Exploration of the Older Adult Informal Caregiver

Self-Care Promoting Well-Being

by

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ABSTRACT

This qualitative descriptive study described caregiver recognition of personal and social contextual resources guiding purposeful participation in self-care and well-being. This research builds on health empowerment theory, which conceptualizes health empowerment as an inherent, relational and ongoing process, expressive of health patterning of well-being (Shearer, 2009). By 2060, Americans 65 years and older will number nearly 98 million, more than double that in 2013. The number of older adults aged 85 and older will double from 6 million in 2003, to 14.6 million by 2040 (Health & Human Services, 2014). Sixty-five million adults serve as informal caregivers, many themselves suffering from chronic conditions (National Alliance for Caregiving & AARP, 2009). Current research has examined the burden of caregiving, but little is known about caregiver strengths and resources that foster personal self-care and well-being. Twenty-one older adult informal caregivers participated in focus groups or individual interviews. Length of time as caregivers ranged from one year to more than ten years; 24% of the participants were men. Seventy-six percent of the participants reported having one or more chronic condition. Themes generated from qualitative content analysis provided a basis for validating and extending the health empowerment theory among older adult informal caregivers. Across participants, empowerment reflected recognition of strengths and resources, as well as growth consistent with valued goals facilitating new health patterns and well-being. The health empowerment theory perspective provided a relevant basis for theory-based intervention focused on promoting strengths, abilities and potential among older adults, limiting vulnerability to diminished health and well-being.

DEDICATION

This dissertation is dedicated to my father, who instilled in me as a young child never to accept the status quo and to continue to reach for the stars and to Stan. I learned from him first-hand the difficulties of balancing caring for a spouse and young son without help or resources. From this experience as a young caregiver, I gained strength and acquired the perspective that there must be more resources to support informal caregiver’s self-care.

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CHAPTER 1

OVERVIEW

Growth in the number and proportion of older adults in the United States (U.S.) is unprecedented. The rapid aging of the United States (U.S.) population is driven by two realities: Americans are living longer than in previous decades; as baby boomers turn 65 there are greater numbers of older adults than in previous generations (Hoffman, Lee, & Mendez-Luck, 2012). By 2060, there will be almost 98 million older adults in the U.S., more than double the number in 2013. The number of those 85 years and older is projected to more than double from 6 million in 2013 to 14.6 million in 2040 (HHS, 2014). These demographic changes are marked by increases in chronic illness and associated social and medical needs. Two of three older adults have multiple chronic conditions associated with poor quality of life, functional disability, psychological and emotional distress, and increased morbidity and mortality (Fortin et al., 2006; Marengoni et al., 2011).

The involvement of informal caregivers has proliferated in an attempt to address these social and medical needs. Schultz (2013) characterizes informal caregivers as, "family members, friends or fictive kin who provide some form of care to an older adult with whom they have a relationship" (p. 1,008). The role of informal caregiver may be thrust upon an individual suddenly or may occur over time. Informal caregivers have a critical role in sustaining the chronically ill older adult, yet caregiving can diminish the caregiver's emotional and physical well-being. Ostwald (2009) has suggested, "Caregiving may negatively affect the health behavior and outcomes of family caregivers, particularly older spouses providing high levels of care" (p. 86). Moreover, older adult informal caregivers may neglect their own self-care needs when caring for others with chronic disease or disabilities or fail to engage in self-care activities designed to promote physical, mental, and emotional well-being (Family Caregiving Alliance, n.d. Schulz, 2013; Wilkinson & Whitehead, 2009). As caregivers are essential to the informal support system, when their health is at risk, so too are the lives of the care recipients (Gitlin & Schulz, 2012).

Informal caregivers have been referred to as "*hidden patients*" due to the increased morbidity and mortality among this group when compared to their non-caregiving counterparts (Coon & Evans, 2009; Reinhard, Feinberg, Choula, & Houser 2015; Reinhard, Given, Petlick, & Bemis, 2008). At considerable cost to themselves, family caregivers serve as a vital resource to family and society, allowing care recipients to remain at home across the course of a chronic illness (Wolff et al., 2009). However, research is lacking that explores informal caregiver self-care needs, experiences, strengths, and resources apart from the care recipient (Blum & Sherman, 2010; Mosher, 2016). The National Institute of Nursing Research (NINR) and the National Institute of Aging (NIA) have advocated for research that includes the development of conceptual frameworks as well as methods for studying the work of caregiving and for evaluating interventions to support the caregiver (Naylor, 2015). Despite these initiatives, there is little research that explores self-care of the older adult caregiver, specifically their own self-care needs promoting well-being. Informal caregivers are a vulnerable and an at-risk population that has been neglected, and must be recognized as care recipients (Blum & Sherman, 2010).

This chapter reviews research related to older adult informal caregiver self-care promoting well-being while providing care to a chronically ill person. The majority of research targeting older adult informal caregivers focuses on understanding and remediating the negative psychological aspects of caregiving such as burden, depression, and stress, rather than optimizing the caregiver strengths and resources to facilitate self-care promoting well-being (Blum & Sherman, 2010; Mosher, 2016; Ostwald, 2009; Schultz, 2013). A summary of theoretical perspectives guiding intervention research on self-care in older adult caregivers is presented, including a discussion of the strengths and limitations of current perspectives. The chapter will conclude with the research purpose guiding the study.

Aging Population in the United States

Over the next several decades, the older adult U.S. population will rapidly increase, impacting both the social and economic structure of the healthcare system (U.S Census Bureau, 2014). People 65 years and older currently represent 14.1% of the population; by 2040, older adults are expected to comprised 21.7% of the U.S population (HHS, 2014; U.S Census Bureau, 2014). The baby boomers are responsible for this rapid increase in the proportion of older adults, as they started turning 65 in 2011. As the U.S. ages, the incidence of chronic illness among older adults has exponentially increased.

Chronic Conditions among Older Adults

During the past century, the leading causes of death among older adults have shifted from infectious disease and acute illness to chronic illness (CDC, 2013). In the U.S., 80% of older adults have at least one chronic condition, and 50% have two or more (CDC, 2009). Two out of every three older adults in the U.S. have multiple chronic conditions or "multimorbidity;" treatment for this population accounts for 66% of the country's health care expenditures (CDC, 2013). National Hospital Survey data indicate an increase in hospitalizations for people 65 years and older, attributed to the rising prevalence of chronic conditions among older adults (Li, Young, & Williams, 2014). The incidence of poor or fair health, chronic conditions such as diabetes, heart disease, and hypertension, and associated difficulty with functional physical and social impairment increase with age. By 2030, the number of Americans with one or more chronic conditions will increase to 37%, an increase of 46 million people (Anderson, 2010).

Having one or more chronic conditions is associated with poor quality of life, functional disability, psychological and emotional distress, and increased mortality (Fortin et al., 2006; Marengoni et al., 2011). In people over age 65, approximately 65% suffer from multiple chronic conditions; in people over age 85, this increases to about 85% (Centers for Medicare and Medicaid Services, 2012; Marengoni et al., 2011; Van den Akker, Buntinx, Metsemakers, Roos, & Knottnerus, 1998; Vogel et al., 2007). Over two-thirds of Medicare expenditures are for enrollees with five or more chronic conditions (Anderson, 2010). Older adults with more than four chronic conditions constitute 25% of the Medicare population, and are responsible for at least 80% of the Medicare expenditures (Boult, Karm, & Groves, 2008).

Hospitalization and Readmission

In 2012, people aged 65 years and older had twice the number of overnight hospital stays compared to persons aged 45-64 years (HHS, 2014). The Centers for Medicare and Medicaid Services (CMS) have reported the cost of readmission for Medicare enrollees at $26 billion dollars annually. These healthcare costs are staggering, totaling more than $17 billion for preventable readmission (Dartmouth Atlas Project, 2013). Based on the financial costs to CMS, as well as the social burden and hardship to patients and their families, preventable readmissions are considered one of the leading issues facing our healthcare system. The reality of shorter hospital stays has resulted in older adults being discharged home “sicker and quicker”, which has significant implications for informal caregivers managing self-care needs, as well as the care recipient, following discharge.

Approximately one in five older adults is readmitted to the hospital within 30 days after discharge. Ninety percent are unplanned admissions and eighty percent are related to acute medical complications (Jencks, Williams, & Coleman, 2009). A national report from the Robert Wood Johnson Foundation (RWJF) used the term “*the revolving door”* to describe this phenomenon (Dartmouth Atlas Project, 2013). Lochner and colleagues (2013) reported that among Medicare beneficiaries with four or more chronic conditions, the 30-day readmission rate was 36%. When readmissions do occur, the outcome is often poor and costly (Naylor et al., 2004). The risk to older adults when discharged from healthcare facilities to home is well described and has been associated with poor outcomes including unnecessary emergency room visits as well as avoidable hospital readmissions (Gibson, Kelly, & Kaplan, 2012; Naylor, Aiken, Kurtzman, Olds, & Hirschman, 2011). Common risks are associated with poor outcomes of older adults who are transitioning from the hospital back to their home. These include: (a) lack of patient/caregiver involvement; (b) absent or inadequate communication among healthcare providers as well as patients/caregivers; (c) absence of interdisciplinary collaboration among team members; (d) limited follow-up care and monitoring of patient after discharge; poor continuity of care; and (e) crucial gaps in services as patient move between the multitude of healthcare providers and settings (Bowles, Pham, O'Connor & Horowitz, 2010; Naylor, 2012; Stevenson, McRae, & Mughal, 2008).

Transition to Caregiving

The transition to informal caregiving has been described as encompassing "passage from one life phase, condition, or status to another…. Transition refers to both the process and outcome of complex person-environment interactions, which may involve more than one person and are embedded in the context and the situation" (Meleis & Trangenstein, 1994, p. 256) When older adult informal caregivers experience different or expanded roles over a short period of time, patterns of response can include increased stress, depression, anxiety, irritability, worry, vulnerability, disruption to daily living, and changes in self-esteem (Schumacher & Meleis, 2010). Being in an informal caregiver role has been linked to a variety of health issues including heart disease, cancer, diabetes, arthritis, self-care, neglect, depression, and social isolation (Donelan et al., 2002; Hirst, 2005; Kim & Schulz, 2008; Robinson et al., 2005; Yeung, 2007).

Transition to the role of informal caregiver may make the older adult caregiver more vulnerable to health issues due to the new or expanding role they are assuming. Participating in self-care activities promoting well-being may be limited during this time due to new or competing demands facing the caregiver. This in turn could negatively impact the older adult caregiver's well-being. Assisting the older adult informal caregiver to acknowledge their own strengths, promote self-capacity, and advocate for self, may facilitate awareness of and choice to participate in self-care activities promoting well-being (Shearer, 2009; St-Cyr Tribble et al., 2008).

Informal Caregiver Health

Thirty-four percent of informal caregivers are 75 years or older. The typical older adult informal caregiver is a 79 year old, white female living with the care recipient, usually a spouse (National Alliance for Caregiving [NAC] & AARP, 2015). The health of the older adult informal caregiver can be impacted in multiple domains, including psychological, physical, social, financial and spiritual (National Cancer Institute: PDQ® Family Caregivers in Cancer, n.d.). During the period at home following hospital discharge, the older adult informal caregiver is at risk for decreased well-being as they try to balance the care of their loved one while attending to their own self-care needs.

Older informal caregivers are particularly vulnerable, as caregiving responsibilities may lead them to be inattentive to their own health issues at an age when they are likely to have one or more chronic conditions requiring self-care and medical monitoring (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Cruikshank, 2003; Katbamna, Bhakta, Ahmad, Baker, & Parker, 2002; Mazanec Daly, Douglas, & Lipson, 2011; McGarry & Arthur, 2001; Navaie-Walliser et al., 2002; Pressler et al., 2009; Reinhard, Given, Petlick, & Bemis, 2008, Spillman, Wolff, Freedman, & Kasper, 2014). The most common health issues facing older adult family caregivers are hypertension, diabetes, headaches, inability to sleep, low energy level, poor nutrition, lack of exercise, or weight gain/loss (NAC & Evercare, 2006; O'Connell, Bailey, & Walker, 2003; Stajduhar, Martin, & Cairns, 2010). There is also increased risk of among informal caregivers including elevated stress hormones and reduced immune function, as well as increased cardiovascular disease (Kiecolt-Glaser et al., 2003; Pinquart & Sörensen, 2007; Schulz & Sherwood, 2008).

Informal caregivers report greater disability associated with chronic illness when compared to the general population, and are more likely to report high levels of stress, burden, and depression (Pinquart & Sörensen, 2003a, 2003b, 2004, 2007). The National Alliance for Caregiving (2015) concluded that older adult informal caregivers suffer a higher burden from care, including increased emotional and physical strain, with one in five reporting that caregiving had negatively impacted their own health.

Despite the risk of negative health outcomes, systematic reviews address the rewards of being a caregiver (Funk, Stajduhar, Aoun, Grande, & Todd, 2010; Li, Cooper, Bradley, Shulman, & Livingston, 2012). Informal caregivers note a sense of pride, satisfaction, purpose and meaning, increased self-esteem, and spirituality as a result of the caregiving experience (Blum & Sherman, 2010; Bull, 2014; Kim, Schulz, & Carver, 2007; Sherman & Cheon, 2012; Wolff, Dy, Frick, & Kasper, 2007). Ability to access personal and social contextual resources has been suggested as attenuating some of the negative outcomes most commonly associated with caregiving (Jones, Winslow, Lee, Bruns, & Zang, 2011; Kim, Carver, Rocha-Lima, & Shaffer, 2013; Lum, Lo, Hooker, & Bekelman, 2014; Sherman & Cheon, 2015; St-Cyr Tribble et al., 2008; Walker, Powers, & Bisconti, 2016).

Informal Caregiver Self-Care

Informal caregivers provide uncompensated care for their loved ones, filling significant care gaps within the U.S healthcare system. Informal caregivers provide the majority of hands-on care, including assistance with activities of daily living (ADL) and care coordination to ensure management of chronic and acute medical conditions (Feinberg, Reinhard, Houser, & Choula, 2105; Gibson, Kelly, & Kaplan, 2012). For informal caregivers aged 50 years and older, the estimate of aggregated lost wages, Social Security benefits, and pensions for those providing care is approximately $3 trillion (NAC & Metlife, 2011). An estimated 34.2 million adults care for persons 50 years and older (NAC & AARP, 2015) and 75% of informal caregivers are women (Family Caregiver Alliance, n.d.).

Informal caregivers often continue to provide care, even while their own health deteriorates due to poor self-care practices (Byrne, Orange, & Ward-Griffin, 2015; Chappell, 1992; Hess & Soldo, 1985; NAC & Evercare, 2006; Reinhard et al., 2008). Women caregivers report higher levels of depression and anxiety and lower levels of well-being, life satisfaction, and physical health compared to their male counterparts (Pinquart & Sörensen, 2006). Older informal caregivers participate in fewer health-promoting activities than their non-caregiving counterparts (Acton, 2002; Janevic & Connell, 2004). Further, the health of informal caregivers worsens over time; older adult caregivers who reported fair or poor health during the first year of caregiving report worse health after providing care for five or more years. Those providing care to spouses are at greater risk for poor health (NAC & AARP, 2015). Funk and colleagues (2010) suggest that informal caregivers are reluctant to seek help or support for their own self-care needs, concerned this may take away from the person for whom they are caring.

Informal caregivers are now providing, and will continue to provide, ongoing and complex care to older adults. Informal caregiving is longer in duration than in the past, begins earlier than previously reported, and is more intensive in roles and responsibilities related to chronic illness (Gitlin, 2012). The impact of managing multiple demands may limit caregiver time, resources, and energy to engage in self-care (Kjallman-Alm, Hellzen, & Norbergh, 2014; Walters, Oyebode, & Riley, 2010). Studies on the experiences of caregivers with chronic health concerns note that these caregivers are more vulnerable and neglect their own self-care needs (Ostwald, 2009).

However, the emphasis on understanding the psychological impact of caregiver burden has limited the understanding of how caregivers care for themselves while caring for others (Furlong & Wuest, 2008).

Few studies have explored informal caregiver self-care from a health empowerment conceptual perspective (Acton, 2002). Further, there has been limited focus on the recognition and engagement of resources for older adult caregivers to purposefully participate in self-care promoting well-being (Gibson, Kelly, & Kaplan, 2012).

Caregiver Empowerment and Self-Care

Health concerns may be intensified by focusing on informal caregiver problems and deficits rather than personal and social contextual resources (St-Cyr Tribble et al. 2008). Indeed, the predominant focus to date has been on the negative aspects of caregiving and development of interventions to reduce such effects. To be able to promote caregiver self-care, knowledge is needed concerning their resources for health and well-being (Wennerberg, Lundgren, & Danielson, 2012).

A health empowerment perspective may be relevant to understanding caregiver self-care behaviors enhancing well-being (Shearer, 2009). Health empowerment reflects a relational process arising from the recognition of personal and social contextual resources, building self-capacity and facilitating awareness of the ability to purposefully participate in self-care promoting well-being. Key to health empowerment is the ability to purposefully participate in self-care and healthcare decisions. An empowerment approach to caregiver self-care emphasizes individual strengths and capacity in the form of personal and social contextual resources (Chadiha, Adams, Biegel, Auslander, & Gutierrez, 2004; Shearer, 2011). Through the health empowerment process, a transformation occurs in awareness of and belief in one's ability to knowingly participate in self-care to promote well-being (Shearer, 2011).

Healthcare providers may fail to acknowledge the experiences and strengths of the older adult informal caregiver. Further, prescribed self-care behaviors may not reflect personal strengths or choices of the older adult informal caregiver, which limits the opportunity to purposefully participate in self-care promoting well-being (Shearer, 2011). Practicing from a health empowerment perspective acknowledges the strengths of the older adult informal caregiver, using personal and environmental resources as a basis for engagement and participation in self-care.

Self-Care Theoretical Perspectives

According to the National Alliance for Caregiving and AARP (2009), nearly 49 million informal caregivers provide care to older adults; this number is expected to increase as the U.S population ages. Meta-analyses have focused on disease processes of the care recipient and the relationships between caregiver burden, depression, quality of life, and stress (Donnelly, Hickey, Burns, Murphy, & Doyle, 2015; Northouse, Williams, & McCorkle, 2012; Pinquart & Sörensen, 2003b; Piquart, Sörensen, & Duberstein, 2002). Leenerts and colleagues (2007) note that interventions in this field of study focus on alleviating or ameliorating negative caregiving outcomes, rather than promoting caregiver self-care. The UK Department of Health (2005) defines self-care “as part of daily living; the care taken by individuals toward their own health and well-being…to maintain physical and mental health and meet social and psychological needs” (p. 2). Theory-based interventions designed to promote self-care among older adult informal caregivers have focused primarily on theories of stress and coping (Lazarus & Folkman, 1984), self-efficacy theory (Bandura, 1997), and, to a lesser extent, self-management (Grey, Knafl, & McCorkle, 2006). This purpose of this review is to provide a summary of theory framing self-care in older adult informal caregivers, to examine how these theoretical perspectives further the science of older adult caregiver self-care, and to foster dialogue on approaches to build the body of knowledge in this field of study.

Stress and Coping

The stress-coping model of Lazarus and Folkman (1984) as applied to caregiving has been the primary theoretical perspective guiding intervention research. Coping has been defined as the thoughts and behaviors used to manage the internal and external demands of situations that are appraised as stressful. The coping process is initiated in response to the individual’s appraisal that important goals have been lost or threatened. Lazarus and Folkman (1984) have described coping with stress as beginning with primary and secondary appraisal and ending with reappraisal. Primary appraisal of a stressful event results in interpreting the experience as irrelevant, positive, or stressful, and if stressful, involving loss, threat, or challenge. Secondary appraisal involves assessment of the resources available for coping. The processes of appraisal and reappraisal allow for interpretation of the meaning and significance of the demands and challenges the informal caregiver is facing.

Coping has been associated with the regulation of emotion, especially distress, throughout the stress process. Categories of coping usually include problem-focused coping, which involves addressing the problem causing distress, emotion-focused coping, which is aimed at ameliorating the negative emotions associated with the problem, and meaning-focused coping, in which cognitive strategies are used to manage the meaning of a situation.

