are you?

07) When is your birthday?

08) In what year were you born?

09) What is the name of the president?

10) Who was president before this one?

MSQ Scores: Severity of brain syndrome

00 - 02 errors = none or minimal
03 - 08 errors = moderate
09 - 10 errors = severe

APPENDIX F

Committee on Human Research

Research title: Motivation for Self-Care in Older Adults

Approval number: H6362-17924-03A

Approval date: January, 2003 Expedited Review

Expiration date: August 17, 2003

UCSF COMMITTEE ON HUMAN RESEARCH

APPLICATION COVER PAGE

NEW! PI and CoPI must complete UCSF online training before approval can be granted. To access please go to https://researchonline.ucsf.edu

Principal Investigator (Must be an eligible faculty member):

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Co-Principal Investigator:

Name and degree **Jaqueline Da SIlva**	University Title **PhD (c) Student**	Department **Physiological Nursing**
Campus Mailing Address (Box No.) **Box 0602**	Phone Number **(415) 566-6254**	E-mail Address **jdasilv@itsa.ucsf.edu**

Send correspondence to (check only one): ☐ PI only ☒ PI and Co-PI ☐ PI and Contact Person identified below:

Name	University Title	Department
Campus Mailing Address (Box No.)	Phone Number	E-mail Address

Study Title (may not exceed 300 characters):	Application Type:
Motivation for Self-Care in Older Adults	☐ New Full Committee Application ☐ New Subcommittee Application Expedited Review Category #: _____ ☒ Modification ☐ Renewal Current CHR #: **H6362-17924-03** Expiration date: **August, 17, 2003**

Other Investigators:	Site(s) (check all that apply):	
Name and Degree/Department/Site	☐Parnassus ☐SFGH ☐VAMC ☐Mt. Zion ☐Stanford ☐UC Berkeley ☐Foreign Country ☐Other: ______	☐GCRC (Parnassus) ☐GCRC (SFGH) ☐PCRC

Special Subject Populations (check all that apply):

☐ Minors (i.e., under 18 years of age) ☐ Those Unable to Speak or Read English ☐ Fetuses, Pregnant Women

☐ Individuals with HIV Infection ☐ Those Unable to Consent for Themselves ☐ Prisoners

How many subjects will be enrolled here? 10-25

Will subjects be paid? ☐Yes ☒No

Special Study Procedures:	Drugs and Devices:	
Check all that apply: ☐ Genetic Testing ☐ HIV Testing ☐ Tissue Banking ☐ Gene Therapy ☐ Chart Review Only	**Investigational** drugs/devices (and IND/IDE No. from FDA): Is a Non-Significant Risk (NSR) determination requested for study devices? ☐Yes ☐No	**Approved drugs/devices:**

Funding (**All sections must be completed even if funding is pending**):

Will study be funded? ☐Yes ☐Pending ☒No If not, how will study costs be managed? **Co-PI will fund the study**	Funding award will be made through: ☐ UCSF ☐ *Gallo* ☐ *Gladstone* ☐ *NCIRE* ☐ VA Research Admin. ☐ *DPH* ☐ *GIOA* Other: ________	Name of sponsor: __________ Award No. (if known): __________ Sponsor is (check all that apply): ☐ Federal Gov. ☐ Other Gov. ☐ *Pharmaceutical/Device Co.** ☐ Other Private ☐ Campus/UC-Wide Program ☐ Dept. Funds

* If study is industry sponsored, identify the Administering Dept./ORU and appropriate financial contact person: ____________

Other Approvals:	Principal Investigator's Signature:
Does research require review by: ☐ Biosafety Committee If so, BSC approval #: ______ ☐ Radiation Safety Committee If so, RSC approval #: ______	Signature Date PI completed training ☐ Yes ☐ No CoPI completed training ☒ Yes ☐ No

General Information:
Principal Investigator P.I.: Margaret I. Wallhagen, PhD Co-P.I.: Jaqueline Da Silva, Doctoral Student
Study Title Motivation for Self-Care in Older Adults

CHR Approval Number	Expiration Date
H6362-17924-03	August 17, 2003 *If the study has expired, an explanation is required at the end of the form