Ducharme and colleagues (2006) evaluated the effects of a stress management intervention for family caregivers of older adults. The authors note significant effects on perceived challenge associated with the caregiver role, control by self, use of social support, and use of problem-solving. However, there were no significant changes found in perceived burden, stress appraisal, perceived psychological distress, or self-assessed health. The Resources for Enhancing Alzheimer's Caregiver Health (REACH II) trial evaluated a multicomponent intervention with one component addressing caregiver self-care and health behaviors (Belle et al., 2006). Using the REACH II protocol, Elliot and colleagues (2010) reported improved self-rated health and subsequent reductions in caregiver burden and bother at 6-month follow up. Caregiver health was found to improve in the domains of general self-rated health, sleep, mood improvement, and physical improvement. REACH OUT adapted the REACH II intervention for implementation through Area Agencies on Aging (Burgio et al., 2009). REACH OUT noted decreases in caregiver burden, as well as improved self-rated health, sleep, and social supports. Moore and colleagues (2013) evaluated an intervention designed to decrease caregiver depressive symptoms and biomarkers of cardiovascular (CVD) risk. The authors found that caregiver CVD risk, as measured by the inflammatory marker IL-6, was significantly lowered at post-treatment (6 weeks); change was nonsignificant at 1 year.

Despite the gains made in understanding the process of coping among informal caregivers, there remains limited understanding of the ways in which coping affects behavioral and physical outcomes consistent with caregiver self-care. Across intervention studies evaluating a stress-coping perspective, conceptualization of the problem of interest focused primarily on caregiver distress and impaired coping processes; few intervention studies have been designed to promote caregiver self-care. As noted by Gitlin (2012), reliance on the stress-coping perspective for understanding caregiving, framing interventions, and identifying outcomes, has limited caregiver interventions to those which address psychological outcomes. Stress, depression, and burden are viewed as inherent in the caregiving process, rather than based on caregiver needs, goals, or resources. However, the processes and challenges of caregiving may have different meanings across caregivers, and lead to different health outcomes.

Self-Efficacy

Self-efficacy reflects the belief that one can successfully execute a specific task or behavior required to produce an outcome (Bandura, 1997). Low self-efficacy has been associated with greater physical and emotional fatigue, and high self-efficacy has been related to lower health risks (Harmell et al., 2011; Rabinowitz, Mausbach, Thompson, & Gallagher-Thompson, 2007). A self-efficacy perspective assumes that the individual attends to information from four sources: (a) the performance of behavior; (b) seeing or visualizing another performing a behavior; (c) verbal persuasion; and (d) physiological cues experienced by the individual. Expectations concerning mastery or coping in a specific situation may be divided into three types: (a) expectancies about environmental cues, or beliefs about how events are connected, (b) expectancies about the consequences of one's actions, or beliefs about how behavior will influence outcomes, and (c) expectancies about one's competence to perform the behavior needed to influence outcomes.

Connell and Janevic (2009) evaluated an intervention incorporating efficacy-enhancing techniques to promote physical activity in female-spouse dementia caregivers. Individual goals were set by participants, in conjunction with a telephone counselor, to maximize the likelihood of success. Participants were encouraged to assume responsibility for working toward their goals, with feedback provided to increase self-efficacy. Authors noted increased physical activity among less active caregivers, enhanced self-efficacy, and decreased perceived stress immediately following the intervention. At 12-month follow up, only the positive effects on self-efficacy remained. Although individual perception of efficacy in a given behavior may be one important factor, the decision to initiate self-care behavior, individual differences in the value of the behavior must also be considered. Bandura (1977) alludes to outcome value when noting the importance of incentive factors on behavior but has not included individual values within his theory of self-efficacy. Thus, individuals may feel efficacious in initiating a self-care behavior, but may perceive greater value in not engaging in the behavior. Farran and colleagues (2016) evaluated a 12-month self-efficacy intervention designed to promote moderate intensity physical activity among dementia family caregivers. Moderate intensity physical activity increased, as did number of steps; self-efficacy was not measured. Kuhn and colleagues (2003) evaluated a group intervention for family caregivers designed to empower them to better care for themselves and enhance self-efficacy regarding the caregiving role. Among spouse caregivers, improvements were noted in measures of self-efficacy, and self-care, including taking care of their own health, participation in relaxation activities, and time spent in physical activity. However, spouse caregivers did not improve in their ability to make time for themselves. Trivedi and colleagues (2016) evaluated a SUCCEED intervention, designed to promote self-efficacy for self-management support among heart failure patients and caregivers. While caregivers realized desired changes for psychosocial outcomes, quality of life decreased, as evidenced by worsening physical well-being.

Self-Management

Self-management in promoting caregiver self-care has been conceptualized as a dynamic, daily process in which individuals engage to manage chronic illness using the following skills: (a) problem-solving; (b) decision making; (c) finding and using resources; (d) forming partnerships with healthcare providers; and (e) taking action (Grey, Knafl, & McCorkle, 2006). Intervention approaches are designed to help individuals with chronic conditions, their families, and caregivers better understand and manage their illness and enhance health behavior (NINR, 2011).

Sisk (2000) explored the relationship between caregiver burden and health promoting behaviors in caregivers of older adults. Caregivers with higher subjective burden engaged in fewer health-promoting behaviors than those with low subjective burden. Acton (2002) compared self-care behavior in family caregivers with demographically matched non-caregivers. Family caregivers scored significantly lower on health promoting activities and significantly higher on perceived barriers to health promotion, including physical activity and hours of sleep. Mochari-Greenberger and Mosca (2012) reported that time demands, sleep disturbance, and caregiver strain were significantly and independently associated with an increase of daily saturated fat intake among family caregivers of patients with cardiovascular disease. To date, the majority of self-management interventions have addressed caregiver burden and ability to manage the needs of the care recipient; few have addressed caregiver self-management consistent with physical health outcomes.

Discussion

To date, there have been few interventions addressing the physical health needs and well-being of the older adult informal caregiver (Hunt, 2003; Gitlin, 2012; Walker, Powers, & Bisconti, 2016). The issue of self-care among informal caregivers is complex, suggesting that new approaches are needed based on the social contextual resources, strengths, and lived experiences of the caregiver (Connell & Janevic, 2009; Foster, Layton, Qualls, & Klebe, 2009; Naylor, 2012).

The theoretical perspectives guiding intervention research on caregiver self-care advance a narrow focus on individual control and responsibility, limiting acknowledgement of the broader social context and resources that influence self-care in older adults (Holstein & Minkler, 2003). Older adult choices about engaging in self-care depend largely on available resources, including an adequate income, access to affordable and nutritional food, a healthy and safe neighborhood in which to live, and affordable, good quality health care (Minkler, 1999). However, these essential resources are not equally available to all older adult caregivers (Meyers, 1989). A better understanding is needed regarding the role of social contextual resources in self-care among older adult caregivers, as well as the capacity of older adults to meet the challenges posed by the environment (Barbosa, Figueiredo, Sousa, & Demain, 2011; Hunt, 2003; Naylor, 2012).

Much of the research on self-care in older adult caregivers has been framed by theory focused on deficits or problems to be solved, with the assumption that promoting self-care is a process of removing deficits and obstacles (Stevens, 2012). A focus on problems and deficits limits the exploration of individual strengths, thereby compounding the risk for vulnerability to diminished health and well-being in older adults (Holstein & Minkler, 2003; McMahon & Fleury, 2012). Jones and colleagues (2011) suggest that changing our “research lens” from a deficit perspective to a strength-based perspective is essential to promoting caregiver well-being. However, few interventions are designed from a strength-based perspective, building upon the caregiver’s own assets and experiences to foster self-care and promote well-being

(Gitlin, 2012; Jones et al., 2011; Teel & Leenerts, 2005; Walker, Powers, & Bisconti, 2016). There remains a paucity of knowledge regarding ways to promote continued growth among older adults by building upon strengths and realizing potential while simultaneously addressing their changing and diverse needs (McMahon & Fleury, 2012).

New paradigms for self-care are needed which reflect the lived experiences of older adults (Dillaway & Byrnes, 2009; Holstein & Minkler, 2003). Tornstam (1992) has challenged researchers and clinicians to let older adults define their own needs, values, and meanings. Naylor (2012) has echoed this perspective, calling for qualitative approaches to understanding the varied experiences and meanings of older adult caregivers as essential sources of knowledge. According to Holstein and Minkler (2003), exploring "How it is for me" opens narrative possibilities that trade generalizability about old age for increased understanding. Knowledge generated from such approaches could influence the design of self-care interventions to better match the needs of older adult caregivers.

The knowledge generated from this research may be essential to inform the design and delivery of interventions that recognize caregiver experiences and strengths that foster self-care promoting well-being. Building upon individual strengths and optimizing potential will advance nursing knowledge about promoting continued growth among older adults while simultaneously guiding care for their changing and diverse needs (McMahon & Fleury, 2012).

Research Purpose

The Theory of Health Empowerment will provide the theoretical basis for this research. This perspective views health empowerment as a relational process emerging from the recognition of personal and social contextual resources; building self-capacity, and transformation of awareness to knowingly participate in change (Shearer, 2011). Current research supports acknowledging the older adult informal caregiver's strengths, including personal and social contextual resources (Jones et al., 2011; Kim et al., 2013; Sherman & Cheon, 2015; Walker, Powers, & Bisconti, 2016). A qualitative descriptive approach is used to explore caregiver recognition and engagement of personal and social contextual resources to purposefully participate in self-care activities.

Significance of the Research

This research supports both the NINR and NIA research agendas of developing conceptual frameworks and methods to investigate the unmet needs of caregivers and designing interventions promoting the health and well-being of informal caregivers (NIA, 2012; Naylor, 2015; NINR, 2016)

As our population continues to age, the role of older adult informal caregivers will grow. Currently, older adult caregivers are performing their roles alone, with many in poor to fair health themselves (Family Caregiver Alliance, 2015; Johnson & Weiner, 2006). The U.S. health care system is designed for the care recipient, not those who care for them (Northouse, Williams, & McCorkie, 2012).

This research will contribute to the body of knowledge in nursing, as well as further the science of relevant, strength-based interventions facilitating older adult informal caregiver recognition and engagement of self-care activities promoting well-being.

Relevance to Nursing Science

As part of the cycle of inquiry, nurses need to continue to question and evaluate the state of nursing science. Caregiver intervention research has been influenced by traditional perspectives including stress-coping, self-efficacy, and self-management. These theories emphasize prescribed change in a linear pattern, consistent with particular-deterministic and interactive-integrative worldviews (Fawcett, 1993; Glanz, Rimer, & Viswanath, 2008). Self-care behavior is predicted under predefined conditions, guiding the search for modifiable factors to ameliorate conditions of illness or deficit (Glanz, Rimer, & Viswanath, 2008). Research framed from this worldview adopts the viewpoint that individuals are the sum of bio-psycho-social-spiritual components, that they react to their environment, and they change in predictable ways (Fawcett, 2005). This worldview is consistent with logical positivism, whereby knowledge and truth are derived from that which is observable, measureable and well-defined (Fawcett, 2005; Whall & Hicks, 2002; Glanz, Rimer, & Viswanath, 2008). The Theory of Health Empowerment is congruent with a unitary-transformative perspective, which views the person as evolving, with change as a process emphasizing personal knowledge and pattern recognition (Fawcett, 1993). A unitary-transformative worldview acknowledges individuals as identified by patterns and interactions with the environment, change is ongoing and unpredictable, and emphasizing personal knowledge and recognition (Fawcett, 1993). Pattern recognition and personal becoming are the primary phenomena of interest (Fawcett, 1993; Reed, 1995, 2008). This research will continue the evaluation and refinement of the Theory of Health Empowerment, contributing to the nursing science and knowledge.

Summary

As the demographics continue to shift in this country, with some estimating as many as one in five Americans will be 65 and older by 2050 (Pew Research Center, 2015), nursing research needs to start developing new and innovative ways to meet the needs of this rapidly growing population. The body of available research focuses on the negative effects of caregiving, with limited research investigating caregiver health from an empowerment perspective (Acton, 2002; Ostwald, 2009). The Theory of Health Empowerment provides a conceptual framework to facilitate the older adult caregiver's awareness and engagement of self-care activities based on personal health goals. This theory views the older adult informal caregiver as the expert in their own care; fostering their self-capacity and optimizing health consistent with their own self-care goals. The Theory of Health Empowerment provides a foundation for nursing theory, practice and research that facilitates a transforming belief in self (Shearer, 2011).

CHAPTER 2

REVIEW OF THE LITERATURE

This chapter provides an overview of the health empowerment theory guiding the research on older adult informal caregiver self-care promoting well-being. The origin and the conceptual basis of the theory, underlying assumptions, and use of the health empowerment theory as a basis for research and practice are addressed.

Theoretical Framework

The Theory of Health Empowerment, a mid-range practice theory, will guide the proposed research. The Theory of Health Empowerment is grounded in nursing science, recognizing the social contextual relationship and complex nature of individuals as they participate in setting goals for well-being. Health empowerment is a transformational process, facilitating one's own awareness of the ability to act and to knowingly choose to participate in health and health care decisions (Shearer, 2009). This transformation occurs as the caregiver draws on their unique characteristics of self-capacity (personal resources) and the support of others and the environment (social contextual resources).

Over the past two decades, researchers and clinicians have questioned a paternalistic paradigm focused on the values, beliefs, and actions of healthcare providers, calling instead for a partnership that focuses on the values, beliefs, and actions of the person when setting goals and taking action for health and well-being. The paternalistic perspective endows the health care provider with the final authority on the goals for care and the course of action, silencing the voice of the individual. A relational perspective has been proposed as an alternative paradigm, engaging both the person and the health care provider in making health care decisions by acknowledging the experiences of the individual, and facilitating the attainment of individual goals for well-being (Reed, Mezza, & Jacobs, 1996).

The Theory of Health Empowerment emerged in response to a paternalistic perspective, recognizing the person as a resource and partner in their healthcare. The focus of care is directed at optimizing the person's strengths and potential rather than trying to change the person's behaviors. The promotion of well-being is considered a developmental process that includes mutual influences of the environment and person (Shearer & Reed, 2004).

Conceptualization of Empowerment

The word *empower* dates back to the mid-seventeenth century. Merriam-Webster defines empower as a noun "to give power to," or as a verb (a) "to give official authority or legal power to," and (b) "to promote self-actualization or influence". Modern day use of the word empowerment originated in 1960s and 1970s, during the fight for equal rights among races, women, the LBGT community, people with disabilities and other disenfranchised individuals and communities (Shearer & Reed, 2004).

Health Education and Promotion

In the health education and health promotion literature, empowerment has been conceptualized as a framework for understanding the process and consequences of efforts to exert control and influence over the decisions that impact life, including perceptions of control (Perkins & Zimmerman, 1995; Rappaport, 1987). Empowerment from this perspective emanated from an ecological basis, incorporating the individual, organizations, and the community, as a participatory process. Empowerment has been defined at the individual level of analysis as "a process by which individuals gain mastery and control over their lives and a critical understanding of their environment" (Zimmerman, Israel, Schultz, & Checkoway, 1992), p. 708). Research by Rappaport (1981, 1987) and Zimmerman and colleagues (1992) suggested viewing individual differences as strengths rather than liabilities; they noted that people have inherent competencies, with community relationships serving as an important resource. Empowerment was viewed as an interaction between the inherent abilities of the person and the environment in which they live. The Theory of Health Empowerment builds on this conceptualization, as it emphasizes the strengths of the individual, recognizing the importance of contextual and relational (personal and social contextual) resources and lived experiences. Using these personal and relational factors as strengths, self-capacity building interventions move the individual to empowerment and purposeful participation in change, with the nurse acting as a facilitator in this process. The Theory of Health Empowerment (Shearer, 2004) draws from the work of Rappaport and Zimmerman, viewing empowerment as a participatory process, where one can take control of their life and environment (Shearer, 2004).

Empowerment as a process focuses on relationships with others and the transfer of power with the outcome of "liberation, emancipation, energy and sharing power" (Leyshon, 2002, p. 467), and can be understood from several perspectives, including social and developmental (Shearer, 2004; Shearer & Reed, 2004).

Social Perspective

As a social process, empowerment is associated with external social forces that act on the person and affect his or her sense of control and feelings of power (Shearer, 2004; Shearer & Reed, 2004). Social support as an external feedback mechanism has been studied as a process that can provide needed reinforcement, resources, assistance, and motivation (Shearer & Fleury, 2006) and enable the individual to make decisions. Other external social forces have been studied from the perspective of emancipation from oppression. Several authors have suggested that empowerment could be promoted by addressing political constraints (Labonte, 1994), environmental constraints (Ryles, 1999), and social constraints (Fulton, 1997).

Lifespan Development Theory

Empowerment may also be understood in reference to a lifespan developmental perspective (Lerner, 1997). From this perspective, empowerment is seen as both a process and an outcome, promoting an individual's ability to meet their own needs and goals (Ellis-Stoll & Popless-Vawter, 1998; Gibson, 1991; Ryles, 1999). The lifespan developmental theoretical approach is a multifaceted view of human development, suggesting that changes across one's lifespan are complex and interrelational (Baltes, P, 1978; Baltes & Lerner, 1980; Lerner, Hultsch, & Dixon, 1983). Development is based on a multitude of experiences over a lifetime and is reflective of the ongoing relationship between the individual and their environment.

Baltes and Lerner (1980) describe lifespan development to be a multidirectional and multidimensional process, reaching across one's life involving both the personal and environmental context in which the individual is embedded. Interventions from a lifespan lens focus on the optimization of individual strengths, while minimizing weaknesses (Baltes & Baltes, 1990; Baltes M. & Carstensen, 1996; Baltes, P.B., 1997, 1998). The individual is seen as the repository of all of their experiences and learned behaviors and is in continual interaction with the environment. It is from this perspective that the individual uses their strengths and abilities to make choices in their own care. The nurse is the facilitator, assisting the individual toward fully optimizing their human potential. Labonte (1989, 1994) stresses the importance of listening, allowing the individual to give voice to their concerns and experiences, suggesting that this is the crux of empowerment and a point of entry into a more collaborative relationship. Health empowerment from a lifespan developmental perspective is the ability to knowingly participate in change, by drawing on personal and social contextual factors to impact health and well-being (Shearer, 2011).

Sociological Frameworks

Theoretical frameworks underlying empowerment interventions often address constraints in order to facilitate power. Three theories that offer a perspective on power related to empowerment include critical social theory, feminist theory, and Bandura's theory of self-efficacy.

Critical social theory. Critical social theory focuses on making people aware of the social constraints under which they live, freeing their thinking, establishing unconstrained communication, and facilitating empowerment through increased participation, including movement toward creating change (Shearer & Reed, 2004). The underpinnings of this theoretical perspective are that no aspect of the experience can be understood unless it is related to the context in which it was found (Fulton, 1997). Consistent with this perspective, Paulo Freire believed that education was a way of freeing people from oppression, with the emphasis on a problem posing approach with no predetermined answers. This approach encouraged reflective thinking leading to dialogue, with individuals solving problems and identifying solutions (Sharma & Romas, 2008). The goal of critical social theory is for people to acknowledge the oppression in which they may live, and free them and their thinking, allowing them to communicate without restraint (Shearer, 2004). Words take on new meanings; they are no longer an abstraction but a means by which people can discover themselves and their own potential. As Freire stated, "each individual wins back the right to say his or her own word, to name the world" (Freire, 2000, pp. 32-33).

Feminist theory. Feminist viewpoints are diverse, yet the common theme connecting these perspectives is a focus on the elimination of oppression and the advancement of human dignity (Gary, Sigsby, & Campbell, 1998; Kane & Thomas, 2000). Feminist scholars aim to give voice to lived experiences. Empowerment from a feminist perspective has progressed from equality and choice for women to the approach of collective equality for all, to develop the potential within (Shearer, 2004).

Self-efficacy. Based on social behavior and social learning theory, Bandura's concept of self-efficacy is often linked with empowerment. Self-efficacy refers to a person's belief that they have the ability to succeed in a given situation. Self-efficacy theory suggests the person is reflective upon their actions, has insight into their situational and physical environments, and has the means to overcome barriers to be successful. Empowerment from a self-efficacy perspective focuses on enhancing perceived self-efficacy and movement toward positive health behaviors, sense of control and choice, and power through mastery experiences, social modeling, social persuasion, and psychological responses (Bandura, 1992, 1994). This approach facilitates personal control and choices that move the person toward positive health behaviors (Jeng & Braun, 1994; Shearer, Fleury, Ward, & O'Brien, 2010). Common among these theories is the premise that health empowerment moves the person forward by drawing on personal strengths, promoting individual choice, finding one's self, and giving voice to one's lived experiences and potential.