Number of Subjects Studied:	
A) 0 Newly enrolled subjects since the date of last renewal.	If enrollment is complete, please indicate the study status below. Explain further in "Plans for the coming year":
B) 07 Total number enrolled to date.	☐ Subjects are still receiving treatment.
C) 0 Total number of refusals. (Subjects asked to be in the study but chose not to participate)	☐ Treatment is complete for all subjects (or the study does not involve treatment). Tests, follow up clinic visits, interviews, or mailings are continuing.
D) 0 Total number of withdrawals (Subjects who were consented but either withdrew or were withdrawn by PI)	☐ Follow up by review of medical records or other private records (no ongoing contact with any subjects).
E) 10-25 Additional subjects needed for study (Note: use "0" if enrollment is complete and then fill in the section at right).	☐ Data analysis only. No subject contact and no records review.

NEW

Protocol Summary Please state the long-term objectives and specific aims and describe concisely the research design and methods for achieving these goals. This description is meant to serve as a succinct and accurate description of the proposed work when separated from the application. (DESCRIPTION MUST BE ONE HALF PAGE OR LESS)
This study intends to explore the views and experiences of older adults regarding their motivation for self-care, defined as what they do to take care of their health, and to learn how they deal with the levels of self-care required or desired by their care providers. What levels of self-care are perceived as feasible, interfering as little as possible with their life. Also, it is intended to try and to understand how older adults deal with care levels recommendedby their providers and others. Note: In this study self-care is explained/defined by: what older adults do to take care of their health.

Summary of Results Please summarize the results to date.
Even though some of the participants had received clinical diagnosis of having specific chronic diseases, these health problems were only perceived as chronic when they started interfering with the older adult's life priorities, social and pleasurable activities. Preliminary findings indicate that motivation for self-care, as experienced by older adults, changes over time, along with the course of the chronic disease.

NEW

Summary of Recent Literature Please provide a summary of recent literature or other relevant information, especially information that may affect the risks or benefits associated with the research.
Current literature suggests that motivation is a complex construct (Bandura, 1991, 1997; Ellingson & Yarber, 1997; Maclean, Pound, Wolfe, & Rudd, 2000). Research in this area has focused on the types and levels of motivation; how it affects adherence; how it is influenced by relationships, coping and self-efficacy; and how it affects self-care practices and health behaviors. These studies were reviewed and critiqued in an attempt to broaden our understanding of motivation in older adults. The literature reviewed rarely addressed how motivation is experienced from the perspective of older adults who have been diagnosed with chronic diseases. These findings along with the findings from initial interviews presented above suggest the need for further exploration of experiences of older adults on what helps and what makes it more difficult to maintain self-care practices in the long course of a chronic disease. None of the literature reviewed affected the risks or benefits associated with the research.

NEW

Reanalysis of Risk/Benefit Ratio *Given the results to date and summary of recent literature has the relationship between study risks and benefits changed since the last renewal?* In answering this question, please analyze how adverse events, protocol modifications, and results from other studies affect the risk/benefit ratio.
No.

Adverse Events, Complications, or Incidents Since Initial Approval or Last Renewal:	
Yes ☐ No ☒	Did adverse events, protocol deviations, or incidents occur?
If adverse events occurred in the past year, please complete sections A and B below.	

(A)	
Yes ☐ No ☐	Were adverse event reports submitted to the CHR? (Note: As the CHR Approval Letter indicates, federal regulations require that adverse events be reported to the Committee within 10 working days. If events occurred since the last renewal and were not reported, you must submit a full report now and discuss how you will prevent such oversights in the future. Please refer to the CHR *Guidelines*, Appendix A)
Yes ☐ No ☐	Were adverse events more frequent than anticipated?
Yes ☐ No ☐	Were any adverse events serious and unexpected?
Yes ☐ No ☐	Did any adverse events require changes to the protocol or consent form?
Yes ☐ No ☐	Do the discussions of adverse events and risks in the protocol or consent form need to be updated at this time?
Please summarize the adverse events with emphasis on serious and unexpected events, deviations from the anticipated frequency of events, and/or any modifications made to the study due to adverse event experiences. Any protocol deviations and/or incidents during the past year should also be described:	
(B) There have been no adverse or unexpected events	

A Summary of Modifications

Please discuss any modifications made to the protocol, consent form(s), recruitment materials, or other study documents.

What modifications were made since the last renewal? Please make sure the study protocol and consent form(s) have been updated and include all previous changes. Remove all bolding or highlighting from changes that have been approved.

None

What modifications are being proposed at this time? The modifications must be bolded or highlighted in the protocol and consent form(s).

1) Participants will be older women, between 65-84 years of age (instead of older adults with more than 65 years of age).
2) Participants will need to have heart disease and/or diabetes (instead of cardiovascular and/or endocrine disease).
3) There will be two interviews (instead of one interview).
4) Two instruments will be included: MSQ (Mental Status Questionnaire) and Demographics (not used in the previous interviews).
5) Besides fliers (see Appendix 1) to be posted in clubs, leisure areas, associations, churches, community facilities and ambulatory care centers the Co-PI will participate in explanatory meetings / invitation sessions at the same locations above mentioned.

Brief Summary of Plans for the Coming Year

Interview 10-25 older women to further explore the phenomenon of motivation in older adults. The data collected will serve as basis for the Co-PI's PhD dissertation.

NEW

Summary of Audit Activities

Was this study audited by an internal or external agency, including DSMP reports? Yes ☐ No ☒

If Yes, please identify the agency and provide a summary and copy of the report(s) if available.

Agency:
Summary:
Audit Report attached? Yes ☐ *No* ☐

NEW

Expired Studies

Has the CHR approval for this study expired? Yes ☐ No ☒

If yes, work must to stop IMMEDIATELY, except for procedures necessary for subject safety, and the following information must be provided:

Why did the approval lapse?
What will you do to prevent this from happening in the future?
Were any additional subjects enrolled or data collected after the expiration date? Yes ☐ No ☐
If Yes, describe all activities that continued, including number of subjects involved and any adverse events or incidents that occurred after expiration of the approval.

NOTE: If renewal is not approved before the expiration date all enrollment and data collection must stop at the expiration date. Procedures and treatment needed for subject safety should continue but data collected during this time cannot be used for research purposes.

COMMITTEE ON HUMAN RESEARCH
INITIAL SHORT-FORM APPLICATION

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SUBMISSION DATE: ______________

PROJECT TITLE: Motivation for Self-Care in Older Adults

STUDY AIM, BACKGROUND, AND DESIGN

Study Aim:
This study intends to explore the views and experiences of older women regarding their motivation for self-care and find how they deal with the levels of self-care required or desired by their care providers. What levels of self-care are perceived as feasible, interfering as little as possible with their life. Also, it is intended to try and to understand how older women negotiate care levels with their providers and others.
Note: In this study self-care is explained/defined by: what older women do to take care of their health.

Background:
The literature on adherence and on client education indicates that motivation is a key element for the success of any learning processes, and for engaging in different activities, including self-care. There are different kinds of motivation that vary between self-generated and outer generated (by someone / something else). In recent studies on motivation, which interviewed older adults living in nursing homes, participants are viewed as people who simply have or have not behaved as expected by the health care provider. In these studies, the perspective of the participants were seldom referred to or pursued in the research design.

Design:
This study will use semi-structured interviews with older adults living in the community, who have heart disease or diabetes, or both, which are highly prevalent in old age, are long-standing and involve more than one of the following self- care practices: constant watchfulness, monitoring across time, following medication regimens, and implementing and maintaining life style changes (e.g., diet, exercise). Furthermore, these conditions require motivation for self-care/participation in the treatment. Thus, the study will focus on these individuals' interpretations and assessments of motivating factors for self-care.

1. SUBJECT POPULATION: INCLUSION/EXCLUSION CRITERIA, USE OF SPECIAL SUBJECT GROUPS, AND METHODS OF ACCESS

Older women between the ages of 64 – 85 years will be invited to participate in the study through fliers (see Appendix 1) to be posted in clubs, leisure areas, associations, churches, community facilities and ambulatory care centers, and through Co-PI's participation in explanatory meetings / invitation sessions at the same locations above mentioned. The snowball procedure will also be adopted, whereby participants will be asked if they know others who might be willing to participate. They will be given information about contacting the Co-P.I. to offer to prospective participants.
Between 10 and 25 community-dwelling older adults will be contacted for interviews. Participants will not be paid for the interviews. The Co-P.I. will interview all the participants.