Origins of Health Empowerment Theory

The Theory of Health Empowerment is derived, in part, from Rogerian theory (1980, 1990, 1992), notably the constructs of human patterning and the desire to knowingly participate knowingly in change. Particularly influential is Rogers' principle of integrality perspective of human beings as integral with their environment in daily living and health experience; characterized by pattern, self-organization, diversity and innovative change, and as holding individual values and views about health. The theory also draws from other Rogerian inspired frameworks including Barrett's (1998) power enhancing change, Newman's (1994) expanding consciousness and Reed's (1997a) acknowledgement of a mutual process of power shared by the nurse and individual to promote well-being. Shearer and Reed (2004) conceptualized empowerment as a dynamic process, defining it as "purposefully participating in the process of changing one's self and one's environment, recognizing patterns and engaging inner resources for well-being" (p. 257).

Empowerment is linked to a social-ecological framework and is described as an inherent social process, involving the individual's sense of control and power, as well as societal forces. In the nursing literature, empowerment is conceptualized as both a process and an outcome. Authors describe the process of empowerment as the marshaling of resources to solve one's own problems, and mobilizing the resources to feel in control of one's life or self-determination (Gibson, 1991; Ellis-Stoll & Popkess, 1998; Cianelli, Ferrer, & Peragallo, 2003), while others define empowerment as a process of transferring "power" from one individual to another or a group, a collective power (Bradbury-Jones, Sambrooks, & Irvine, 2007; Ryles, 1999). The concept of empowerment is associated with outcomes including increased self-worth, well-being, trust and respect. Empowerment is described using affirming words such as potential, self-awareness, transforming beliefs, and participate knowingly (Caroselli & Barrett, 1998; Feste & Anderson, 1995; Fleury, 1991). Intervention critical inputs designed to promote empowerment include fostering a sense of power or control (Barrett, 2010; Bradbury-Jones, Sambrooks, & Irvine, 2007; Caroselli & Barrett, 1998; Kuokkanen & Leino-Kilpi, 2000; Manojlovich, 2007; Polifroni, 2010; Rodwell, 1996; Ryles, 1999).

Assumptions of the Theory of Health Empowerment

The application of Rogers' science of unitary human being to nursing research and practice acknowledges the uniqueness of each person, the diversity of the person and their behaviors, and the understanding that the individual is a reflection of the continuous, innovative, reflective patterns of being as they interact with an open fluid environment (Fawcett, 2005). Although Rogers' theory does not directly apply the concept of empowerment, a Rogerian perspective of empowerment has been suggested through Rogerian theory and practice paradigm (Shearer & Reed, 2004). From a Rogerian worldview, people have the capacity to participate knowingly in change; through the process of mutual patterning, Rogers' outlines the relationship between the nurse and person (Fawcett, 2005). These constructs infer the active role of the individual in their care, with the nurse facilitating the individual to optimize their potential for health and well-being. Emphasis is not on the nurse as in "power" or "in control" but rather as a facilitator, using knowledge, relevant personal and social contextual resources to optimize the individual's health potential. Shearer (2011) identified the following attributes of empowerment: "belief in self, personal strength and abilities; choice, control over factors affecting one's life, recognition, transformation, resources, and a desire or willingness to take action as participation in change" (pp. 87-88). The Theory of Health Empowerment is built on the following assumptions:

(a) Empowerment is neither external to the person nor bestowed on others; power is inherent and ongoing (Labonte, 1989).

(b) Empowerment is a relational process, expressive of the mutuality of person and environment.

(c) Empowerment reflects ongoing change that is continuously innovative.

(d) Empowerment is expressive of the human pattern of well-being, and can be assessed and enhanced through nursing knowledge, including practice and science-based inquiry (Shearer & Reed, 2004, p. 256).

These assumptions reflect a synthesis of Parse's (1987) simultaneity worldview (openness, becoming, and patterns), Newmans' expanding consciousness (patterns, humans continuous with the environment, and nurses and client mutually participate), and are congruent with Rogerian worldview (Fawcett, 2005). These assumptions are central to Barrett's (1998) work in health patterning and dimensions of power. Reed (1997a) defines nursing as a process of well-being; that nursing is inherent in all human beings, recognizing evolving complexity, with integration generating well-being.

Theory of Health Empowerment

The health empowerment theory informing this research was developed by Shearer (2004), addressing caregiver personal and contextual resources, purposeful participation in goal attainment, and well-being (see Figure 1).

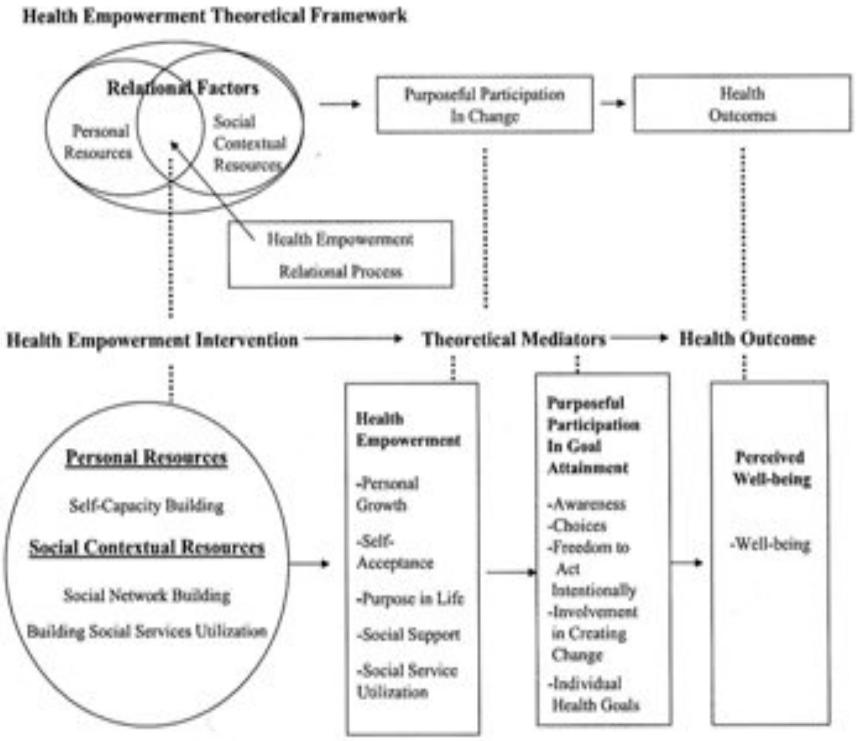

Figure 1. Health Empowerment Theoretical Framework.

Personal resources. Personal resources reflect the individual's resources for self-capacity building (Shearer, 2004) and interventions focused on building self-capacity may enhance well-being. Shearer conducted research (2004, 2007, 2008, 2010) with homebound older adult women to continue the refinement of the health empowerment theory.

Shearer found that personal resources are multidimensional and unique for each person, reflective of the woman within. The acknowledgement of strengths, growth, and change are characterized as self-capacity. Recognition of self-capacity enhances ability to problem solve and make meaningful changes in one's overall well-being (Shearer, 2007). For example, a woman can begin building self-capacity by advocating for one's self. Schulz and colleagues (1995) found that perceived control at the individual level was a factor in building self-capacity.

Shearer's findings are consonant with other researchers who have studied the relationship of personal factors to well-being (Cornwell, Laumann, & Schumm, 2008; Learmonth, Taket, & Hanna, 2012; Rappaport, 1981; Schulz et al., 1995; Zimmerman et al., 1992). Rappaport (1981) suggests that people need genuine places and opportunities for personal development. Zimmerman (1992) noted that personal resources may make a difference in the empowerment process from one individual to another. Personal contextual factors and social engagement were found to influence older adult's perspective or outlook on life, including things such as retirement, bereavement and health issues (Cornwell, Laumann, & Schumm, 2008), and enabled the participants to have a sense of value, independence, and feelings of support and positive orientation toward health (Learmonth, Taket, & Hanna, 2012).

Social contextual resources. Personal and social contextual resources are interconnected. Shearer (2011) views social contextual resources as the social contacts and supportive networks the person identifies, enhancing their ability to be connected and find support. They are operationalized by identifying and building the person's own social network and community resources. Shearer and Fleury (2006) studied social contextual resources among older adults in a senior congregate meal program. Contextual resources included community building and neighborhood resources, as well as the individual and collective capacity to gain knowledge from networking through friendships. Participants acknowledged feelings of connectedness and collectivism as well as the physical and mental benefits of the interactions. The existence of a social network of close friends and neighbors provided informal routes to invaluable resources in times of need. Helping the older adult identify their social contextual resources reinforced the recognition of these resources, promoting problem-solving while continuing the connection with social networks and resources (Shearer, 2009).

Bull (1990, 1995) examined caregiver burden during the transition of a loved one from hospital to home and found social support to be a key determinant in a successful transition for the caregiver. Additional research supports these early findings, supporting the benefit of an intact personal network as well as social support enhancing the care process (Fabbre, Buffington, Altfeld, Shier, & Golden, 2011; Neiterman, Wodchis, & Bourgeault, 2015; Wallace, Perkhounkova, Tseng, & Schillinger, 2013; Washington, Meadows, Elliot, & Koopman, 2011).

Social contact and supportive networks are essential to the health of older adult caregivers, especially those that are chronically ill (Boland, 2000). Research suggests that a decreased or lack of social network is consistently linked with the risk of dependency and a reduced level of function, particularly in older adult caregivers with multiple chronic illnesses (Boult et al., 1994; Ditewig, Blok, Havers, & van Veenendaal, 2010). Conversely, social support, including having supportive networks, has been linked to older adults experiencing an overall healthier life, including improved immune, endocrine, and cardiovascular function (Arbaje, Boonyasai, & Dilworth-Anderson, 2008; Cohen, 1988; DiMatteo, 2004; Helgeson &

Cohen, 1996). In a cross-sectional study examining care recipients and caregivers when discharged from the hospital, Bull (1990) found that larger social networks were associated with the caregiver experiencing fewer burdens. Social isolation has been associated with older adult caregiver well-being and has been tied to the use of health care services and resources in the community (Berkman & Syme, 1979; Chappell & Badger, 1989; de Jong Gierveld, & Havens, 2004; Pinquart & Sörensen, 2001). Thus, social network, support networks and community resources are essential to the well-being of individual's living in the community.

The quality of social interaction was found to be more important to the older adult than how often they interacted with people. Interaction with friends and neighbors decreased feelings of loneliness, compared to interacting with only family members (Pinquart & Sörensen, 2001). Cornwell and colleagues (2008) found that many factors influenced social support and the feeling of connectedness. Social connectedness was greater among women, widows, and people who reported poorer health. While older adults may have smaller personal social networks, they were more connected to the community compared to their younger counterparts, suggesting alternative ways of socializing may enhance feelings of connectedness. These findings support earlier research that stresses the positive effects of neighbors in social contextual resource building among older adults, even more so than family (Pinquart & Sörensen, 2001).

Hawranik and Strain (2007) describe the social isolation in caregivers of persons with dementia and its effects on overall well-being. The older adult caregiver's personal, social, and contextual resources, their "lived experiences", were instrumental in their well-being. The purposeful engagement of caregivers in identifying and working toward self-defined goals was key to the outcome of well-being. Thus, promoting the engagement of older adults in social contextual activities may increase participation in health care activities

Older adults with chronic conditions suffer from long-term adverse health events, limiting health and functional status. In a systematic review of programs and studies for patients and caregivers with multiple chronic illnesses, de Bruin and colleagues (2012) noted that the majority of interventions did not build upon the older adult's personal contextual factors. Sachs-Ericsson and colleagues (2006) suggest the need for research to understand the complex dynamics of the older adult's multiple chronic illnesses and their personal contextual resources. Interventional strategies are needed which acknowledge the older adult caregivers' strengths; to recognize and promote self-capacity for change, growth, and self-advocacy, thereby enhancing ability to purposefully participate in change, and to make meaningful decisions regarding their own health care and well-being.

Purposeful participation. A health empowerment approach has been suggested as a meaningful approach to encourage purposeful participation in self-care among older adult informal caregivers (Anderson & Funnell, 2005; Chadiha et al., 2004; Jones et al., 2011; St-Cyr Tribble et al., 2008). Purposeful participation in change reflects awareness of what you are choosing, choosing it freely and intentionally. Purposeful participation in change is consistent with health patterning and openness as well as the principles of helicy, resonancy, and integrality as described in Rogerian theory (Barrett, Malinski, Ann, & Philips, 2003; Shearer & Fleury, 2004). According to Barrett and colleagues (2003), the concepts of awareness, choices, freedom and involvement are interwoven. These concepts reflect a dynamic process of awareness and freedom, in which older adults can purposefully participate in making choices, actualizing their own human potential toward goal attainment. Being aware and feeling free are crucial, since these feelings impact the magnitude, strength, and kind of health goals an individual makes. The nurse has no investment in the ways the older adult may be changing. The role of the nurse is to encourage the older adult toward discovery and ensure that their choices are consciously made with freedom (Barrett, 1998).

Purposeful participation in change needs to be congruent with individual values, beliefs, and strengths to enhance awareness to knowingly participate in the healthcare process, and to allow for purposeful change in oneself and one's environment. The relationship with the nurse allows the older adult to recognize patterns consistent with self-care, make meaningful decisions, and purposefully participate in change with the awareness and freedom of choice in setting their own health care goals.

Levasseur, Desrosiers, and Whiteneck (2010) viewed purposeful participation as being actively engaged in life situations, drawing personal meaning and satisfaction from experiences. They note that feelings of accomplishment and satisfaction positively contribute to social participation (personal factors, health, and impairment, and environment). In addition, this research emphasizes the importance of acknowledging the perspectives and lived experiences of older adults in formulating a successful plan for self-care (Levasseur et al., 2010).

Goal attainment. Goal attainment reflects the individual meeting self-determined health goals. The individual must be open and aware, knowingly participating, making decisions and creating change (Barrett, 1986). Goal attainment reflects a relational process in which inner potential and nursing knowledge are assimilated (Shearer, 2007). The individual has life experiences and personal knowledge to determine specific health goals consistent with their values and beliefs. The nurse has knowledge and expertise to work with the individual to achieve goals. Collaborative care models encourage individuals to be active participants in their own care and decision-making, resulting in improved health-related behaviors and outcomes (Bodenheimer, 2005; Bodenheimer et al., 2002; Mead & Bower, 2002; Norris, Engelau, & Narayan, 2001). Fabbre and colleagues (2011) describe a collaborative relationship among social workers, older adults and caregivers, resulting in the development of useful relational skills and tools, fostering a smoother transitional period from hospital to home. Shyu (2000) explored how caregivers addressed the complex needs of their care recipient.

Shearer and colleagues (2010) noted that homebound older adults receiving a health empowerment intervention were more likely to attain health goals that they had personally set. Research supports that when chronically ill older adults are given the freedom to set their health goals based on their own values, beliefs and priorities, goal attainment is more likely (Leveille, Wagner, & Davis et al., 1998; Lorig et al., 1999; Lorig, Ritter, Sobel et al., 2001; Lorig, Sobel, Stewart et al., 2001).

Becker and colleagues (2009) explored goal attainment in a descriptive study of chronically ill women, concluding that when an individual selects and determines a course of change based on their own values and beliefs, identified goals can be attained.

Lorig and colleagues (1999, 2001, 2001) explored the impact of a chronic disease self-management program on health status, healthcare utilization, and perceived self-efficacy among adults suffering from chronic diseases, noting improvement in health behaviors, health status, and health service utilization. Fundamental to the success of this self-management program was the opportunity to self-identify problems and health goals based on their own care needs. This intervention supports the importance of individual participation in setting and attaining goals.

Rockwood and colleagues (1992, 1993) noted that goal attainment was a sensitive measure of health status in frail older adults. Frail older adults often had multiple, complex, chronic problems; often a standardized plan of care was not sufficient to meet their needs. When personalized goals were introduced based on the older adult's self- identified health care needs, goals were viewed as more attainable.

Well-being. Rogerian theory conceptualizes well-being as a life process and a value (Rogers, 1970, 1990, 1994b). According to Rogers, health and illness are part of the same continuum. The multiple events taking place along the axis of life denote the extent to which people achieve maximum health potential, with health varying in its expression from greatest health to those conditions which are incompatible with maintaining life processes (Rogers as cited in Fawcett, 2005, p. 323).

Health is the synthesis of values, beliefs, and awareness, and is a way of life. Conceptually, the health outcome of well-being reflects the construct of health (Shearer, 2009). Well-being emerges through the health empowering process; a transformation which characterizes individual awareness of and ability to knowingly participate in the changes inherent in health and health outcomes (Shearer, 2009). Health empowerment reflects a mutual process between the practitioner and the individual for the purpose of promoting health and well-being.

Well-being in the research literature reflects two distinct types of psychological well-being; hedonic and eudaimonic (Ryan & Deci, 2001: Vanhoutte, n.d.; Waterman, 1993). Hedonic well-being is associated with pleasure, contentment, and avoidance of physical or psychological discomfort (Ryan & Deci, 2001; Waterman, 1993). The measure most often associated with this perspective on well-being is life satisfaction (Vanhoutte, n.d.). Eudaimonic well-being includes self-appraisal, developing one’s self, and realizing potential; the ability to effectively manage one’s life; purpose in life and the presence of social ties (Ryff & Keyes, 1995). Eudaimonic well-being more closely reflects the constructs of health empowerment theory and the outcome of the health empowering process (Shearer, 2009).

Friedman and Ryff (2012) explored the relationship between multiple chronic conditions and both hedonic and eudaimonic psychological well-being in older adults. Life satisfaction (hedonic well-being) declined with an increasing number of chronic conditions; neither purpose in life nor a positive relationship with others was significantly associated with number of chronic conditions. The authors suggested that a eudaimonic sense of purpose and strong social relationships were predictive of improved well-being in older adults with multiple chronic conditions.

Anaby and colleagues (2011) studied the unique contributions of personal and social contextual resources as influencing participation in activities to support well-being in older adults with multiple chronic illnesses. The authors concluded that social support and satisfaction with participation positively contributed to the older adult's well-being. Nyqvist, Forsman, Giuntoli, and Cattan (2013) also explored the effects of personal and social contextual resources on well-being in older adults through a systematic literature review. Their review supported the role of social and contextual resources in promoting well-being in older adults, emphasizing the importance of relevant current and past experiences.

Health Empowerment: Self-Care in Older Adult Informal Caregivers

The medical needs and support of care recipients during the caregiving trajectory have been studied for over a decade (Araje et al., 2008; Coleman, Parry, Chalmers, & Min, 2006; Howell, Silberberg, Quinn, & Lucas, 2007). The majority of caregiving interventions emphasize psychosocial health deficits of caregivers, particularly among those caring for persons with a cognitive impairment. While there has been attention to self-care processes among chronically ill persons, little is known about the self-care activities to promote well-being in the context of caregiving (Martinez-Marcos & De la Cuesta-Benjumea, 2014; Schulman-Green et al., 2012). Self-care promoting well-being is complex and may change over time and across experiences. Research exploring self-care promoting activities among informal caregivers suggests that self-care is multifaceted, and requires an individualized approach based on the values, beliefs, and experiences of the caregiver (Anderson & Funnell, 2010; Arvidsson, Bergman, Arvidsson, Fridlund, & Tingsrtrom, 2012; Leenerts, Teel, & Pendleton, 2002; St-Cyr Tribble et al., 2008).

Jones and colleagues (2011) tested a health empowerment model which consisted of health empowerment, stress, and meaning-focused coping to promote positive outcomes among caregivers. Intervention critical inputs addressed personal and social resources, caregiving demands, filial demands, and appraisal of the caregiving situation. Outcomes include perceived health, personal growth and well-being. The authors noted that most research focused on positive caregiver outcomes is not based on well-defined theoretical perspectives, compared to research evaluating negative outcomes of caregiving. Chadiha and colleagues (2004) suggest two theoretical models designed to empower caregiving in African America informal caregivers, including stress/coping and empowerment. The authors offer three strategies to support women in caregiving, which include raising critical consciousness through storytelling, teaching problem-solving, and fostering advocacy skills to mobilize internal and external resources. Shearer's (2004) view of health empowerment is not defined by disease or boundaries of health, as health is conceptualized as defined by the individual and their perception of what health means to them.

Martinez-Marcos and De la Cuesta-Benjumea (2014, 2015) explored self-care among female caregivers with chronic illness. Themes that emerged included self-regulating treatment by balancing available resources without neglecting the care of the care recipient, maximizing their strength by reprioritizing tasks that need to be completed while managing personal and social resources, and managing emotions. Bull (2014) used a mixed method design to explore approaches used by caregivers of persons with dementia to sustain their own self-care and promote well-being. Emerging themes included drawing on past experiences, nourishing the self (self-care activities) to restore or maintain energy, and spirituality. Social support has also been shown to positively affect well-being in caregivers (Bull, 1990). Janevic and Connell (2004) explored the role of social support promoting physical activity among older adult caregivers of persons with dementia. Themes emerged including verbal and tangible support in performing physical activities. Barriers included not have support and being concerned about leaving care recipient alone. Durcharme and colleagues (2006) explored self-care among older adult caregivers, reporting that greater support (social interactions and perceived support) led to increased self-care activities, as well as increased awareness and self-capacity to seek and accept help. Popejoy (2011) explored the hospital discharge process and its effects on older adults and their caregivers.