2. PROCEDURES TO BE DONE FOR PURPOSES OF THE STUDY

The procedures are:
1) Signed consent (Appendix 2) will be obtained just prior to the first interview.
2) A set of two informal interviews in person, which are estimated to last from forty-five minutes to an hour and a half. The interview topics are attached (Appendix 3).
3) Two instruments will be administered in the first interview: a socio-demographic questionnaire (Appendix 4) and the 10-question Kahn and Goldfarb Mental Status Questionnaire - MSQ with a recommended cut-off point of 5 (Kahn et al., 1960, Kane & Kane, 1981 - Appendix 5).
Estimated completion time of these tests combined is less than ten minutes.
4) Participants will receive UCSF Experimental Subjects' Bill of Rights before the first interview (Appendix 6)
5) The second interview will have questions and probes based on preliminary data analysis of each participant's first account and will be aimed at achieving more depth, better description, more information and/or clarification of data.
6) Time between the first and the second interview will vary from one to four weeks, according to the participant's availability.
7) Both interviews will be audiotape-recorded if participants agree, and will be conducted at a time and place of their convenience.
Inclusion criteria:
A convenience sample will be selected from community-dwelling, English-speaking, White women residing in the Bay Area. Participants are required to be 65-84 years of age, self-evaluated as cognitively fit and willing to participate in a set of two interviews.

In order to assure satisfactory levels of ability to discuss participants' experiences, their cognitive status will be also evaluated during the first interview by using the 10-question Kahn and Goldfarb Mental Status Questionnaire -MSQ (Kahn et al., 1960) (see Appendix 5). Because this study seeks learning about motivation over the long run of chronic diseases, participants should have been diagnosed with diabetes and/or cardiac disease for at least one year, who will have moved beyond initial phases of the diagnosis of a chronic disease (Thorne, 1990; Thorne & Patterson, 2001). The intent is to recruit participants who have one or both chronic diseases because these conditions are highly prevalent in old age, are long-standing and involve more than one of the following self-care practices: constant watchfulness, monitoring across time, following medication regimens, and implementing and maintaining life style changes (e.g., diet, exercise).

<u>Exclusion criteria:</u>

This study is aimed at studying community-dwelling older adults who live alone or with another older adult in the same household. Therefore, older adults living with younger adults in the same household and residents of facilities for retired citizens or of nursing homes are not eligible for this study. Older adults who have not received a formal diagnosis of either diabetes or heart disease cannot participate in the study.

3. RISKS: POTENTIAL RISKS/DISCOMFORTS TO PARTICIPANTS, INCLUDING POSSIBLE LOSS OF CONFIDENTIALITY, AND METHODS OF MINIMIZING THESE RISKS

Audiotape-recorded interviews may be uncomfortable for some participants. They will be able to refuse the recording prior to or at any time during the interviews. Participants are free to decline to answer any questions they do not wish to answer or stop the interviews at any time. The Co-P.I. will explain the confidentiality procedures when obtaining consent before initiating the interviews. The interviews will be audiotape-recorded and transcribed with permission only. During transcription, only a pseudonym chosen by the participant will be used, rather than her/his actual name. The tapes and transcripts will be destroyed after the study is completed – in four years at most. Tapes, transcriptions and documents will be kept in a separate, metal, locked box, at a location known only by the Co-P.I. Small transcribed segments may be used for educational and publication purposes, without any identification of respondents. The small transcribed segments may be translated into Portuguese, the native language of the co-P.I., also for educational and publication purposes, without any identification of respondents aside from their pseudonyms.

4. BENEFITS: POTENTIAL DIRECT BENEFITS TO SUBJECTS AND GENERAL BENEFITS TO SUBJECT GROUP, MEDICAL SCIENCE AND/OR SOCIETY

No or limited personal benefit can be guaranteed. However, past experience in interviewing older adults indicate that there may be satisfaction derived in making participants' voices heard. Also data from this study compiled with other works in progress may provide health care providers with more resources to find, in a partnership with older adults, more realistic means for achieving better health outcomes. Motivation factors for self-care in community-dwelling older adults have not been extensively studied.

5. CONSENT PROCESS AND DOCUMMENTATION

The Co-P.I. will obtain informed consent prior to conducting the first interview with each participant. Each participant will receive a copy of the informed consent form. The consent forms will be coded with an identification number will be the only document that provides a link between their real names and pseudonyms A pseudonym chosen by the participant will be used on the verbatim transcripts. The consent forms will be kept in a separate, metal, locked box, which is separate from tapes and transcriptions, at a location known only by the co-P.I. Only designated study personnel will have access to the consent documents.
The consent form is attached (Appendix 2).

6. QUALIFICATIONS OF INVESTIGATORS

The Co-PI, Jaqueline Da Silva, is a doctoral student in the Department of Physiological Nursing, UCSF, and this study is a student project. Jaqueline Da Silva has worked as a clinical specialist nurse and researcher in gerontology for 11 years at Universidade Federal do Rio de Janeiro, São Francisco de Assis Teaching Hospital – a community hospital, in Brazil. She will be conducting this research under the orientation and guidance of the P.I., Margaret I. Wallhagen, PhD, Professor of Nursing, Department of Physiological Nursing, who is Ms. Ds Silva's academic advisor. Dr. Wallhagen is experienced in Gerontological Nursing and has published the results of many studies.

8. NUMBER OF SUBJECTS TO BE ENROLLED PER YEAR: 10 – 25
TOTAL: 10 – 25

9. WILL THIS STUDY BE FUNDED? No

10. EXPEDITED REVIEW CATEGORY NUMBER: 11

11. PRINCIPAL INVESTIGATOR'S SIGNATURE:

Margaret I. Wallhagen, RN, CS, GNP, PhD

Jaqueline Da Silva, RN, BS, CNS, PhD (c)

LIST OF APPENDIXES:

Appendix 1: FLIER

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

Are you 65-84 years?

We would like to talk with you

If you are a woman and have heart disease and / or diabetes

We are interested in learning from you whether the health problem:

➔ Interferes with your social life or participation in leisure activities

➔ About what you do to take care of your health and,

➔ How you try to keep your health balanced

IF YOU ARE INTERESTED IN LEARNING MORE
ABOUT THIS STUDY, PLEASE CONTACT:

JACKIE
Phone/Fax: **(415) 566-6254**
E-mail: **jdasilv@itsa.ucsf.edu**

65 to 84 years? - Call Jackie
(415) 566-6254

65 to 84 years? - Call Jackie
(415) 566-6254

65 to 84 years? - Call Jackie
(415) 566-6254

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(415) 566-6254

65 to 84 years? - Call Jackie
(415) 566-6254

Appendix 2: SIGNED CONSENT

UNIVERSITY OF CALIFORNIA SAN FRANCISCO
SCHOOL OF NURSING

CONSENT TO BE A RESEARCH PARTICIPANT

PROJECT TITLE: Motivation for Self-Care in Older Adults

Researcher/Doctoral Student: Jaqueline Da Silva, B.S., C.N.S., M.S.
Department of Physiological Nursing

Principal Investigator/Professor: Margaret I. Wallhagen, RN, CS, GNP, Ph.D.
Department of Physiological Nursing

STUDY PURPOSE AND BACKGROUND

Jaqueline Da Silva, B.S., C.N.S., M.S. and Margaret I. Wallhagen, PhD, of UCSF School of Nursing, are conducting a study about what motivates older women who have cardiac disease and/or diabetes regarding self-care, that means, what we do to take care of our health. We would like to learn about what motivates you regarding self-care and how you do it.

PROCEDURES

If you agree to be in this study, the following will happen:
You will talk with Jaqueline Da Silva (Jackie) twice over a period that can vary from one to four weeks, according to your availability. Each interview will last form forty-five minutes to an hour or so. Questions will be about your health condition, your memory and what helps or makes it more difficult for you to care for yourself. The interviews will be will be audiotape-recorded if you agree, and will be arranged at a time and place convenient to you.

RISKS/DISCOMFORTS

Participation in the study may involve a loss of privacy, but several precautions are taken to avoid this. For example, when the tapes with your interview are transcribed to written form, and all tapes, transcriptions as well as identification numbers are locked in a metal box, at all times. Your real name is not marked on the data; just the nickname you choose will be used. Only Jaqueline Da Silva (Jackie) and her supervisor, Dr. Wallhagen, will have access to the original data, which will be destroyed when the study is complete. You will never be identified with quotations and/or stories in any publication.