Themes generated specific to the self-care needs of the caregiver included advocacy in the process of going home and a lack of community resources.

In a systematic review of physical activity interventions promoting self-care among informal caregivers, Lambert and colleagues (2016) note the positive effects of group-based interventions. Their review found that physical activity interventions could have a beneficial effect on caregivers' psychosocial outcomes and physical activity levels; however, the potential of physical activity interventions to enhance caregiver self-care has only recently been acknowledged.

There has been much discussion regarding the need to empower older adults to make informed health decisions (HHS, 2007) and to test interventions targeting empowerment to promote health among older adults (DeCoster & George, 2005; Keller & Fleury, 2000). An empowerment approach may nurture an older adult's participation in healthcare decisions and promote positive health outcomes (HHS, 2007; Toofany, 2006, 2007). Further research is needed to explore older adult caregiver self-care promoting well-being based on their individual perspectives, goals, and experiences. The Theory of Health Empowerment provides a relevant approach to exploring strengths and resources for the older adult caregiver to engage in self-care promoting well-being (Acton, 2002; Jones et al., 2011; Ostwald, 2009). Theory provides a framework to guide research, assist in choosing the appropriate methodology, as well as frame data collection, analysis and interpretation (Charmaz, 1990; Sandelowski, 1993). Using a theoretical framework for descriptive qualitative research provides clarity in determining key concepts and relationships in study design (Miles & Huberman, 1994).

Summary

There are gaps in the literature regarding self-care promoting well-being in older adult informal caregivers (Borthwick, Newbronner, & Stuttard, 2009; Bull, Maruyama, & Luo, 1995; Popejoy, 2011). Research has focused on a disease or condition of the care recipient, most often Alzheimer's/dementia or at the end of life (Brouweret al., 2004; Guo, Phillips, & Reed, 2010; Han & Haley, 1999; Harding & Higginson; Schulz et al., 2002; Washington et al., 2011; Wolff & Kasper, 2006). Personal and social contextual resources central to self-care promoting well-being among the older adult informal caregiver have not been adequately addressed. The Theory of Health Empowerment provides a strong foundation for exploration of the experiences of the older adult caregiver emphasizing awareness of the ability to knowingly participate in self-care promoting well-being.

CHAPTER 3

METHODOLOGY

This chapter introduces the research design and methods used. A qualitative descriptive approach was used in this research. An overview of qualitative descriptive design methods used in this study is presented. Discussion of the setting and participants, research protocol, protection of human subjects, data analysis and approaches to rigor and trustworthiness are addressed.

Research Design

Qualitative research allows for the discovery of personal knowledge, fostering reflection on personal experiences (Sandelowski, 2004). Qualitative description is grounded in the general principles of naturalistic inquiry, providing a "comprehensive summary of an event in the everyday terms of those events" (Sandelowski, 2000, p. 336), making no attempt to manipulate or control outcomes. Cronin and colleagues (2014) note that the purpose of qualitative descriptive design is to describe phenomenon of interest, incorporating a broad range of questions pertaining to experiences, knowledge, attitudes, beliefs, feelings, perceptions, values and viewpoints. Qualitative descriptive design allows researchers to remain close to the communicated words and events, allowing for a rich, unfiltered description of experience (Sandelowski, 2000).

Qualitative descriptive design employs multiple methods to gather data which provide different views into the human experience (Thorne, 2008, 2011). The research design encompasses a variety of approaches to generate information specific to a phenomenon of interest, including focus groups, individual interviewing, participant observation, or gathering of documents or artifacts (Sandelowski, 2000, 2010).

Within qualitative descriptive design, a theoretical framework may be used to frame a problem of interest, as well as guide approaches to data collection and analysis (Sandelowksi, 2010). Theoretical frameworks serve as organizing structures for research design: sampling, data collection, analysis, and interpretation (Sandelowski, 2010). Features of the qualitative descriptive approach include: (a) choices of theoretical perspective, (b) varied sampling approaches, (c) the use of structured interview or focus group questions, (d) content analysis and descriptive statistical analysis as data analysis approaches, and (e) a descriptive summary of the data organized in a way that best fits the data (Sandelowski, 2000, 2001, 2010). Using a theoretical framework to guide data collection and analysis differs from approaches of grounded theory and ethnography, which approach data collection assuming that the collection template is a tabula rasa.

The Theory of Health Empowerment guided this research, providing a conceptual lens focused on recognition of strengths and purposeful participation in self-care for older adult informal caregivers, promoting well-being (Shearer, 2011).

Research Methods

Sample and Setting

Approaches to sampling determine the types of conclusions that may be drawn from qualitative research (Miles, Huberman, & Saldana, 2014). Qualitative descriptive methods foster a variety of sampling techniques. The study used a purposive sampling approach; recruiting caregivers with diverse characteristics allowed for both variability and common patterns in the data generated (Miles & Huberman, 1994; Sandelowski, 1995). Twenty-four adult informal caregivers expressed interest and were screened for eligibility. Three eligible participants withdrew in advance of focus groups. The sample included adults self-identified as an informal caregiver for an older adult care recipient. Participants had varying lengths of time in the caregiving role, ranging from one year to greater than ten years. Participants provided care to recipients with a variety of chronic conditions, including Parkinson's disease, Dementia/Alzheimer's, heart disease, cancer and COPD.

Contemporary caregiving research has typically focused on females, moderate to long-term caregivers, and caring for persons with cognitive impairment disorders (Gitlin, 2012; Naylor; 2012; Stevens, 2012). This study addressed the need for research which reflects diversity in caregivers, acknowledging that the caregiving role may start much earlier than currently thought, that greater numbers of males are providing care, and that caregiving encompasses a wide array of conditions (Gitlin, 2012; Naylor, 2012). In this study, purposive sampling was expanded to include the perspective of those caring for parents, prompting a revision in inclusion criteria for age. This age modification was approved through the Arizona State University IRB (see Appendix A).

Participants were recruited through Duet Partners in Health and Aging, a non-profit community agency serving the greater Phoenix metro area. The agency promotes health and well-being through its broad range of services to older adults. Participants were recruited from caregiving support groups affiliated with this agency within the greater Phoenix area; older adult caregivers attending Duet are representative of the larger caregiver population (see Appendix B).

Duet Partners in Health and Aging serves a majority of women caregivers (88.3%), aged 60 and older (88%), and Caucasian (90.8%). The majority of caregivers are spouses (54.55% women; 18.2% men) and have provided care for various lengths of time. Thirty-six percent of self-identified caregivers have been in the role for two years or less (11.5% less than one year). Care recipient conditions include Alzheimer's/Dementia (48%), followed by Parkinson's (32.7%) and other (19.2%).

Inclusion criteria include self-identified older adult informal caregiver living independently, 45 years and older who can speak and understand English. The criteria for inclusion were:

- Self-identified informal caregiver, age 45 years and older, providing care to a care recipient 60 years and older
- Speak and understand English
- Willing to participate in 60-minute focus group
- Provide informed consent to participate in focus group discussion

Protection of Human Subjects

Institutional Review Board (IRB) approval for study was obtained through Arizona State University (Appendix C). All ethical standards in regards to informed consent and the right to withdraw from the study were upheld. Participants were assured of confidentiality and privacy regarding their identity and participation in the focus groups (Appendix D). Participants were informed they may leave the focus group at any time, without negative consequence. Disclosure was provided before the focus group activity commenced reminding participants that all statements made would be used for study purposes and confidentially would be maintained at all times.

Participants were informed that there should be minimal psychological or social discomfort while attending focus group sessions. Participants may experience benefit from the opportunity to share personal experiences during the focus group sessions. Every effort was made to safeguard the privacy and comfort of the participants. Participant description of their experiences was not stored with any identifying labels, and codes were used to replace names. At the completion of the focus group, a small monetary "gift card" was provided as a way of thanking the participants for their willingness to participate.

Procedures

Recruitment. Recruitment flyers inviting participation in the research were distributed at community agencies serving older adult informal caregivers within the greater Phoenix area (Appendix D). Directed participant recruitment efforts included presentations regarding the research at community agencies serving older adult informal caregivers. Investigators presented the study before and after scheduled events.

After explaining the study purpose, methods, and assurance of confidentiality, informed consent was obtained from those meeting eligibility criteria, and who were willing to participate (Appendix E). A brief questionnaire was distributed requesting demographic information (age, gender, ethnic group identification, number of years of education), length of time the caregiver has been providing care, health conditions of the caregiver, and health conditions of the care recipient (Appendix F).

Data collection. In qualitative descriptive research, data collection attempts to discover the "the who, what and where of events or experiences" (Sandelowski, 2000, p. 338). A focus group approach was used to explore caregiver recognition of personal and social contextual resources, and purposeful participation in self-care activities to promote well-being, consistent with the health empowerment theory (Morrison-Beedy, Côté-Arsenault, & Fischbeck-Feinstein, 2001; Neergaard et al., 2009). Data collection for this study included focus groups in groups of four to six older adults and used open-ended questions to guide discussion. As data were collected through focus group interviews, open-ended introductory questions were used, followed by targeted questions exploring concepts consistent with the Theory of Health Empowerment.

A focus group approach is appropriate as a way to generate rich and diverse data. Group discussion encourages the participants to share experiences in their own words. "The most important characteristic, however, is the nature of the group itself as expressed through the interaction of the members, the flow of discussion, and the evolution of the experiences described" (Carey, 1994, p. 227). Although focus group size identified in the literature can vary from five to twelve, it is suggested that for older adults, smaller groups of four to six be considered (Cary, 1994).

Focus groups began with semi-structured, open-ended questions to gain insight into caregiver self-care (Morrison-Beedy et al. 2001). The Theory of Health Empowerment provided a conceptual lens to frame the focus group questions. Table 1 outlines the links between the focus group questions and concepts within the health empowerment theory. Open-ended questions allowed the investigators to reframe the discussion with participants when particular concepts or issues needed further exploration.

Table 1

Questions that Link to Each Health Empowerment Theory Concept

Health Empowerment Concept	Focus Group Question
Recognition of Personal and Environmental Resources	How have you managed thus far in your role as a Caregiver?
	Tell me about a time when you felt strong in your role as a Caregiver?
	During this time, what personal or environmental strengths did you draw on?
Purposeful Participation in Attainment of Health Goals	As a Caregiver, tell me about a time you consciously placed yourself first?
	During this time, what resources (environmental and personal) did you draw on?
Well-being	As a Caregiver, how do these resources (environmental and personal) promote well-being?

Focus groups were audiotaped, and later transcribed to be used for data analysis. Written field notes captured behavior and non-verbal interactions during each session. Investigators moderated the focus group sessions. Laura Blank led focus groups, while Dr. Fleury observed non-verbal behavior and recorded field notes and key quotes. Focus groups were held in accessible community centers at a time convenient for participants; sessions included snacks and beverages. Immediately following each focus group session, a debriefing occurred between the investigators to reflect on the session and to identify patterns, similarities, themes, and differences, per Miles and Huberman (1994).

Data Management

Participants recruited for the research study were assigned a pseudonym. The pseudonym was not linked to any identifiable information including telephone contacts or demographic questionnaire. During the focus group, the assigned pseudonym was used for field observations, interactions and quotes. Raw data (including contact information and signed consent forms) were protected in a secure, locked file cabinet.

Voice recording from the audiotaped focus group sessions were converted to a written transcript of the session via an audio-transcription device. Recordings were uploaded to a professional transcription service via a password protected website. The transcription service, Landmark Associates Qualitative Research, is certified, and all transcribers signed confidentiality disclosure forms. Verbatim transcripts were converted to Microsoft (MS) Word files. The accuracy of the transcriptions was verified by the investigator by comparing recordings to transcriptions. Any discrepancies were noted and corrected. The transcripts of the focus group sessions, written content analysis and the original audio recordings were stored in a locked file cabinet.

All computerized digital audio recordings, transcribed data and field notes were maintained on a password-secured computer accessible only to Dr. Fleury and Laura Blank. The audio recordings for the focus group sessions were deleted and destroyed once they were transcribed and verified. No information that could disclose participant personal identification will be released or published.

Data Analysis

Each transcribed document was formatted with wide right margins, to allow the investigator to apply codes and generate marginal remarks by hand. Marginal remarks are handwritten comments entered by the investigator, representing an attempt to form ideas and reflect on the meaning of the data. Marginal remarks may suggest new interpretations and connections within the data (Miles, Huberman, & Saldana, 2014).

Qualitative content analysis is proposed as the research method to analyze narrative data through the process of coding and identifying themes, or patterns, in the data (Hsieh & Shannon, 2005). Research using qualitative content analysis focuses on the characteristics of the language used by participants, with attention to the content or meaning of the text. Data analysis in this research followed a directed approach to qualitative content analysis. The goal of a directed approach to content analysis is to validate or extend conceptually a theoretical framework or theory. Existing theory or research is used to focus the approach to data collection (Hsieh & Shannon, 2005). The basic coding process in qualitative content analysis is to organize text into meaning units (Weber, 1990). Categories include groups of meaning units expressed or derived from the text, with relationships among categories identified.

In the coding process, a coding scheme is used to guide decisions in the analysis of content. A coding scheme includes the process and rules of data analysis that are systematic, logical, and scientific. As analysis proceeds, additional codes are developed, and the initial coding scheme is revised and refined. A coding manual containing a beginning list of codes derived from the health empowerment theory and related literature guided initial coding (Hsieh & Shannon, 2005) is presented in Table 2. Codes reflect action-oriented words or labels assigned to meaning units, or segments of text that contain a single idea. In coding narrative data, meaning units which are conceptually similar are grouped together (Hsieh & Shannon, 2005).

Table 2

Coding Manual

Construct	Concepts	Operationalization
1. Person-Environment Process	1A personal resources	Self-capability building Reinforce Strengths
	1B Social contextual resources	Social Network Building Building Social Service Utilization
2. Health Empowerment	2A Personal growth	Promoting change by acknowledging personal strengths and potential
	2B Self-acceptance	Positive attitude toward self, acknowledging good and bad qualities
	2C Purpose in life	Goals in life, feels life has meaning
	2D Social support	Positive relations with others
	2E Social services utilization	Utilization of community and social service resources
3. Purposeful Participation in Goal Attainment	3A Awareness	Being aware of choices
	3B Choices	Making choices freely and intentionally
	3C Creating Change	By being aware and making choices, creates change
	3D Individual health goals	Individual meets own self-determined health goals
4. Perceived Well-being	4A Self-care activities	Awareness and willingness to engage is self-care activities
	4B Well-being	Well-being relational to the person-environmental process

(Adapted from Shearer, Fleury & Belyea, 2010)

Data from the transcripts were placed into a template allowing for each sentence or thought to be numbered for easy reference and coding. Each transcript was formatted using a color-coded system, reflecting the concepts of the health empowerment theory. Coding began as soon as the written transcripts were available. The investigator re-read the transcripts, writing memos and using the color-coded schematic based on initial impressions (Hsieh & Shannon, 2005). The concepts of the health empowerment theory were explored as initial meaning units; theory-based operational definitions for each concept guided coding decisions.

The investigator examined sentences or paragraphs in the transcripts and divided them into meaning units. Codes were applied to each meaning unit during first level coding, which is descriptive in nature (Colorafi & Evans, 2016). Conceptually similar codes were organized into categories through revisiting the health empowerment theory framing the study. Data that could not be coded according to the health empowerment theory were identified and analyzed to determine if they represent a new category or a subcategory of an existing code.

Corbin and Strauss (2015) outline a technique that includes growing a list of codes, then applying a more abstract label to the code, creating new categories of codes with each revision (Colorafi & Evans, 2016). This reflects second level or pattern coding, an approach to grouping data into a smaller number of categories. During the analysis of these data, patterns were generated, with the Investigators exploring different codes, asking questions of the data, and evaluating relationships within the data. A reflective iterative process was used as pattern codes were revised and redefined. Table 3 provides exemplars clarifying the meaning of the codes in the personal resources concept in the health empowerment theory.

Table 3

Personal Resources Exemplars

Concept	Operationalization	Exemplar Quotation
Promoting change by acknowledging personal strengths and potential to increase self-capacity.	Recognition of personal strengths and potential. Recognition of self-capacity enhances problem-solving and making meaningful changes to promote well-being.	*"The strength comes from – I've had lots of things go on in my life that have required a great deal of strength and resilience."* *"I've never been afraid of tackling anything or handle anything, or if I didn't know how I'd find a way."* *"I think I draw on the fact that, you know, I got through that and I can get through this."* *"I'm willing to tell my story. I think that's a strength."* *"I think something you have, and I always enjoy it, is a sense of humor. I think that' a strength that can get a lot of people through these things."* *"Prayer and being thankful for what I do have and what went on. Every night I would say a prayer and thank the Lord for what happened that day, no matter how small or how large it was."* *"Prayer, a lot of prayer, a lot of arguing with God."*

Analytic memos provided a narrative documenting reflections and thinking processes about the data. Memos included personal, methodological, or substantive thoughts and questions. Memos were used throughout data collection, continuing through analysis.

The outcome of qualitative content analysis is a descriptive summary of the data organized in a way judged to best fit the data (Sandelowski & Leeman, 2012). The findings from a directed content analysis offer supporting and non-supporting evidence for a theory (Hseish & Shannon, 2005). These findings are presented in Chapter 4 by sharing codes and data categories with exemplars, and by offering descriptive support. The Theory of Health Empowerment and related research guided the presentation and discussion of the findings. Newly identified categories may offer a contradictory view of the health empowerment theory in promoting self-care among older adult informal caregivers, as well as further refine, extend, and enrich the theory. The descriptive summary will focus on the extent to which participant experiences in self-care paralleled the health empowerment theory, as well as the newly identified concepts or processes that were experienced by participants in the study.

Methodological Rigor

Qualitative description is grounded in naturalistic inquiry, which reflects truth as "a systematic set of beliefs, together with their accompanying methods" (Lincoln & Guba, 1985, p. 16). Using qualitative descriptive methods, the investigator studies something in its natural state and does not attempt to manipulate or interfere with the unfolding of events, fostering "true understanding" (Colorafi & Evans, 2016). Criteria to ensure the trustworthiness of conclusions are guided by approaches to objectivity, dependability, credibility, and transferability (Lincoln & Guba, 1985; Miles, Huberman, & Saldana, 2014).

Objectivity or confirmability of conclusions in qualitative content analysis reflects freedom from bias and was addressed in this study through: (a) providing detailed description of methods and procedures, (b) providing verifiable steps in data collection and analysis, and (c) debriefing between investigators to minimize potential bias, including attempts to disprove conclusions drawn from data. The directed approach to qualitative content analysis using the health empowerment theory has limitations, in that the investigators approach the data with an informed bias (Hsieh & Shannon, 2005). Throughout the research process, Investigators maintained close and consistent contact. Both Investigators were present during six of the eight focus groups, allowing sharing of written field notes, observations and debriefings. In the two focus groups with one Investigator present, debriefing and sharing observations occurred the next day. Review of written transcripts were coded individually and then shared, providing verifiable steps in data collection and analysis. Differences in coding and meaning were discussed and reconsidered, resulting in consensus. During this ongoing process, themes and shared conclusions were developed, both consistent with, and extending concepts of the health empowerment theory, until data saturation occurred. The audit trail included shared field notes, observations, data reduction and reconstruction methods, recorded audio tapes, and written transcripts of focus groups.

Dependability reflects aspects of reliability, and was addressed in the research by: (a) deriving focus group questions based on the health empowerment theory, (b) developing a coding manual to guide data analysis, including defined codes derived from the theoretical framework and relevant literature (Hsieh & Shannon, 2005), (c) ensuring consistency in data collection methods across focus groups, (d) monitoring data analysis and interpretation through an audit trail and investigator review of data codes and categories, and (e) sharing analytic memos exploring data meaning, coding and patterns throughout the research process. As noted above, study procedures were clearly outlined and consistent with the health empowerment theory, so that data analysis could be linked back to theoretical constructs. Data collection was standardized for all participants, with focus group questions based on theory, and a coding approach derived from the theoretical framework. Data analysis and collection occurred simultaneously, allowing exploration and revision of both the data and the approach to coding.

Credibility, characterized as objectivity or truth value, promoting evaluative understanding, was addressed through: (a) exploring data interpretation with researchers familiar with the health empowerment theory, (b) linking findings to the health empowerment theory, and (c) Investigator following each focus group, to ensure a comprehensive account of the data.

Transferability speaks to the extent to which findings have application to other populations and settings and was addressed in this study by: (a) fully describing the characteristics of the participants, allowing comparison with other groups, and (b) presenting findings that are congruent with the health empowerment theory.

Summary

This chapter described the research study including design, sampling, procedures, data collection and analysis, and maintaining rigor and trustworthiness. Qualitative descriptive design provided an excellent approach to generate new insights on older adult informal caregivers’ self-care activities to promote well-being, framed within the Theory of Health Empowerment.

CHAPTER 4

FINDINGS

This research explored the recognition and engagement of personal and social contextual resources fostering purposeful participation in self-care among older adult informal caregivers. The Theory of Health Empowerment (Shearer, 2011) provided the conceptual framework guiding the qualitative research. In Chapter 4, the results of the qualitative descriptive analysis are presented. This chapter will: (a) describe the research participants, and (b) present the findings and interpretation of qualitative descriptive content analysis through the conceptual lens of the health empowerment theory.

Participant Demographics

The participants in this study included 21 English speaking adults, self-identified as informal caregivers, and recruited from caregiving support groups affiliated with Duet Partners in Health and Aging, a non-profit community agency serving the greater Phoenix metro area. All participants resided within the greater Phoenix metropolitan area.

Purposive sampling was used in this research to recruit a diverse sample of participants, including caregivers experiencing various lengths of time in the caregiving role, men who self-identified as caregivers, and those caring for older adults with a diagnosis other than Alzheimer's disease or dementia. Participants ranged in age from 46 - 83 years old (mean age = 71.8 years, *SD* = 10.0). The sample included 16 (76%) women and 5 (24%) men. Forty-three percent of self-identified caregivers had served in the role for between five and nine years; nineteen percent reported serving for less than five years. The majority of caregivers were caring for a spouse (76%). Sixty-seven percent of the caregivers reported their health as good, thirty-three percent reported their health as fair, and none reported their health as poor. All of the care recipients were 60 years and older (mean age = 80.4 years, *SD* = 8.1), with conditions including Alzheimer's/Dementia (19%), Alzheimer's/Dementia with other conditions (38%), Parkinson's (29%), and other (15%). Table 4 displays the demographic characteristics of the participants and Table 5 displays the characteristics of the care recipients.

Table 4

Demographic Characteristics of the Caregiver Sample

Caregiver Characteristic	*n* (%)	Range in Years	*M (SD)*
Gender			
Male	5 (24)		
Female	16 (76)		
Age			
Male		47-83	68.8 (13.4)
Female		46-82	72.7 (10.6)
Total		46-83	71.8 (10)
Years of Education	21 (100)	12-20	16.3 (2.5)
Race/Ethnicity[1]			
White, Non-Hispanic	17 (81)		
Hispanic	2 (9.5)		
Native American Indian	1 (4.8)		
White, Hispanic	1 (4.8)		
Self-Rated Health Status			
Good	14 (67)		
Fair	7 (33)		
Poor	0		
Years in Caregiving Role			
1-4 years	4 (19)		
5-9 years	9 (43)		
10 years or more	8 (38)		
Number of Caregiver Health Conditions			
None	5 (4)		
One	9 (43)		
Two or more	7 (33)		

Note: Sample size: *n* = 21.

[1] Percents do not sum to 100 due to rounding.

Table 5

Demographic Characteristics of the Care Recipients

Care Recipient Characteristic	*n* (%)	Range in Years	*M (SD)*
Gender			
Male	13 (62)		
Female	8 (38)		
Relationship to Caregiver			
Spouse	16 (76)		
Parent	4 (19)		
Sibling	1 (5)		
Age			
Male		66-91	80.5 (6.7)
Female		68-93	80.3 (10.6)
Total		66-93	80.4 (8.1)
Race/Ethnicity			
White, Non-Hispanic	19 (90)		
Hispanic	1 (5)		
White, Hispanic	1 (5)		
Care Recipient's Health Condition			
Alzheimer's/Dementia	4 (19)		
Alzheimer's/Dementia and Other Conditions	8 (38)		
Parkinson's Disease	6 (29)		
Arthritis	1 (5)		
COPD	1 (5)		
Frailty	1 (5)		

Note: Sample size: *n* = 21.

Theory of Health Empowerment

The theory of health empowerment guiding this research is a middle range theory based on Rogers science of unitary human beings principle of integrality; human beings are in continuous interaction with their environment, reflected through pattern, self-organization, diversity and innovation, and reflecting individual values and beliefs (Rogers, 1992; 1994). Health empowerment is viewed as a dynamic health process, which emphasizes purposeful participation in a process of changing oneself and one's environment, recognizing pattern, and engaging inner resources for well-being (Shearer & Reed, 2004; Shearer, 2007, 2009). Shearer (2009) emphasizes recognition of and engagement in personal and social contextual resources to purposefully participate in the attainment of health goals, thereby promoting well-being. The Theory of Health Empowerment emphasizes a focus on strengths as including personal and social contextual resources (Shearer, 2004).

The Relational Process of Health Empowerment

Health empowerment is conceptualized as a relational process, emerging from the recognition of personal resources and social contextual resources (Shearer, 2009). Person and environment are in mutual and continuous exchange of matter and energy and affect each other in the process. Empowerment is an ongoing process of change that is continuously innovative and evolving. An empowerment perspective fosters understanding of caregivers purposefully participating in the attainment of personal goals for self-care, thus promoting well-being. In this research, older adult caregivers partnered with researchers to explore health empowerment within the context of their personal experiences and environmental resources.

Personal Resources

Older adult caregivers reflected on the experience of health empowerment within the context of personal and social contextual resources. Older adults shared personal strengths and experiences which fostered purposeful participation in self-care. Personal resources included past experiences and knowledge, awareness, choices, and freedom to act intentionally (Shearer, 2009). Personal resources were reflected in processes of change and growth, as a recognition of strengths. As the recognition of strengths may continuously change, access to personal strengths may reshape the world for caregivers, providing new meanings and relationships that foster health empowerment. In this study, informal caregivers shared personal resources promoting self-care as acknowledging strength, seeking solace, and opening to potential.

Acknowledging strengths. Reflections on the past guided the acknowledgement of strengths in the caregiving role. The strengths and experiences of older adults were valued and freely shared during the focus groups. Caregivers reached back through their memories, recalling past strengths as providing a path for moving forward in the caregiving role. Participants recalled meaningful experiences when they felt able to change, remembering the richness of their past in order to reconcile and enrich their changing experiences. Participants noted that they recognized strengths both by sharing their stories and hearing the stories of others.

Acknowledging strengths for older adult caregivers included the view that they were strong individuals, had a purpose in life, and were protectors and caregivers to their family.

> *"The strength comes from – I've had lots of things go on in my life that have required a great deal of strength and resilience."*

> *"I've never been afraid of tackling anything or handle anything, or if I didn't know how I'd find a way."*

> *"I think I draw on the fact that, you know, I got through that and I can get through this."*

Seeking solace. Seeking solace emerged as opportunities for comfort and inner strength, including approaches to life, such as humor, religious faith, spirituality, and participation in prayer, blessing rituals, and church attendance. Solace was found from within the caregiver, as well as through reaching out to others. Sources of solace represented a "sheltering rock" to lean on in times of fear, sadness, and exhaustion. Solace as strength prepared older adults to face an unknown future and strengthened their ability to persevere despite many challenges in the role of caregiver.

> *"I think something you have, and I always enjoy it, is a sense of humor. I think that is a strength that can get a lot of people through these things."*

> *"Prayer and being thankful for what I do have and what went on. Every night I would say a prayer and thank the Lord for what happened that day, no matter how small or how large it was."*

> *"I always made time for meditation, prayer"*

Opening to potential. Participants' spoke of the need to incorporate previous and new ways of being; constructing a new sense of who they were in the role of caregiver, reflective of their own beliefs and strengths. While some struggled in this process, others spoke of a rewarding sense of discovering resilience and inner strength, despite adversity. Caregivers acknowledged growth through the knowledge and skills gained in caregiving, and a sense of purpose derived from providing care. For many, caregiving represented a transformation from their former selves, fostering a redefinition of values and priorities in light of their new role. Caregivers moved beyond the belief that life had to be a certain way, fostering a perspective that supported their ability to adapt to change, and embracing life changes as including growth and meaning.

> *"You can learn from any situation. You may not always want to learn what you're learning, but really, I can't change the situation."*
>
> *"What is it I am supposed to learn from this experience? I think that it's very important."*
>
> *"Letting go of your own way. One of the hardest things to let go of is to having your own way."*
>
> *"Realize that your life is changing. You can fight it, or you can understand how to make the best of it."*
>
> *"You know, I pretty much accepted it. I'm understanding that there's going to be changes. I can either fight it or not accept it, or really work together. I think that would make our lives much better as we move forward."*

Social contextual resources. Empowerment is a relational process, expressive of the mutuality between the person and their environment. The concept of environment within the health empowerment theory reflects social contextual resources, reflecting supportive relationships, opportunities for nurturance, and the exchange of information and materials to foster self-care and well-being.

Social contextual resources provide encouragement, which fosters health empowerment through availability and support in negotiating life changes. Support systems have been characterized as enduring patterns of attachment among individuals and groups that assist older adults in managing life challenges, difficulties, and transitions. Support provided information, feedback, and reinforcement as well as acknowledging and encouraging the open expression of feelings. Support included providing assistance in exploring options. Engaging socially in life took on new meaning for caregivers. Staying connected to the present encompassed socially engaging in life through family, friends, and other supportive persons.

Contextual resources were characterized as including both community and organizational structures. These structures included, but were not limited to neighborhood resources and clubs, senior centers, and social service organizations which provided resources as well as opportunities to remain physically and mentally active in the community and to create new and valued friendships. Through the use of supportive resources, strengths emerged. In this study, informal caregivers shared social contextual resources promoting self-care as connecting with others, bearing witness, and sharing strengths.

Connecting with others. Through connecting with others, the community served as a source of reinforcement, empathy, and assistance. Participants often turned to family members or friends for support relevant to health and well-being. Support included offers of assistance, as well as emotional and instrumental support.

Friends and family supported older adult caregivers by being available, and providing support related to caregiving. However, a number of older adult caregivers expressed a sense of isolation, with family members or friends not readily available or physically able to assist or provide support.

> *"I do have some wonderful supports that make a huge difference in my life."*
>
> *"Our family, I have the best neighbors in the world who are always there. Anything you need, just come call us."*
>
> *"Friends of mine had passed away, or they had moved out of town, or we had lost touch, or they were in worse physical shape than we were and were unable. I didn't know who I could ask."*
>
> *"I just thought, "Oh my gosh, you're more alone on a street than you think."*
>
> *"I contacted the Alzheimer's Association right away and found this support group that I have attended now all these years."*

Bearing witness. Bearing witness reflected the caregiving community serving as witness to the experiences and emotions of one another. Caregivers often felt isolated as friends or family withdrew due to progressive changes in the care recipient. However, caregivers were able to share similar experiences with one another, validating or bearing witness in happy and difficult times. Participants felt valued by their peers in sharing and honoring their personal history and accepted each other and what they had experienced in their life. This type of social resource allowed fellowship and laughter, even when caregiving was difficult. For many, sharing with peers allowed them to "bounce back" more quickly when responding to the challenges of caregiving. Caregivers found comfort in others experiencing the same situation, feeling a sense of community and support.

> *"I think socialization is such a gift to me of having people that I care about and care about me that I see effortlessly because of our situation."*
>
> *"I don't have any other friends outside of the Parkinson's group, and that is something that I have lost, and I really feel the loss sometimes."*
>
> *"We didn't have any [friends]. It took a long time to find them through the Parkinson's group, and really, since—it's only happened since we met you guys and started going to these other support groups."*
>
> *"It's kind of like it's a—disease is awful, but I can't imagine now not having my friend in my life and not having these people in my life that I know will be in my life no matter what, now."*
>
> *"That's how my soul gets nourished, with these women and men who are living what we are all living through now. I can't imagine not being friends with these people."*

Sharing strengths. Sharing strengths reflects the exploration of strategies and resources for managing the caregiving process and creating needed resources for self-care. The mutuality inherent in sharing strengths was a powerful source of support for participants. By discussing alternatives related to self-care and the caregiving process, participants became aware that they were able to participate in change and self-care decisions. Participants noted consistent acknowledgement and encouragement from others in realizing valued hopes for the future. Community and organizational agencies provided a forum for communicating and validating feelings, and promoted a sense of strength and possibility, fostering ability to participate in self-care.

> *"But it's somebody looking at me and saying, "Well, what do you think about this? Have you tried this? How did this work out for you when you did this, the next time we meet?" That kind of thing is where I get my strength from the group."*

> *"The most important to me [as a caregiver] in every aspect of my life, is having friends to talk to and to—friends that understand. No matter what problems we may have or what we're doing, we're pretty sure that somebody else will know where we are."*

Health empowerment. For older adult informal caregivers, health empowerment reflected a relational process emerging from the recognition of personal resources and social contextual resources (Shearer, 2011). Embedded within health empowerment was the recognition of new perspectives in personal meaning, values, and potential. This relational process acknowledges the caregiver's growth and acceptance of their complex role, seeking meaning and purpose in their lives. Health empowerment facilitated purposeful participation in self-care promoting well-being. In this study, the informal caregivers shared the process of empowerment in the themes of seeking meaning, living values, and accepting self, consistent with their personal values and beliefs.

Seeking meaning. For many, caregiving provided new opportunities to consider themselves, their relationships, and their lives, moving toward personal growth (Gibbons, Ross, & Bevans, 2014). Seeking meaning included an integration of new, potential, and past experiences, clarifying personal values, goals, and life purpose, and forming a basis for constructing new understandings. Seeking meaning was noted in the face of life changes, forming a basis for constructing new understandings.

For many, meaning was found in taking responsibility for the well-being of their loved one, and in providing them with care. Many expressed growing love and admiration, and an increased connection to their loved one. The love central to the caregiving process provided caregivers with strength, even while moving into the unknown. Caregivers spoke of a sense of directedness and meaning in their role, in which caregiving gave life purpose. For participants in this study, caregiving fostered a sense of meaning and satisfaction in reaching out to help others. This awareness and connectedness to the person-environmental process facilitated health empowerment among the older adult caregivers, fostering well-being (Reed, 1997a)

> *"For my mind, I've always thought of it [caring for mother], this is the circle of life."*
>
> *"I did for him what I would want someone else to do for me."*
>
> *"It's a very positive thing that came out of a very negative thing. We're both blessed for that."*

Living values. Living values among older adult caregivers involved continually developing and moving toward chosen goals. In the caregiving role, shifting priorities and values emerged, with caregivers reappraising life values and priorities in a lasting and meaningful way. One expression of this new perspective was "learning to value every day," an appreciation that was generalized beyond the care recipient, and into the caregivers' overall world view. Participants reflected on life goals and purpose in life; highlighting what was most important to them and the elements of their lives for which they were thankful, despite the loss they were experiencing. Older adults sought knowledge and experience consistent with maintaining purposeful participation in change and sought opportunities to live their values as they moved forward.

> *"Do I want to continue worrying about stuff like that, the peripheral stuff in life, where I really want to enjoy each day that we have together, and to really appreciate my family, and do things that we can do."*

> *"My role had to change if we wanted to continue to have a really open, loving relationship. I've worked very hard on that to understand."*

> *"Like I said, it's brought us closer together. Our relationship is the most important thing we have, I have. I think she'd say the same thing. It's pretty cool."*

Accepting self. Caregivers recognized that they had a choice to make about how to approach their caregiving role, choosing a positive attitude and determining to be happy about good moments when they occurred. Consistent with self-acceptance in change, many caregivers noted the role of keeping a positive attitude in providing care, acknowledging and accepting multiple aspects of themselves and their experiences, including both good and bad days. Participants spoke of their inability to change current circumstances, acknowledging the need to accept and grow within difficult situations. Participants reflected on positive thinking and reframing their experiences to promote a sense of comfort in their role; that they were "doing the best they could" during challenging times. In response to the uncertainty of caregiving outcomes, some caregivers develop spoke of the need to "determine a new metric for success in caregiving," which allowed them to be flexible in the face of ongoing changes within their own situation. This flexibility was useful in assisting the caregiver to find meaning and acceptance, forming a basis for constructing new understandings in the caregiving process (Boss, 2006).

> *"It's accepting the shortcomings you're trying to deal with and saying, 'I'm going to do the best I can. I may make a heck of a lot of mistakes, but I'm doing the best I can. That's all I can do."*

> *"Then I realize that I'm not perfect. I can't do that all the time. This is an unbelievable trying situation and I'm doing the best I can with what I have at this particular moment."*

> *"You're a failure because you've had a bad day, a bad week, a bad month.' She [mother] said 'everything you're doing is sufficient because you love me. In that you don't waiver. I had to agree. I don't resent caring for her. I don't second-guess caring for her. I thought 'Oh, I have to get a new metric for success. The metric is the love metric."*

Purposeful participation in change. Purposeful participation in change reflects the construct of health patterning, a dynamic, non-sequential process of participating in the attainment of personal goals for self-care, promoting well-being (Barrett, 1990; Shearer, 2009). According to Barrett (2003), it is through awareness of choices, freedom, and involvement that older adults purposefully participate in making choices for self-care. While the recognition of personal social contextual resources facilitated participation in self-care among older adult informal caregivers, awareness of choices, freedom to act, and involvement were often embedded in an uncertain future marked by loss and challenge. In this study, the informal caregivers shared the process of purposeful participation in change in the themes of reframing life plans, dwelling with uncertainty, acknowledging alternatives, reevaluating roles, and considering investment.

Reframing life plans. For participants in this study, assuming the role of caregiver represented an unexpected life transition. In light of the health concerns of the care recipient, caregivers were faced with reframing their life plans, their relationship with the care recipient, and their outlook for the future. Caregivers accepted a situation not of their choosing, purposefully participating in choices central to their own well-being and the well-being of the care recipient. Caregivers reflected on the ways in which their relationships and life plans had changed as a result of illness changes in the care recipient. Many experienced a loss of meaningful connection from their loved one as the condition progressed. Caregivers grieved what once was, and dreams lost, even while their loved one was still present. Participants struggled with the loss of comfort and companionship, and the parts of themselves unique to their relationship with the care recipient. The struggle to acknowledge and reconcile these losses was ongoing. Reframing life plans reflected an evolving process of recognition, awareness, and choice.

> *"At some level, implicitly, we accepted the change in the journey."*
>
> *"Not being able to share the little things that happened, a funny joke, a cartoon, something. Not being able to share the ever day, little things in life that – it's a lonely existence without being able to share moment to moment."*
>
> *"We don't have any humor at home anymore. We don't have any conversation. That's probably the harder thing, is the silence is deafening."*
>
> *"I think that's one of the saddest things. That you see people out with their spouses or their significant other and they are food shopping together – stupid little things, like the husband is going and picking up apples and the wife is over there getting pears. It doesn't happen anymore."*
>
> *"We used to love to dance, and that's one thing I really do miss, our whole – our courtship and our whole marriage, we always tried to do dancing. Now we are at totally different beats, and you can't dance with somebody when they are only on one when you are doing three beats and they're doing four, whatever. I miss that because that was a time we would be close together."*

Dwelling with uncertainty. For many caregivers, purposeful participation in self-care integrated the experience of dwelling with uncertainty. Caregivers acknowledged uncertainty as continuous and reflective of the caregiving process.

The expectation of certainty and predictability in everyday life were abandoned in light of constant changes and challenges to overcome. Uncertainty arose from changes in the care recipient, fears about disease progression, and an uncertain future. Caregivers anticipated that life would become more difficult due to decline in their loved one. By dwelling with uncertainty, caregivers expressed awareness and chose strategies and approaches which allowed them to move forward, with uncertainty integrated into their view of themselves and their role as a caregiver. In dwelling with uncertainty, many caregivers chose to avoid thinking about the future, choosing instead to focus on the present. The focus on the present provided an element of order or control, while the future was generally considered as being bleak and uncertain. A strategy used to manage the uncertainty of the future was avoidance of thinking too far into the future.