Some of the topics may cause you to reflect or may cause discomfort. You can refuse to answer any question. You can stop the interview at any time.

BENEFITS
There are no direct personal benefits to you. However, you will provide health care providers with more realistic information for helping older adults to achieve better health outcomes. Also, past experience in interviewing older adults indicates that there may be satisfaction derived in making your voice heard.

COSTS/REIMBURSEMENT:

There will be no costs to you for being in the study.
PAYMENT
There is no reimbursement for the interview(s).
QUESTIONS
This study has been explained to you by Jaqueline Da Silva and your questions were answered. If you have any other questions or concerns about the study, you may contact either Dr. Wallhagen or Jaqueline Da Silva at:

Researcher:
Jaqueline Da Silva, B.S., C.N.S., M.S. - Doctoral Student
Department: Physiological Nursing
Mailing Address:
95 Behr Ave., Apt. # 305
San Francisco, CA 94131
Tel./Fax: (415) 566-6254
E-mail: jdasilv@itsa.ucsf.edu

Supervisor/Researcher:
Margaret I. Wallhagen, RN, CS, GNP, PhD - Associate Professor
Department: Physiological Nursing
Mailing Address:
Parnassus Campus: 2 Koret Way
San Francisco, CA 94143 - 0610
Box 0610 - UCSF
Teaching Office N631
Tel.: (415) 476-4965 Fax: (415) 476-8899
E-mail: meg.wallhagen@nursing.ucsf.edu

If for some reason you do not wish to contact them, you may contact the Committee on Human Research, which is concerned with the protection of volunteers in research projects. You may reach the committee office between 8:00 and 5:00, Monday through Friday, by calling (415) 476-1814, or by writing: Committee on Human Research, Box 0962, University of California, San Francisco / San Francisco, CA 94143.

CONSENT

PARTICIPATION IN RESEARCH IS VOLUNTARY. You have the right to decline to participate or to withdraw at any point in this study. Whether or not you choose to participate will have no effects on your care as a client/patient whatsoever. If you find that any of the interview topics are bothersome or difficult, you can refuse to talk about them. You can also stop the interview at any time you want.

Thank you very much for considering participating in this research project.

If you wish to participate, you should sign below.
(You will be given a copy of this consent form to keep.)

Date Participant's Signature

Date Researcher's Signature – Jaqueline Da Silva, BS, CNS, MS

Address (only if you wish to receive a copy of a final report of the research)

Once again, we would like to thank you for your consideration, time and support.

Appendix 3: INTERVIEW QUESTIONS

UNIVERSITY OF CALIFORNIA SAN FRANCISCO
SCHOOL OF NURSING

INTERVIEW QUESTIONS

PROJECT TITLE: Motivation for Self-Care in Older Adults

Researcher/Doctoral Student: Jaqueline Da Silva, RN, BS, CNS, MS, PhD(c)
Department of Physiological Nursing

Principal Investigator/Professor: Margaret I. Wallhagen, RN, CS, GNP, PhD
Department of Physiological Nursing

SUGGESTED QUESTIONS / TOPICS

The interviews will be conducted in an open-ended fashion, giving the opportunity to participants to fully articulate their own experiences and perspectives. The questions / topics will serve primarily as a list of concerns of the researcher. Other related issues may emerge during the interviews and will then be addressed.

01. Tell me a little about yourself, your health in a typical day.

02. What do you do to take care of yourself? Can you describe all the things you do to keep yourself as healthy as possible?

03. What has it been like for you since you were first diagnosed with (chronic condition)?

04. If it was a long time ago, did you feel any difference after a specific age or life event?

05. Can you tell me what you have been told by your health care providers (cause and treatment)? How did you feel about these recommendations?

06. Please tell me what else you have heard or read you should do to in relation to (chronic condition)? Where did you hear and/or read this?

07. How do you deal with these recommendations? How do you decide whether or not to take these recommendations? What makes it easier or more difficult for you to follow them?

08. What would help you to follow your health care provider's recommendations? / What helps you to follow the recommendations?

09. What hinders you or stops you from pursuing / following your health care provider's recommendations? / What hinders or stops you from following the recommendations?

10. When you feel things are not going well with your condition, what do you do to manage situation (i.e., chronic condition)?