> *"A self-care goal for me is not thinking about the future. I'm not going to that place."*
>
> *"I try to live—I can't live in the future. I just can't think about that, because first of all, you don't know what it's going be. It's not going to be better, that's for sure."*

Acknowledging alternatives. Many caregivers found uncertainty as an impetus to action, allowing a new acceptance of multiple alternatives, choices and possibilities in enacting their role. Caregivers learned the importance of flexibility and began to re-evaluate the degree of control needed as important and meaningful, while appreciating the fragility of their situation. The effectiveness of medical intervention, or their own actions in caregiving, were appraised in terms of varying probabilities for success.

> *"She very well may end up in a wheelchair at some point, and then I thought, you know what, we will deal with that situation when we get to it".*

> *"The thought that things are either black or white. That they have beginnings and they have ends. That they have directions and they're going to have this kind of strategy and that kind of development, and then this is going to happen, and that's going to happen. We are so conditioned for that type of line or plot, if you will."*

> *"Linear thinking. It is very difficult, I think, for many people to develop that tolerance for ambiguity. We just don't know."*

Reevaluating roles. Emerging from uncertainty, while acknowledging the need to move forward, caregivers noted a disruption in roles and responsibilities, including care of the home, arranging appointments, and managing finances. Caregivers, particularly caregiving spouses, engaged in unfamiliar tasks as they took responsibility for activities previously fulfilled by the care recipient. The network of roles within the family changed, with husbands caring for wives and children caring for parents. Some caregivers struggled with a new role as primary decision maker in the household, noting limited awareness and choice to purposefully participate in change. For others, awareness and choice in learning and implementing new skills resulted in validation, pride, and increased satisfaction in their role.

> *"I think it's fair for me to say that one of the hardest things has been the inability of him to help with any more decisions as man and wife."*

> *"It's a reality check. If I don't do this, who is going to? Yes, it was a big step into the unknown."*

> *"The deal is, this is the first exposure to making your decisions without any input from the people or the person that's normally been the input person."*

> *"Being the one in charge I think is one of the harder things. Being the man of the house."*

> *"I think for a caregiver, particularly for someone like in my position where your wife is taking care of all this stuff, your wife has been the caregiver. Almost on an instantaneous moment, you become the caregiver. It's a total change. I had to step back and really analyze where I've been, and where I was now going."*

> *"All of a sudden, in this last year, I have discovered that now 100 percent that we used to share in keeping the home alive and all this thing, now is on my shoulders."*

> *"I felt very empowered, very, without him [spouse], without his input, without his help."*

> *"We drove away in our new car—in my new car. He has never driven it. It's in my name. It's also in the trust. I felt empowered. I really did."*

Considering investment. Many caregivers began in their role by assuming full responsibility for the care recipient and their home. Over time, caregivers began to recognize the extent of their commitment, and the difficulties of enacting responsibilities as the care recipient worsened. Caregivers struggled with choices to consider their investment in light of their own self-care and well-being. Considering investment as a caregiver included purposeful participation in choices to seek help, problem-solving and acknowledge uncertainty in order to live well.

> *"Realizing I have to set boundaries, realizing I have to actually physical and verbally ask others for help."*

> *"I feel one part of my acceptance has been – realizing I can't do it alone."*

> *"I just made the decision I needed to come right out and say I just can't handle it myself."*

> *"I called my daughter and I said, 'I need some help' and she responded. I've said it to my son, too, and he's responded, and my daughter-in-law. I really learned from that was the reason they weren't helping is because they saw me as very capable."*

Some caregivers noted that while they had resources they could access for help and support, they were reserving this help for a time later down the road, when this assistance would be greatly needed. Thus, caregivers strategically "banked" help and support anticipating a future time when they could call on resources.

> *"If I needed her I think she would be on the doorstep. At this point I'm pretty much handling everything myself, but things aren't very bad. I just have her in the bank, so to speak."*
>
> *"I don't call upon her very often for anything because I feel like I'm going to need her down the line, and I know she's there."*

Well-being. Health empowerment as promoting well-being represents a dynamic human health process. Well-being is generally defined as life satisfaction and harmony, with empowerment expressive of a human health pattern of well-being (Shearer & Reed, 2004). The caregivers reflected on the meaning of well-being to them, integrating approaches to self-care based on their personal values and beliefs and within the context of their caregiving role. In this study, the informal caregivers shared the process of well-being in the themes of becoming, integrating self-care, and relating.

Becoming. Caregivers in this study reflected on well-being as a process of realizing their own potential, both as an older adult and as a caregiver. Becoming involved developing and moving toward valued goals, with self-care reflecting the emergence of new and positive health patterns.

> *"My own health, take care of my own health so I can see my first granddaughter graduate from high school."*
>
> *"I'm having a new value for a quiet time – you know because even if you are with someone who is healthy, there is some degree of commitment on your*

> *part to care for them, to make entertaining conversation, to give them food, to whatever. This time apart is my new discovery.”*

> *“I think it’s important to remember, as you talk about feeding, not just with food, feeding your soul, your mind.”*

Integrating self-care. Integrating new, potential, and past experiences allowed valued approaches to self-care to be balanced with the caregiving role, in order to maintain or regain purposeful direction. Integrating reflected developing knowledge of what to do to maintain purposeful direction in engaging in self-care. Caregivers attempted to integrate self-care within their experiences of caregiving, in a way that made sense to them. Integrating self-care was described as establishing patterns where self-care becomes part of daily life patterns.

> *“I give myself permission to have slow days when Mom is at adult day health services, I just read the paper and relax and don’t worry about getting things done.”*

> *“I have my out, and that's my Thursday morning golf. Now, when I'm on the golf course, what is my concentration on? Hitting that ball. [Laughter] Putting that ball. You're not thinking about at home.”*

Relating. Relating is characterized by reciprocity and interdependence of caregivers with others as a form of self-care. Self-care is reflected as older adults give support to and receive support from friends, family, and social networks, and engage in social activities meant to heal.

> *“Because I care for a loved one who has dementia, I follow the advice very literally, that once a day, I talk to someone who is fully present, someone other than my mother.”*

> *“I got there [to dinner] – I gave myself permission that if I was going to go, I sure as hell might as well enjoy it.”*

> *"My friends would make sure that we would go out at least once a month and spend a good three hours or more and just enjoy. We knew that we just enjoyed ourselves so much going out and being able to talk."*

Summary

This chapter discussed the results of the descriptive qualitative analysis of older adult informal caregiver's awareness and engagement of personal and social contextual resources in purposeful participation of self-care through the conceptual lens of the Theory of Health Empowerment. The chapter included a description of the research participants (caregivers) and the care recipients. Consistent with the Theory of Health Empowerment, data themes were presented characterizing personal resources, social contextual resources, health empowerment, purposeful participation in change, and well-being.

CHAPTER 5

DISCUSSION AND RECOMMENDATIONS

This research explored the awareness about and the engagement of personal and social contextual resources in purposeful participation in self-care among older adult informal caregivers. The Theory of Health Empowerment (Shearer, 2011) provided the conceptual framework guiding this qualitative research. Chapter 5 provides a discussion of the research findings, both enriching and extending the Theory of Health Empowerment as experienced by older adult informal caregivers. Discussion of the research findings is presented consistent with the conceptual perspective of the Theory of Health Empowerment, including recognition of personal and social contextual resources, health empowerment, purposeful participation in change, and self-care promoting well-being. The Chapter concludes with a discussion of research contributions to nursing science, recommendations for practice, and directions for future research.

Theory of Health Empowerment

The National Institute of Nursing Research and the National Institute of Aging have advocated for research that includes the development of conceptual frameworks and methods for studying the work of caregiving and evaluating interventions to support the caregiver (Naylor, 2015). Despite these initiatives, research is lacking regarding self-care of the older adult caregiver, specifically their own self-care needs promoting well-being.

An empowerment approach to caregiver self-care emphasizes individual strengths and capacity in the form of personal and social contextual resources (Chadiha, et al., 2004; Shearer, 2011).

The Theory of Health Empowerment has been proposed as a relational perspective; the focus of care is on optimizing strengths and potential. The promotion of well-being reflects a developmental process acknowledging the mutual influences of the environment and person (Shearer & Reed, 2004). Health empowerment is viewed as a transformational process, facilitating awareness of the ability to knowingly participate in health and health care decisions (Shearer, 2009). This transformation occurs as the caregiver draws on their unique personal resources and the support of others and the environment.

Personal Resources

Personal resources are unique, multidimensional, and reflect individual values and beliefs. Recognition of personal strengths in growth and change enhances the ability to successfully problem solve, fostering self-care and promoting well-being (Shearer, 2007). Participants in this study shared rich descriptions of resources reflective of their own personal values and beliefs. Caregivers noted past experiences instrumental in recognizing inner strengths and ability to grow, promoting self-care. Participants acknowledged the role of encouragement from others, drawing on past experiences for strength, and the importance of being the protector of their families. Caregivers shared that these personal resources continued to change and evolve, reflecting new meanings and relationships, increasing self-capacity and problem-solving to engage in self-care. Emerging from the analysis of these shared experiences, themes were identified including: (1) acknowledging strengths; (2) seeking solace; and (3) opening to potential.

Through the focus groups, caregivers voiced how their past experiences and strengths enabled them to respond to the complex issues facing them due to the illness of the care recipient. Caregivers shared how important it was for them to be strong, not only for themselves, but for the care recipient. These strengths were embedded in meaning and purpose and reflected deeply held beliefs.

Acknowledging strengths is consistent with Shearer and colleagues (2006, 2007, 2009) research with older women. In each of these studies, acknowledging strength through past and current experiences, finding meaning and purpose within the context of their own beliefs and values were reported. These findings have been echoed by other researchers who have explored the impact of personal resources in relation to well-being (Bull, 2014; Donnellan, Bennett & Soulsby, 2015; Shim, Barroso, Gilliss, & Davis, 2013). Sharing past life challenges provided caregivers with strength and enhanced problem-solving skills (Bull, 2014; Shim et al., 2013), while shared expertise and insight acknowledged strength, value and purpose in life.

Seeking solace in older adult caregivers reflects recognition of personal strength through sources of connection and comfort when facing challenges. Through this connectedness, hope and strength emerged. Many of caregivers noted the role of humor, religion, spirituality, beliefs, prayer and church attendance in their ability to weather the everyday challenges of caregiving. The role of solace has been supported by researchers examining the relationships between religious and spiritual beliefs and practices and strength, meaning and purpose in life (Adams, Mosher, Cannady, Lucette, & Kim, 2014; Bull, 2014; Klass, 2013, 2014). Bull (2014) observed faith as a source of strength for caregivers, providing meaning and purpose in life. Adams and colleagues (2014) correlated caregiving and social support with spiritual well-being, noting positive benefits for the caregiver's overall well-being. Klass (2013, 2104) notes that solace, as being connected to a reality that transcends the self, can be pleasurable, bringing joy in the face of loss and despair. Peacock and colleagues (2010) noted the benefits of caregivers using humor as a safe way to express the difficult and challenging situations they were facing, finding comfort among others who shared common experiences. Shearer (2007) has reflected on the importance of reaching inward, building on personal strengths from past experiences, and outward, by seeking assistance from others, noting the participants were able to transcend self by engaging in life with purpose. Through the comfort and nurturing of one another, caregivers found solace to overcome obstacles and thrive in the face of an unknown future.

The majority of caregivers expressed satisfaction in caring for their loved ones, fostering a sense of meaning in helping others. This awareness and connection to others facilitated transcendence, promoting well-being. Reed's (1997a) Theory of Self-Transcendence draws from Rogers' Science of Unitary Human Beings; individuals are continuously interactive with their environment, reaching both within and beyond the physical realm. Reed (1991b) suggests that the expansion of conceptual boundaries can occur in response to a life event, increasing awareness of mortality. Shearer's (2006, 2007) qualitative work with older women note themes reflective of this process, *honoring*, *transcending boundaries* and *engaging in the future*. These themes recognize the older adult in constant interaction with their environment, building self-capacity through awareness of needed resources and purposeful participation in health changes. *Honoring* acknowledges the complexity of life challenges, looking both inwardly and outwardly, opening up to others to promote a sense of strength and hope, fostering well-being.

Participants shared the need to construct new understandings of who they were as caregivers, and how to enact the work of caregiving congruent with their own beliefs and values. Indeed, the transition to informal caregiving has been described as encompassing "passage from one life phase, condition, or status to another… Transition refers to both the process and outcome of complex person-environment interactions, which may involve more than one person and are embedded in the context and the situation" (Meleis & Trangenstein, 1994, p. 256). Caregivers shared experiences of self-discovery, finding inner strengths and resilience. Caregivers spoke of the personal growth experienced in the caregiving role, including a sense of purpose and meaning obtained from caring for their loved ones. Older adults shared strategies for staying positive and reframing their past experiences in positive and encouraging ways. *Opening to potential* is reflective of Shearer's (2009) work with chronically ill older adult women; her theme of *listening to the energy flow* reflected awareness, listening and finding meaning within the context of their situation. Older women opened to potential, developing strategies for staying positive and finding inner strength (Shearer, 2009). Other researchers have studied caregivers finding meaning in their role (Ayres, 2000; Peacock et al., 2010), noting the discovery of personal strengths among adult caregivers as providing meaning in their lives, reflecting their beliefs and values. Schulz and Sherwood (2008) note caregivers can find opportunities within the context of their role, reporting learning new skills, strengthening personal relationships, and feeling positive about themselves.

Social Contextual Resources

Within the Theory of Health Empowerment, the constructs of personal and social contextual resources are interrelated, expressing mutuality between the person and their environment (Shearer, 2009). As a social process, empowerment is associated with external social forces that act on the person and affect his or her sense of control and feelings of power (Shearer, 2004; Shearer & Reed, 2004). Social support as an external feedback mechanism has been studied as a process that can provide needed reinforcement, resources, assistance, and motivation (Shearer & Fleury, 2006) and enable the individual to make decisions. Social resources reflect social and supportive networks identified by the caregiver as assisting and supporting them in navigating the complexity of their role. Contextual resources are structural in nature, and may include neighborhood resources, support groups, senior centers and social service organizations. These types of resources provide opportunities for caregivers to be mentally and physically active, as well as create or add to an invaluable supportive network of friends. Through the recognition of social contextual resources strengths emerged, fostering health empowerment through engagement and support in the face of life changes.

Participants shared the importance of knowing how, when, and where to access resources for support. Several participants mentioned the benefit of accessible community resources in the area where they lived, noting that they felt very fortunate to have the depth and breadth of resources available to them, compared to their friends who lived in other states. Participants noted the crucial roles played by formal and informal support groups in the following themes: (a) connecting with others; (b) bearing witness; and (c) sharing strengths.

A common thread throughout this research was the importance of support provided by support groups, community resources, friends, and family. Participants noted that these resources were invaluable, sustaining them through the difficult and painful times they faced by providing a network of support and fellowship. Some participants shared feelings of social isolation, acknowledging that they had lost touch with friends due to the illness of the care recipient. The importance of social connections is supported by Shearer (2006, 2007) noting themes of *connectedness, transcending boundaries*, and *engaging in life process.* These themes acknowledged the importance of support and assistance from family and friends, as well as community agencies, highlighting the importance of social engagement to purposeful participation in self-care. Shearer and Fleury (2006) note the theme of *connectedness,* reflecting the reciprocity of giving as well as receiving support, promoting inner strength and growth, fostering well-being. Claassens and colleagues (2014) suggested older adults felt empowered when they had an active and supportive social structure, enhancing self-care and promoting well-being. Learmouth and colleagues (2012) noted a positive relationship between engagement in a community and well-being among older women. For older women, the community consisted of social contact, feeling supported, and interacting with the community around them. Caregivers experience increased satisfaction, usefulness and worthiness when they have strong social networks, fostering a sense of belonging and well-being (Dam, Boots, Van Boxtel, Verhey, & Vugt, 2017; Savundranayam, 2014).

Participants in this study noted the role of supportive others in bearing witness to their struggles and having a unique understanding of their experience and personal journey as a caregiver. A sense of “not being alone” in this journey provided comfort and validation for the participants. The opportunity to share experiences with others who were experiencing the same situation provided a forum for fellowship, laughter, and at times tears, knowing they were all “in this together.” Some caregivers felt isolated, as old friends did not understand or were uncomfortable with changes in the care recipient. These caregivers found accepting friendship from caregivers experiencing the same challenges. Participants noted they felt valued by their peers, honoring and accepting each other for the experiences they shared together. Within the cohesive network of caregivers, they were able to share their journey with those who were also travelling.

Research by Shearer and Fleury (2006) support this perspective through the themes of *social engagement, emotional sharing, and honoring.* These themes acknowledge the important and meaningful role of the caregiver, as well as the special relationship between caregivers; sharing and honoring what few understand. Shearer and Fleury (2006) noted a bond between peers, providing a sense of family, which fostered self-care and well-being among their “families of choice” (p. 10). Donnellan and colleagues (2015) noted similar sentiments in their qualitative study of spousal dementia caregivers. Participants sought support from friends, particularly those in similar situations. This support facilitated resilience among caregivers by allowing them to share their expertise and insight with others. Peacock and colleagues (2010) noted similar findings regarding the importance of caregiver support groups; knowing that they were on the same journey was comforting and valuable. Acknowledging these positive relationships and supports fostered empowerment in self-care promoting well-being.

The participants voiced the importance of sharing informal and formal resources among caregivers. This mutual sharing of strategies assisted participants in the caregiving process and helped them recognize the value of self-care. While each caregiver’s journey was different in many aspects, including length of time and diagnosis, these perspectives provided a community among the caregivers to share strengths, knowledge, validation, encouragement, and hope for the future. This perspective is reflective of Shearer’s (2006, 2007) identified themes of *collectivism* and *engaging in life process*. Shearer and Fleury (2006) viewed the process of interaction between the individual and their supportive environment as essential to promoting health. The theme *collectivism* captures the strength and power of the collective group. Within the community, the individual shares strengths and resources, creating a synergistic effect, contributing to the capacity of all within the group. Shearer's (2007) qualitative work with homebound older adult women also supports the experience of mutuality between the individual and their supports, recognizing the theme *engaging in life process.* This integration encompassed the relationship between the individual, supportive family and friends, as well as community resources. The process of sharing strength and resources provides an environment to promote hope, fostering the ability to intentionally participate in self-care activities. Other researchers (Donnellan, Bennett, & Soulsby, 2015; Peacock et al., 2010) support this theme of sharing strengths or collectivism, noting the cohesiveness of the collective group provides strength, comfort and resources. Reed (1997a) put forth the idea that nursing is inherent in all, recognizing the complexity of well-being. The participants in this study reflect this thought, acknowledging the strength from within as well as the strength of the group in providing care for their loved one, valuing the hope of possibility, fostering self-care and promoting well-being.

Health Empowerment

Health empowerment reflects a relational process acknowledging personal and social contextual resources (Shearer, 2009). Through this emerging process, caregivers recognize personal growth and acceptance of their role, allowing them to seek purpose and meaning in their lives. This recognition fosters purposeful participation in self-care, promoting well-being.

Recognition of personal and social contextual resources have been suggested as attenuating some of the negative outcomes most commonly associated with caregiving (Jones et al., 2011; Kim et al., 2013; Lum et al., 2014; Sherman & Cheon, 2015; St-Cyr Tribble et al., 2008; Walker, Powers, & Bisconti, 2016). Through the process of recognition, participants became empowered to move forward with purpose, as reflected in the themes: (a) seeking meaning; (b) living values; and (c) accepting self.

A common thread among the participants was finding meaning within the caregiving context. Finding meaning during this difficult time allowed integration of past, present and future experiences, framed within the context of the caregiver's personal values, beliefs, goals and life purpose. When caregivers can assign meaning, they are able to create a sense of logic, providing a foundation to move forward (Boss, 2010). Meaning can determine whether there is hope or hopelessness and is inherently tied to the caregiver's health and well-being (Boss, 2010). Meaning can be found in the act of caregiving, loving and providing care to their loved one, or being challenged to change or grow from the difficult experience facing them (Shim et al., 2013). Ayres (2000) suggests that caregivers may use the past and current life experiences to integrate caregiving within their lives and provide meaning. Many of the caregivers in this study voiced feelings of satisfaction in their ability to take care of their loved one, sharing personal growth and strength. Research supports caregiving as fostering a sense of pride, satisfaction, purpose and meaning, increased self-esteem, and spirituality (Bull, 2014; Blum & Sherman, 2010; Kim, Schulz, & Carver, 2007; Sherman & Cheon, 2015; Wolff et al., 2007).

Shearer's (2006, 2007, 2009) work is consistent with these findings, noting that participants found meaning within their family roles, relationships with others, and ability to achieve goals that were meaningful to them. Seeking meaning is reflected in the themes of *social connectedness, engaging in life process* and *realizing the potential for purpose* (Shearer, 2007; Shearer & Fleury, 2006; Shearer, Fleury, & Reed, 2009), noting that meaning can be found within the context of being needed as well as giving to others, fostering strength to achieve personal goals. Shearer and Fleury (2006) found that the act of giving and being needed by others provided a source of meaning, as *social connectedness* within their supportive network. Shearer's (2007) qualitative work further supports these findings, with the theme *engaging in life process* reflecting the mutual support between older adult women and her family, friends and community. This mutuality between the person and environment provided meaning and support for participating in health promoting action. Shearer and colleagues (2009) described the importance of recognizing personal strengths and abilities attain personally relevant goals, providing purpose and meaning in life. The theme *realizing the potential for purpose* captures the importance of self-care and care for others in the face of chronic illness. In research with caregivers of people with dementia, Quinn and colleagues (2012, 2015) noted that caregivers found meaning in the action and role of being a caregiver, as a way to stay engaged, love, and give back to their loved one.

Qualitative research has explored meaning in the context of caregiving, suggesting that when a caregiver can find meaning, subsequent personal growth, strength, and purpose in life can occur (Ayres, 2000; Bull, 2014; Claassens et al., 2014; Quinn, Clare, McGuinness, & Wood, 2012; Quinn, Clare, & Woods, 2012; Shim et al., 2013). Bull (2014) noted that participants found meaning in being a caregiver; acknowledging the activities associated with the role provided them with a sense of meaning and purpose in life. Finding meaning within the context of caregiving is inherent to purpose in life, providing a lens to view oneself and in their world (Shim et al., 2013). When people perceive their suffering as a sacrifice for someone they love, it has meaning for them, giving them the strength to care and move forward (Boss, 2006).

Through the process of health empowerment, shifting values and priorities emerged as the participants continued to assess their goals, adopting a new perspective of valuing each day, and shifting their focus from what was lost to cherishing what remained. This acknowledgment can be freeing, allowing caregivers to focus on what is meaningful to them. Ayres (2000) noted that caregivers use expectations, explanations, and strategies in interpreting the caregiving role in context of their own lives. Caregivers who were able to accept, adapt, and appreciate their lives were more likely to find satisfaction (Kim, Schulz, & Carver, 2007; Solomi & Casiday, 2017). Shearer and colleagues (2009) describe the theme *realizing the potential for purpose* as acknowledging the need for participants to act on their own strengths and abilities to achieve valued goals. Caregivers may incorporate a "new normal" in their life, reconstructing meaning and rituals to strengthen resiliency and health (Boss, 2006).

Participants voiced the need to remain flexible in managing their complex role as caregiver. Part of this flexibility encompassed personal growth, realizing that life was now different, and they could not go back to what once was. In light of this knowledge, caregivers developed strategies, allowing them to be fluid in response to ongoing changes within their role. Many participants were empowered by this growth, finding strength, acknowledging they could do things successfully on their own. Shearer (2007) visualized this as a "beam of strength," helping the older adult women's recognition and ability to change in the face of adversity (p.41). *Listening to the energy flow* (Shearer, Fleury, & Reed, 2009) reflects the integration of the older adult's ability to be flexible in the light of change, growing and finding strength to persevere during difficult times. Similarly, Peacock and colleagues (2010) acknowledged continual adaptation during caregiving, resulting in growth, peace, and meaning. Staying positive allowed caregivers to overcome obstacles inherent in managing their own chronic illness and the everyday challenges of caregiving. When caregivers are faced with difficult and complex life events, personal growth and a sense of new opportunities can occur (Kim, Schulz, & Carver, 2007). These themes are supported in research among caregivers, noting personal growth, capacity, increasing resilience, and building confidence to deal with difficult and complex situations (Netto, Jenny, & Philip, 2009; Peacock et al., 2010, 2017). Caregivers can learn to live and grow in light of an unpredictable future, drawing on personal strengths to promote change in challenging situations (Boss, 2006).

Caregivers acknowledged the need to accept continual change, while reconciling that life is not always fair. The participants reflected on the positive aspects of caregiving, finding understanding and strength in their situation, while continuing to move forward. Acceptance, or coming to terms with the present situation, has been identified as instrumental to the process of positive caregiving (Donovan & Corcoran, 2010; Duggleby, Williams, Wright, & Bollinger, 2009; Lloyd, Patterson, & Muers, 2016; Shim et al., 2012, 2013). When one decides to accept and live with an uncertain future, they are no longer passive or helpless; a subjective sense of control may be more important than objective control of the situation (Boss, 2006, 2010). Shearer's (2007) research recognizes *"staying positive"* as the awareness of an inner potential to change, providing strength for older women in overcoming health care obstacles. To maintain a positive attitude, participants drew on past experiences and developed strategies for overcoming obstacles, fostering personal growth. Shim and colleagues (2013) note that when caregivers accepted the reality of their situation, understanding what they could and could not control, they were able to focus on the positive aspects of caregiving and found things to be grateful for.

Purposeful Participation in Change

Barrett (2010) has described power as the capacity to participate knowingly in change by being aware, making choices, feeling free to act intentionally, and being involved in creating change. Shearer (2009) noted that this purposeful participation in self-care occurs through the recognition of personal social contextual resources, represented in this study by themes including: (a) reframing life plans; (b) dwelling with uncertainty; (c) acknowledging alternatives; (d) reevaluating roles; and (e) considering investment.

Lloyd and colleagues (2016) noted caregivers' awareness, choice and strategies for managing the caregiving role as essential to their own health and well-being and the well-being of their loved one. In assuming the caregiver role, participants engaged in a process of reconstructing their life plans, many acknowledging that the "journey had changed," and an unplanned chapter had begun. Reconstruction of life plans included reconciling future plans and hopes with the reality faced, and for some, a choice to live one day at a time. Shearer (2008) explored the experiences of older adult homebound women in health and aging. The theme *acknowledging changes* emerged reflective of the process of accepting change. The participants acknowledged their past and present experiences, recognizing that although they could not predict what might happen in the future, they were able to determine the ways in which they participated. Through the theme *purposefully participating in change* the women actively recognized the choices available to them in light of changes occurring in their lives.

While purposefully participating in change, caregivers reflected on what was important to them, based on their own beliefs and goals, creating a sense of empowerment (Shim et al., 2013; Solomi & Casiday, 2017). Many caregivers poignantly reflected on the changes in their relationship with the care recipient, some losing the essence of their loved one as illness progressed. Shearer and Fleury (2006) described a sense of reciprocity among older adult women, noting that both giving and receiving promoted health within the context of the relationship. Research supports the notion of reciprocity and health among caregivers; those who viewed their relationship with their care recipient as reciprocal in nature experienced better health outcomes (Peacock et al., 2017; Savundranayagam, 2014; Solomi & Casiday, 2017).

Feelings of uncertainty were voiced by many of the participants. Dwelling with uncertainty arose from fears and anxiety of an unknown future. Dwelling with uncertainty was often accompanied by a sense of loss, yet many found it as a catalyst to recognize alternatives, choices and possibilities exclusive of the future. Participants were able to re-evaluate what was important and meaningful to them in life, while appreciating the fragility and impermanence of their current life situation. Dwelling with uncertainty allowed caregivers to express awareness and make choices within an acceptable reality, with uncertainty integrated into their life perspective and role as a caregiver. In dwelling with uncertainty, caregivers focused on the present as an opportunity, allowing them to move forward (Mishel, 1990). Shearer and colleagues (2009) qualitative work with older adult women suffering from chronic illness reflects the concept of uncertainty, noting the themed *listening to the energy flow and purposefully participating in health-related decisions. Listening to the energy* describes the awareness of change in chronic illness, acknowledging the uncertainty of the future. *Purposefully participating in health-related decisions* acknowledges the role of uncertainty in decision-making, challenging the chronically older adult's strength and ability to participate in self-care. Additional qualitative research supports these findings, noting that caregivers dwelling with uncertainty were reflective, flexible and fluid in attempts to reconstruct their reality, drawing on strengths, and promoting opportunity in the face of loss (Duggleby et al., 2009; Duggleby, Bally, Cooper, Doell, & Thomas, 2012; Jones, Nowels, Sudane, Ahluwalla, & Bekelman, 2014).

Vaslieiou and colleagues (2017) found caregivers were challenged to redefine their relationship with the care recipient and uncertainty of role, noting the collision of personal and social responsibilities. Gibbons and colleagues (2014) noted role ambiguity as being "caught between the private world of chronic illness and the public world" (p.6). Silvia-Smith (2007) explored the experience of new family caregivers following a family member's stroke, noting the dimension of "restructuring life" (p104). Solomi and Casiday (2016) found that spousal caregivers missed the partnership of shared role and responsibilities, acknowledging that carried all of the responsibility in the caregiving role. Some caregivers in this study embraced their expanded role, experiencing a sense of growth, feeling strong and confident. Research supports caregivers find personal growth and an increase in self-capacity when they are able to successfully assume some of the roles previously assumed by the care recipient (Peacock et al., 2017).

Shearer (2007) noted older adult women with chronic illness considering alternatives for self-care, making choices based on their own values and beliefs. The theme, *choosing to ask for help* exemplifies the process of drawing on personal strength to make choices for self-care by asking for help from others. By acknowledging choices and resources, balancing abilities with desired outcomes, women were able to participate with purpose in self-care. Shim and colleagues (2013) supported these findings, noting caregivers balanced multiple alternatives and resources, choosing to purposely participate self-care promoting health. As caregivers take on additional roles and responsibilities, they often struggle to balance their need for self-care with the needs of the care recipient. Many older adult caregivers are reluctant to seeking out assistance, not wanting to impose on family and friends. Grasser and Craft (2000) noted that within reciprocal relationships, older adults may "bank" resources and assistance until needed. Wan and Antonucci (2016) noted the health benefits for older adults in reciprocity and support banks; when older adults feel that they have "deposited" into the bank, they are more likely to ask for assistance (Grasser & Craft, 2000; Murayama, Fujiwara, & Kawachi, 2012; Nyquist, Forsman, Giuntoli, & Cattan, 2013; Wan & Antonucci, 2016), leading to improved health and well-being. Through this mutual sharing, older adults became more aware to purposefully participant in change related to self-care and well-being.

Well-Being

Through the health empowerment process, well-being emerges. This transformation represents awareness of, and ability to knowingly participate in self-care promoting well-being (Shearer, 2009). Well-being is personally defined by the individual, reflective of their past, current and potential experiences, personal strengths, values and beliefs. Caregivers in this study expressed well-being in the themes: (a) becoming; (b) integrating self-care; and (c) relating.

Rogerian theory conceptualizes well-being as a life process and a value (Rogers, 1970, 1990, 1994b). According to Rogers (as cited in Fawcett, 2005), health and illness are part of the same continuum. The multiple events taking place along the axis of life denote the extent to which people achieve maximum health potential, with health varying in its expression from greatest health to those conditions which are incompatible with maintaining life processes. Similarly, McMahon and Fleury (2012) noted that wellness reflects a continuous state of change, encompassing both health and illness as defined by the individual. Becoming is the movement toward potential as an older adult and as a caregiver, reflective of growth and development, leading to new and positive health patterns (Fleury, 1991, 1996).

Well-being among informal caregivers reflects becoming as a movement toward self-determined health goals. The individual must be open and aware, knowingly participating, making decisions and creating change (Barrett, 1986). In a descriptive study with chronically ill women, Becker and colleagues (2009) concluded that when an individual selects and determines a course of change based on their own values and beliefs, identified goals can be attained.

Research with older adult caregivers' support becoming as reflective of opportunities to "nourish" oneself with activities that are personally relevant and meaningful (Bull, 2014; Peacock et al., 2017). Parse (1987) has conceptualized health as a synthesis of values, a process of being and becoming which occurs as man structures meaning in situations. Becoming reflects the selection and commitment to values. Older adults choose meaning and values, and have both the freedom and responsibility to fulfill their potential.

Caregivers realize their own potential for self-care within the context of complex and changing situations. Through integration of self-care, participants recognized opportunities for self-care consistent with their personal values. Fleury (1991) conceptualized integrating change as a process through which self-care practices became a part of the “new normal” for older adults with cardiovascular disease. Older adults integrated self-care practices through establishing rituals or including self-care practices as part of a daily routine, self-care as part of defining themselves as a healthy person, and the construction of future goals for self-care. Solomi and Casidy (2016) found that caregivers chose self-care activities that were meaningful to them. In exploring health promoting behaviors among caregivers, Acton (2002) found that those who activity practiced self-care reported an overall improved sense of well-being. Shearer and colleagues (2009) noted that engaging in self-care in spite of chronic illnesses provided purpose and meaning among older adults, reflected in the theme *realizing the potential for purpose.*

Caregivers in this study acknowledged the importance of support from family and friends as a form of self-care promoting well-being. Through these relationships, caregivers were able to nourish and heal their souls, reflecting purpose and meaning.

In research with community-dwelling older adults, Shearer and Fleury (2006) found themes of *connectedness* and *emotional sharing,* acknowledging the value of emotional support from others as a form of self-care promoting well-being. Bull (2014) used a mixed method design to explore approaches used by caregivers of persons with dementia utilized to sustain their own self-care and promote well-being. Emerging themes included drawing on past experiences, nourishing the self (self-care activities) to restore or maintain energy, and spirituality. Social support has also been shown to positively affect well-being in caregivers (Bull, 1990).

Contribution to Nursing Science

Much of the research on self-care in older adult caregivers has been framed by theory focused on deficits or problems to be solved, with the assumption that promoting self-care is a process of removing deficits and obstacles (Stevens, 2012). A focus on problems and deficits limits the exploration of individual strengths, thereby compounding the risk for vulnerability to diminished health and well-being in older adults (Holstein & Minkler, 2003; McMahon & Fleury, 2012). Jones and colleagues (2011) suggest that changing our "research lens" from a deficit perspective to a strength-based perspective is essential to promote caregiver well-being. However, few interventions are designed from a strength-based perspective, building upon the caregiver's own resources and experiences to foster self-care and promote well-being (Gitlin, 2012; Jones et al., 2011; Teel & Leenerts, 2005; Walker, Powers, & Bisconti, 2016). There remains a paucity of knowledge regarding ways to promote continued growth among older adults by building upon strengths and realizing potential while simultaneously addressing their changing and diverse needs (McMahon & Fleury, 2012).

This study contributes to nursing science by furthering knowledge of a strength-based perspective facilitating older adult informal caregiver recognition and engagement in self-care promoting well-being. A strength-based perspective provides a lens for understanding the interaction of caregivers and their environment, acknowledging the uniqueness of the person inclusive of their personal values, beliefs, hopes, meaning and purpose in life. A strength-based perspective acknowledges negative experiences but allows the individual to assign meaning and purpose to each experience, fostering recognition of strengths (Lloyd, Patterson & Muers, 2014; Peacock et al., 2017).

The findings of this study enrich and extend dimensions of the Theory of Health Empowerment (Shearer, 2009), furthering understanding of caregiver loss, uncertainty, hope, and solace as sources of strength, meaning, and purpose in life. Findings support Rogerian (1980, 1990, 1992b) constructs of human patterning and the desire to knowingly participate in change, as well as the integrality perspective of human beings as integral with their environment; characterized by pattern, self-organization, diversity and innovative change, and as holding individual values and views about health. The Theory of Self-Transcendence (Reed, 1991b) integrates the complex elements of life, aging, and loss confronting older adults. Reed (1997a) suggested individuals expand their boundaries, while gaining new perspectives, patterning their challenges into meaning, sustaining themselves and well-being.

Through the lens of Parse's (1992) simultaneity world view, findings support the person-environmental process, noting that change is both creative and innovative (Shearer & Reed, 2004). Parse proposed that individuals seek meaning in all aspects of their life; acknowledging meaning creates a new or acceptable reality, with the individual as an open being, and health as a process of becoming (Parse, 1981).

Contribution to Nursing Practice

New paradigms for self-care are needed which reflect the lived experiences of older adults (Dillaway & Byrnes, 2009; Holstein & Minkler, 2003). Tornstam (1992) has challenged researchers and clinicians to let older adults define their own needs, values, and meanings. Naylor (2012) has echoed this perspective, calling for qualitative approaches to understanding the varied experiences and meanings of older adult caregivers as essential sources of knowledge. According to Holstein and Minkler (2003), exploring "How it is for me" opens narrative possibilities that trade generalizability about old age for increased understanding.

Knowledge generated from this study contributes to nursing practice by informing the design of self-care interventions to better match the needs of older adult caregivers. Approaches addressing purposeful participation are new strategies in the science of caregiver self-care. Building upon individual strengths and optimizing potential will advance nursing approaches to promoting continued growth among older adults while simultaneously guiding care for their changing and diverse needs (McMahon & Fleury, 2012). Proactive approaches to practice with older adult caregivers are needed, focused on individual values, goals, and meaning. Each older adult defines health, self-care and well-being based on their own personal values. Caregivers may benefit from self-care approaches seeking, acknowledging and fostering strengths of the caregiver (Shearer, 2009). The findings of this study move beyond self-management theoretical approaches and evaluation, furthering the science of self-care that promotes well-being from a strength-based perspective. Nursing practice from a health empowerment perspective acknowledges the strengths of the older adult informal caregiver, using personal and environmental resources as a basis for engagement and participation in self-care.

Limitations of the Research

This study used purposive sampling to recruit a diverse sample of older adult informal caregivers with varying length of time in the caregiving role, both men and women, as well as caregivers of recipients with various chronic conditions. Older adult choices in engaging in self-care depend largely on available resources, including an adequate income, access to affordable and nutritional food, a healthy and safe neighborhood in which to live, and affordable, good quality health care (Minkler, 1999). However, these essential resources are not equally available to all older adult caregivers (Meyers, 1989). A better understanding is needed regarding the role of social contextual resources in self-care among older adult caregivers, as well as the capacity of older adults to meet the challenges posed by the environment (Barbosa et. al., 2011; Hunt, 2003; Naylor, 2012).

Participants in this study included 80% Caucasian caregivers. Pinquart and Sörensen (2005) noted that minority caregivers are typically younger, less educated, and of lower socioeconomic status. Hispanics account for 18% of the U.S population; Arizona ranks as one of the top 10 states with the largest Latino population, growing to 62.4% since 2000 (Flores, 2017). Evans and colleagues (2017) emphasize the need to better understand the experience of family caregiving and self-care among Mexican American caregivers, given documented health disparities resulting in earlier and more severe health needs, and increasing the likelihood of disability. Findings from this study may not adequately capture the unique perspective of older Hispanic caregivers. Ongoing research is needed with ethnically diverse older adult informal caregivers.

While purposive sampling found males in the caregiving role, the majority of participants were female. Male participants in the study tended to approach caregiving from a managerial perspective, drawing on their past employment experiences to provide structure in their caregiver roles. Calasanti and King's (2007) research among male caregivers found that a managerial approach provided strength and sense of control. Several of the female participants echoed this same perspective, noting that this approach had helped them to be successful in their work-world roles.

Research has been mixed regarding gender differences in caregiving. In a review of caregiving literature, Pinquart and Sörensen (2006) found gender differences in burden, depression, the amount of care provided, and quality of the relation with the care recipient, however, the differences were smaller than in previous reviews. The authors suggested that gender differences may be subject to societal role changes, and that caregiving experiences between spouses were similar.

Swinkels and colleagues (2017), suggested that gender differences among older adult caregivers may be influenced more by secondary stressors such as financial and relational issues rather than gender. Additional research in this area is needed to determine if gender influences the caregiver's approach to caregiving among older adults.

The purposive sampling for this study sought participants having experienced varying lengths of time in the role; it also sought care recipients with a variety of medical conditions. Current caregiving research generally includes moderate to long-term caregivers caring for persons with cognitive impairment disorders (Gitlin, 2012; Naylor, 2012; Stevens, 2012). The majority (43%) of the participants had been providing care for a moderate amount of time, 5 to 9 years, while 19% had provided care for less than 5 years. Several participants voiced uncertainty when they actually became caregivers, one noting they still did not refer to themselves as a caregiver. Wolff and Roter (2011) suggests caregiving can begin much earlier than previously examined in research, noting it can start when caregivers first accompany the older adult to their physician appointments or assisting during the transition to home from a healthcare facility. The participants in this study cared for older adults with diverse medical conditions, including Alzheimer's/Dementia (19%), Alzheimer's/Dementia with other conditions (38%), Parkinson's (29%), and other (15%). Additional research is needed to better understand the self-care needs of caregivers early in their role.