11. Can you tell me whether these activities/procedures influence with your social life and/or leisure time?

12. When they do interfere with your social life and/or leisure time, what happens? What do you do you do? What do others do?

13. Can you tell me about a recent episode? How did it come about? What do you think caused that episode? What did you do?

14. What advice or suggestions do you have for health care providers who work with people with chronic conditions to help motivate them for self-care?

15. Is there anything else you want to tell me about?

Appendix 4: DEMOGRAPHIC QUESTIONS

Participant # __________ Pseudonym: ________________ Age: ______________

1) Gender: A☐ female

2) Marital status: A☐ single B☐ married C☐ partnered D☐ divorced
E☐ widowed If B / C / D, for how long? ____________________

3) Religion: ____

4) Education:
A☐ grade school B☐ high school C☐ technical training
D☐ college E☐ graduate school F☐ other_______________

5) Former occupation: ____________________ Age at retirement _______________

6) Current occupation: ____

7) Living arrangement
A☐ alone B☐ with spouse/partner C☐ with friend
D☐ with family E☐ with tenant F☐ other (specify)__________

8) Level of income
A☐ under $6,000 B☐ $6,000-$10,000 C☐ $10,000-$20,000
D☐ $20,000-$30,000 E☐ $30,000-$40,000 F☐ over $40,000

9) Sources of income
A☐ social security B☐ general assistance C☐ pension
D☐ investments E☐ employment F☐ family assistance
G☐ other ____

10) Health Conditions Duration

____
____
____
____

11) Medications in use

____
____
____
____
____
____
____
____

Appendix 5: MENTAL STATE QUESTIONNAIRE

Kahn and Goldfarb Mental Status Questionnaire - MSQ[46]

11) What is this place?

12) Where is this place located?

13) What day if the month is it today?

14) What day of the week is it?

15) What year is it?

16) How old are you?

17) When is your birthday?

18) In what year were you born?

19) What is the name of the president?

20) Who was president before this one?

---

[46] Score shows severity of brain syndrome:

0-2 errors = none or minimal
3-8 errors = moderate
9-10 errors = severe

Appendix 6: EXPERIMENTAL SUBJECT'S BILL OF RIGHTS

Experimental Subject's Bill of Rights

University of California, San Francisco

The rights below are the rights of every person who is asked to be in a research study. As an experimental subject I have the following rights:

1. **To be told what the study is trying to find out,**
2. **To be told what will happen to me and whether any of the procedures, drugs, or devices is different from what would be used in standard practice,**
3. **To be told about the frequent and/or important risks, side effects, or discomforts of the things that will happen to me for research purposes,**
4. **To be told if I can expect any benefit from participating, and, if so, what the benefit might be,**
5. **To be told of the other choices I have and how they may be better or worse than being in the study,**
6. **To be allowed to ask any questions concerning the study both before agreeing to be involved and during the course of the study,**
7. **To be told what sort of medical treatment is available if any complications arise,**
8. **To refuse to participate at all or to change my mind about participation after the study is started. This decision will not affect my right to receive the care I would receive if I were not in the study,**
9. **To receive a copy of the signed and dated consent form,**
10. **To be free of pressure when considering whether I wish to agree to be in the study.**

If I have other questions I should ask the researcher or the research assistant. In addition, I may contact the Committee on Human Research, which is concerned with protection of volunteers in research projects. I may reach the committee office by calling: (415) 476-1814 from 8:00 AM to 5:00 PM, Monday to Friday, or by writing to the Committee on Human Research, Box 0962, University of California, San Francisco, CA 94143.
Call 476-1814 for information on translations.

APPENDIX G

Committee on Human Research – HIPAA Form

UCSF Subject Authorization for Release of Personal Health Information for Research

1. Study Information.

Study Title: **Motivation for Self-Care in Older Adults**
Principal Investigator: **Co-PI: Jaqueline Da Silva** CHR No: H **6362 - 17924 - 03A**

2. Purpose of Authorization.

The Consent to Participate in Research for this study requests your participation in a research study. This Authorization for Release of Personal Health Information is a required supplement to the Consent to Participate in Research. The Authorization does not change any of the information or permissions described in the consent form. The reason for a separate Authorization is new federal law, the Health Insurance Portability and Accountability Act (HIPAA). HIPAA protects the privacy of personal health information contained in your medical records. As of April 14, 2003 the University of California has to obtain this separate Authorization from you so it can use your personal health information for the medical research outlined in the Consent to Participate in Research. This personal health information will be used for the research purposes described in the Consent Form for the study named above. You will be given a copy of this consent form.

This Authorization gives you information about the use and disclosure of your health information for research requests and your permission to use and share your personal health information.

3. Individual Health Information to be Used or Disclosed. By signing this document, you will authorize the parties listed under item 2 (below) to provide the principal investigator and members of the research team to access the following information about you:

- ☐ Entire Medical Record
- ☐ Billing Statements
- ☐ Pathology Reports
- ☐ EKG
- ☐ Progress Notes
- ☐ Laboratory Reports
- ☐ Dental Records
- ☐ Operative Reports
- ☐ Radiology Reports
- ☐ Discharge Summary
- ☐ Emergency Room Reports
- ☐ History & Physical Exams
- ☐ Diagnostic Imaging Reports
- ☐ Consultations
- ☐ Outpatient Clinic Records
- ☒ Psychological Tests
- ☒ Other: Information shared in Interviews 1 and 2

4. Specific Authorizations. The following information will not be released unless you specifically authorize its disclosure by initialing the relevant line(s) below:

____ I specifically authorize the release of information pertaining to drug and alcohol abuse diagnosis or treatment
____ I specifically authorize the release of information pertaining to mental health diagnosis or treatment.
____ I specifically authorize the release of HIV/AIDS testing information.
____ I specifically authorize the release of genetic testing information.

5. Parties Who May Disclose Your Individual Health Information. The researcher named above and his or her research staff may obtain your individual health information from the following hospitals clinics, providers, or other entities:

____

6. Parties Who May Receive or Use Your Individual Health Information. The research team may also need to disclose the information to others as part of the study process. This may include:

- ☐ We do not plan to share your data outside the research team.
- ☐ The study sponsor: ____
- ☐ The US Food & Drug Administration (FDA)
- ☐ Others: ____

7. Duration of Investigator Access and Use of your Individual Health Information. *(The researcher must indicate one of the options below.)*

- ☐ This Authorization to use your information will expire at the end of the research study.
- ☒ This Authorization has no expiration date.
- ☐ This Authorization will expire ____

8. Right to Revoke or Cancel Your Authorization.

You can cancel your Authorization to allow use of your health information at any time by:

- **a.** Writing to the principal investigator identified in the Informed Consent Form, or
- **b.** Informing a member of the research team that you wish to revoke your authorization. They may ask you to fill out a form.

If you cancel the Authorization, you will not be able to continue to participate in the research; this decision could affect your current research-related treatment. You may want to discuss with your research team any impact on your treatment if you do decide to revoke this authorization. If you cancel the Authorization, the principal investigator and his or her research team may continue to use information about you that has already been collected. No information will be collected about you after you cancel the Authorization

9. Potential for Redisclosure

Once your health information is disclosed to the research team it is not protected under HIPAA; by signing this Authorization you allow that disclosure. Although HIPAA no longer protects your health information once it is disclosed to the research team (and the study sponsor, if there is one), the research team (and the study sponsor) will continue to protect your personally identifiable health information as described in the Consent to Participate in Research. The University of California complies with the requirements of HIPAA and its privacy regulations, and with all other applicable laws that protect the confidentiality of your health information.

10. Authorization.

By signing this Authorization you agree that you have read this Authorization form and that you have been given the opportunity to ask questions. If you do not sign this Authorization, you will not be able to participate in this study because the researchers need to access your personal health information for this study. However, your right to receive health care at UCSF will not be affected. If you have questions later, you may contact the principal investigator. You will be given a signed copy of this Authorization for your records.

______________________	______________________	______________
Subject signature	Printed Name	Date

FOR MINORS *(Where Applicable And Approved By The IRB):*

______________________________	______________
Signature of Parent or Guardian	Date

FOR ADULTS NOT CAPABLE OF GIVING CONSENT *(Where Applicable And Approved By The IRB):*

______________________________	______________
Signature of Legally Authorized Representative	Date

Relationship of Representative to Subject: ______________________________

______________________________	______________
Translator signature	Date

APPENDIX H

Motivation Trajectories in Sustaining Self-Care Practices:

"Going off Track" and "Shoulds"