The health outcomes for older adult caregivers in contemporary research has been mixed, with National Alliance for Caregiving (NAC & AARP, 2015) suggesting that the health of informal caregivers worsens over time; older adult caregivers who reported fair or poor health during the first year of caregiving report worse health after providing care for five or more years. Roth and colleagues (2015) suggests caregivers with strong personal and social contextual resources may have better health outcomes and reduced mortality rates compared to non-caregivers. The majority (67%) of the participants in this study rated their health as good or fair (33%), although 96% reported one or more chronic health condition. Ongoing research in this area is needed reflecting the impact of personal and social contextual resources on the older adult's health and well-being.

The participants in this study lived in a large urban area with accessible instrumental resources readily available including respite care, adult day care, and support groups. Thus, study findings may not reflect the experiences of older adult caregivers living in smaller urban or rural areas without readily available resources. Additional research is needed to reflect the experiences of older adult caregivers from rural or small urban areas with limited access to resources.

Directions for Future Research

Contemporary caregiving research has reflected perspectives grounded in stress and coping, self-efficacy, and self-management. These theories emphasize prescribed change in a linear pattern, consistent with particular-deterministic and interactive-integrative worldviews (Fawcett, 1993; Glanz, Rimer, & Viswanath, 2008). Self-care behavior is predicted under predefined conditions, guiding the search for modifiable factors to ameliorate conditions of illness or deficit (Glanz, Rimer, & Viswanath, 2008). Research framed from this worldview address individuals as the sum of bio-psycho-social-spiritual components, reactive to their environment, and changing in predictable ways (Fawcett, 2005). This worldview is consistent with logical positivism, whereby knowledge and truth are derived from that which is observable, measureable and well-defined (Glanz, Rimer, & Viswanath, 2008; Fawcett, 2005; Whall & Hicks, 2002).

The health empowerment theory is congruent with a unitary-transformative perspective, which views the person as evolving, with change as a process emphasizing personal knowledge and pattern recognition (Fawcett, 1993). A unitary-transformative worldview acknowledges individuals as identified by patterns and interactions with the environment, change as ongoing and unpredictable, and emphasizing personal knowledge and recognition (Fawcett, 1993). Pattern recognition and personal becoming are the primary phenomena of interest (Fawcett, 1993; Reed, 1995, 2011). Future research will continue to evaluate and refine the theory of health empowerment, contributing to the nursing science and practice.

Conclusion

By the year 2050, over one fifth of the U.S population will be 65 years and older (Pew Research Center, 2015), with corresponding increases in chronic conditions and associated social and complex medical needs. As our population continues to age, the role of older adult informal caregivers will grow. Currently, older adult caregivers are performing their roles alone, with many in poor to fair health themselves (Family Caregiver Alliance, 2015; Johnson & Weiner, 2006). The National Institute of Nursing Research and National Institute of Aging research agendas emphasize developing conceptual frameworks and methods to investigate the unmet needs of caregivers, as well as the design of interventions promoting the health and well-being of informal caregivers (National Institute on Aging, 2012; Naylor, 2015). The Theory of Health Empowerment provides a conceptual framework to facilitate the older adult caregiver’s awareness and engagement of self-care. This theory views the older adult informal caregiver as the expert in their own care; fostering personal and social contextual resources consistent with their own self-care goals.

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APPENDIX A

INSTITUTIONAL REVIEW BOARD

APPROVAL OF AGE MODIFICATON

Knowledge Enterprise
Development

EXEMPTION GRANTED

Julie Fleury
CONHI - PhD
602/496-0773
Julie.Fleury@asu.edu

Dear Julie Fleury:

On 10/30/2017 the ASU IRB reviewed the following protocol:

Type of Review:	Modification
Title:	An Exploration of Older Adult Informal Caregiver Self-Care Promoting Well-being
Investigator:	Julie Fleury
IRB ID:	STUDY00005617
Funding:	None
Grant Title:	None
Grant ID:	None
Documents Reviewed:	• Older Adult Caregivers, Category: IRB Protocol; • CITI Certificate of Completion for Laura Blank, Category: Other (to reflect anything not captured above); • Demographic Questionnaire, Category: Recruitment Materials; • Focus Group/Study Consent, Category: Consent Form; • Telephone Script, Category: Recruitment Materials; • Letter of Support from Duet, Category: Off-site authorizations (school permission, other IRB approvals, Tribal permission etc); • Focus Group Questions, Category: Recruitment Materials; • Eligibility Screening Check-list, Category: Screening forms; • Age Modification Eligibility Screening Check-list, Category: Recruitment Materials; • Recruitment Flyer, Category: Recruitment Materials;

The IRB determined that the protocol is considered exempt pursuant to Federal Regulations 45CFR46 (2) Tests, surveys, interviews, or observation on 10/30/2017.

In conducting this protocol you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103).

Sincerely,

IRB Administrator

cc: Laura Blank
Laura Blank

APPENDIX B

LETTER OF SUPPORT

Duet
Partners In Health & Aging
555 West Glendale Avenue Phoenix, Arizona 85021

November 28, 2016

Laura Blank
PhD Student, College of Nursing and Health Innovation,
Arizona State University
Phoenix, AZ 85003

Dear Laura,

I am in full support of the application entitled "*An exploration of older adult informal caregiver self-care promoting well-being*". Given health disparities for older adult informal caregivers, knowledge about the processes and resources used to engage in self-care is urgently needed. The research proposed is essential to advance both science and clinical practice related to improving self-care in a vulnerable group of older adults.

It is my pleasure to partner with you and Dr. Julie Fleury in the conduct of this research. The resources of Duet, Partners in Health & Aging will be available for the successful completion of this research. We look forward to our ongoing collaboration.

Sincerely,

Ann Wheat

Ann Wheat, Director Caregiver Services

Executive Director: Elizabeth Banta **Phone:** (602) 274-5022 **Email:** info@duetaz.org **Web:** www.duetaz.org

APPENDIX C

INSTITUTIONAL REVIEW BOARD APPLICATION

ASU Knowledge Enterprise Development
ARIZONA STATE UNIVERSITY

SOCIAL BEHAVIORAL INSTRUCTIONS AND TEMPLATE

NUMBER	DATE	PAGE
HRP-503a	10/23/2017	1 of 5

Instructions and Notes:

- Depending on the nature of what you are doing, some sections may not be applicable to your research. If so, mark as "NA".
- When you write a protocol, keep an electronic copy. You will need a copy if it is necessary to make changes.

1 Protocol Title

AN EXPLORATION OF OLDER ADULT INFORMAL CAREGIVER SELF-CARE PROMOTING WELL-BEING

2 Background and Objectives

Provide the scientific or scholarly background for, rationale for, and significance of the research based on the existing literature and how will it add to existing knowledge.

- Describe the purpose of the study.
- Describe any relevant preliminary data or case studies.
- Describe any past studies that are in conjunction to this study.

Older adult informal caregivers are at increased health risk, as caregiving responsibilities may make them less attentive to their own health care needs. Health care needs include one or more chronic conditions that require self-care and medical oversight. Informal caregivers report higher levels of disability associated with chronic disease when compared to the general population; one in five reports that the role of caregiver has negatively impacted their own health. The majority of caregiver health related research is viewed from a stress-illness conceptual lens, focusing on the caregiver's deficits rather than personal strengths and resources leading to self-care promoting well-being. Current interventions have had mixed results effecting change and engaging the older adult informal caregiver in self-care activities. Research exploring self-care promoting activities among informal caregivers note that self-care is multifaceted, requiring an individualized approach based on the values, beliefs and experiences of the caregiver. We do not currently know enough about the specific personal, social and environmental resources that contribute to the older adult's awareness and ability to knowingly participate in self-care activities to promote well-being. The purpose of this formative research is to explore personal, social, and environmental resources influencing self-care activities to promote well-being in older adult caregivers. Specific questions (objectives) that the research will answer include: 1) How has the older adult caregiver managed thus far in the caregiving role? 2) What personal strengths has the caregiver drawn on to be successful? 3) What environmental strengths and resources have assisted the caregiver to be successful? 4) What strengths does the caregiver drawn on to participate in self-care activities? And 5) How does self-care promote the caregiver's well-being? The proposed research will generate new knowledge regarding older adult informal caregiver self-care activities to promote well-being from a strength-based perspective. This knowledge will inform development of theory-based interventions designed to facilitate participation in self-care activities to promote well-being among older adult caregivers.

3 Data Use

Describe how the data will be used. Examples include:

- Dissertation, Thesis, Undergraduate honors project
- Publication/journal article, conferences/presentations
- Results released to agency or organization
- Results released to participants/parents
- Results released to employer or school
- Other (describe)

De-identified data collected during 1- hour focus group interviews enrolling approximately 20 older adult informal caregivers will provide the basis for this dissertation research. The information obtained will be used to explore the personal, social and environmental resources that contribute to caregiver awareness and ability to knowingly participate in self-care activities promoting well-being from a strength-based perspective using a Health Empowerment framework.

4 Inclusion and Exclusion Criteria

Describe the criteria that define who will be included or excluded in your final study sample. If you are conducting data analysis only describe what is included in the dataset you propose to use.

Indicate specifically whether you will target or exclude each of the following special populations:

- Minors (individuals who are under the age of 18)
- Adults who are unable to consent
- Pregnant women
- Prisoners
- Native Americans
- Undocumented individuals

Inclusion criteria for the study include the following:

1) Self-identified informal caregivers
2) Age 45 years and older
3) Providing care to someone 60 years and older
4) Ability to speak and understand English; and
5) Willing to participate in a 1-hour audiotaped group interview session held at the Duet, Partners in Health & Aging Community Centers in North Phoenix and Scottsdale AZ (Letter of Support Attached)
6) Ability to provide informed consent to participate in focus group sessions

Minors under the age of 18, adults who are unable to consent, pregnant women, prisoners, Native Americans, and undocumented individuals are not targeted for, or the subject of, this research. However, as part of developing a diverse complement of study participants, if an individual who is Native American or undocumented volunteers to participate in the study, and meets the inclusion criteria, they may be included in the focus groups, and will not be excluded simply by virtue of their status as a special population.

Only older adult informal caregivers will be included in this study. This is a study exploring resources for self-care activities promoting well-being in this population (age 45 and older). The literature indicates caregiver health often deteriorates during the caregiving period. The study will recruit both male and female participants from caregiver support groups (Duet, Partners in Health & Aging) for focus group interviews enrolling approximately 20 participants.

5 Number of Participants

Indicate the total number of participants to be recruited and enrolled: Approximately 20 participants will be enrolled.

6 Recruitment Methods

- **Describe who will be doing the recruitment of participants.**
- **Describe when, where, and how potential participants will be identified and recruited.**
- **Describe and attach materials that will be used to recruit participants (attach documents or recruitment script with the application).**

The Principal Investigator (PI) Dr. Julie Fleury and PhD student Laura Blank (Investigator) will recruit focus group participants.

Participants will be recruited for the study in the following manner:

1. Upon approval of the IRB application, Fleury and Blank will present the research at the Duet, Partners in Health & Aging caregiver support group sites before/after scheduled caregiver group events. Presentation will include a description of the research and Investigator contact information. A Recruitment Flyer (Flyer Attached) describing the research and Investigator contact information will be distributed at scheduled events.
2. The Recruitment Flyer will be available to key Duet personnel to distribute at caregiver support events as needed. The Recruitment Flyer will also be placed on designated communication boards within Duet community agency sites.
3. The Flyer will include Blank telephone contact information; interested caregivers will be encouraged to contact Blank to obtain additional information about the research, and/or express interest in participating.
4. In communication with potential research participants (Script Attached), study inclusion criteria will be reviewed, with potential participants screened for eligibility.
5. Eligible participants will be asked to provide a valid telephone number for Blank to notify them regarding the time and place of the focus group interview.
6. Participants will be assigned a number to be used as an identifier during the focus group interview/data collection.
7. Telephone contact with instructions for attending the scheduled focus group interview will be provided.
8. A written consent form for participation in the research will be provided to each participant for review and signature prior to the start of the scheduled focus group interview (Consent Form Attached). A copy of the consent form will be provided to each participant. Participants will be asked to complete a paper and pencil questionnaire outlining demographic characteristics (Demographic Questionnaire Attached).

7 Procedures Involved

Describe all research procedures being performed, who will facilitate the procedures, and when they will be performed. Describe procedures including:

- The duration of time participants will spend in each research activity.
- The period or span of time for the collection of data, and any long term follow up.
- Surveys or questionnaires that will be administered (Attach all surveys, interview questions, scripts, data collection forms, and instructions for participants to the online application).
- Interventions and sessions (Attach supplemental materials to the online application).
- Lab procedures and tests and related instructions to participants.
- Video or audio recordings of participants.
- Previously collected data sets that that will be analyzed and identify the data source (Attach data use agreement(s) to the online application).

Dr. Julie Fleury, PhD, RN, FAAN is the PI on the research, mentoring Laura Blank, PhD Candidate (Investigator).

The research involves one-hour audio-taped focus group interviews at Duet, Partners in Health & Aging caregiver support sites, with approximately 20 caregivers, age 45 and older, to engage in a facilitated discussion about personal, social, and environmental resources in the caregiving role, perceptions of self-care, and engagement in self-care promoting well-being.

Informational presentations for potential participants will be completed by the Fleury and Blank to correspond with scheduled events. Duet key personnel will also distribute Recruitment Flyers during various caregiver support events, as well as placing them on designated communication boards with their community agency sites.

Interested participants will be screened for eligibility to participate by calling Blank to express their interest. A brief questionnaire to establish eligibility (See Attached Eligibility Screening Check-list) will be completed. Eligible participants will be notified of the date, time and location of the focus group meeting. Eligible participants will be provided with a follow up telephone call reminder prior to the focus group meeting with meeting date, time and location details. The one-hour focus group meeting/sessions will be held at Duet's community agency sites.

Research participants arriving at the focus group meeting will sign a research consent form, and will receive a $20 gift card to thank them for their time. They will be notified at that time that their participation is voluntary, and they may choose to not participate in the focus group discussion, or that they may leave the focus group meeting at any time once it has commenced, if they no longer choose to participate.

The research participants will not be identified by actual name, but at check in will be provided with 2-sided nameplate with a letter to be used for their name during discussions (Participant A, Participant B, etc).

Dr. Julie Fleury (PI) and Laura Blank (PhD student) will facilitate the focus group discussion, using an introductory script, and list of guiding questions. Dr. Julie Fleury will call the focus group meeting to order, initiate the meeting introduction, announce that the meeting will be audio-recorded, prior to starting the recording, and will announce when the recording is stopped at the end of the focus group session. Laura Blank will be responsible for providing a brief overview of the research, and documenting meeting notes and observations, utilizing only assigned participant names. Both Dr. Fleury and Laura Blank will ask guided interview questions of the focus group, and facilitate discussion and responses from research participants. At the completion of the 60-minute focus group session, Dr. Fleury and Laura Blank will thank participants, ask if there are any additional follow up questions, and provide a synopsis of the meeting.

The total amount of time anticipated for participation in the research study would include the single 60-minute audio-taped session of the group, and a few minutes of additional preparatory, travel, or evaluation time. Additional time for participants may include walking or travel time from their home, responding to telephone requests for participation, and completing a brief, voluntary survey regarding the research participant's focus group experience.

8 Compensation or Credit

- Describe the amount and timing of any compensation or credit to participants.
- Identify the source of the funds to compensate participants
- Justify that the amount given to participants is reasonable.
- If participants are receiving course credit for participating in research, alternative assignments need to be put in place to avoid coercion.

Participants who attend the scheduled focus group session, and sign the participant consent form will receive a $20 gift card from Target. The gift card will be presented to them upon enrollment. The participant does not have to complete the focus group interview in order to receive the gift card.

Scholarship funding from Hartford Center for Gerontological Nursing Excellence at Arizona State University College of Nursing and Health Innovation will be used to pay for the gift cards.

The focus groups will be scheduled during the mid-morning or mid-afternoon at the North Phoenix and Scottsdale Duet agency sites. Appropriate refreshments will be provided to focus group participants, with funds also coming from Hartford scholarship funding.

These items are strictly a token of thanks for participation in the focus group interview.

9 Risk to Participants

List the reasonably foreseeable risks, discomforts, or inconveniences related to participation in the research. Consider physical, psychological, social, legal, and economic risks.

There is potential for minimal psychological or social discomfort when attending a focus group format interview, or discussing health or personal experiences regarding caregiving and self-care activities promoting well-being.

There are no expected economic risks due to participation in the focus group interview.

10 Potential Benefits to Participants

Realistically describe the potential benefits that individual participants may experience from taking part in the research. Indicate if there is no direct benefit. Do **not** include benefits to society or others.

Participants may experience some benefit from the opportunity to share their personal experiences in caregiving and its impact engagement of self-care activities. There is also an opportunity for participants to identify personal, social, and environmental resources used to foster participation in self-care activities. It is anticipated that the benefits of participation will exceed any risk.

11 Privacy and Confidentiality

Describe the steps that will be taken to protect subjects' privacy interests. "Privacy interest" refers to a person's desire to place limits on with whom they interact or to whom they provide personal information. Click here for additional guidance on ASU Data Storage Guidelines. Describe the following measures to ensure the confidentiality of data:

- Who will have access to the data?
- Where and how data will be stored (e.g. ASU secure server, ASU cloud storage, filing cabinets, etc.)?
- How long the data will be stored?
- Describe the steps that will be taken to secure the data during storage, use, and transmission. (e.g., training, authorization of access, password protection, encryption, physical controls, certificates of confidentiality, and separation of identifiers and data, etc.).
- If applicable, how will audio or video recordings will be managed and secured. Add the duration of time these recordings will be kept.
- If applicable, how will the consent, assent, and/or parental permission forms be secured. These forms should separate from the rest of the study data. Add the duration of time these forms will be kept.
- If applicable, describe how data will be linked or tracked (e.g. master list, contact list, reproducible participant ID, randomized ID, etc.).

If your study has previously collected data sets, describe who will be responsible for data security and monitoring.

Participants will not be identified by name during the recorded focus group interview. Telephone contact numbers and demographic data will be stored in a secure, locked file cabinet in Laura Blank's locked office. Following data analysis, data will be destroyed. Signed consent forms of research participants will be housed in a locked file cabinet in Laura Blank's locked office.

Participants will be informed that responses to any interview questions and/or demographic data collected are confidential, and no personally identifying information will be required. Information obtained from the focus group interviews will be de-identified, and used in summary to inform future development of theory-based interventions facilitate the engagement of purposeful participation in self-care activities to promote well-being among older adult caregivers. Participants will also be informed at every step in the process that they may choose to withdraw from the study at any time, without negative consequence.

Dr. Julie Fleury and Laura Blank are the designated individuals who will have access to the audio transcript of the focus group meeting. Participants will not use their actual names during the recorded focus group interview, and will be given name plates with letters so that no identifying information will be used on the group audio-recording.

Voice recording from the audio-taped focus group session will be converted to a written transcript of the session via audio-transcription device. The written transcripts of the focus group sessions, data analysis, and audio-recordings will be stored in a locked file cabinet in Laura Blank's locked office.

All computerized digital audio-recordings, transcribed data and field note will be maintained on a password protected secured computer accessible only to Dr. Fleury and Laura Blank.

The audio-recording for the focus group sessions will be deleted and destroyed once the file has been transcribed and verified. No information that would disclose participant personal identification will be released or published.

12 Consent Process

Describe the process and procedures process you will use to obtain consent. Include a description of:

- Who will be responsible for consenting participants?
- Where will the consent process take place?
- How will consent be obtained?
- If participants who do not speak English will be enrolled, describe the process to ensure that the oral and/or written information provided to those participants will be in that language. Indicate the language that will be used by those obtaining consent. Translated consent forms should be submitted after the English is approved.

Only older adult caregivers who speak, and understand English will be enrolled in this research.

Dr. Julie Fleury and Laura Blank will be responsible for obtaining written consent from the focus group participants, prior to the start of the focus group interviews. Dr. Fleury, as the principal investigator, has primary responsibility for obtaining consents, and will supervise Laura Blank in obtaining consent from participants at the designated focus group meeting time.

Preliminary interest in research participation is given when the older adult caregiver verbalizes consent on the telephone to attend the focus group session. The consent form is signed prior to initiating the focus group interview.

The consent form will be reviewed individually with each participant prior to their signature at the focus group meeting location.

13 Training

Provide the date(s) the members of the research team have completed the CITI training for human participants. This training must be taken within the last 4 years. Additional information can be found at: Training.

Dr. Julie Fleury completed CITI training on 6/15/2015.
Laura Blank completed CITI training on 12/31/2016 (See Attached Completion Certificate)

APPENDIX D

CAREGIVER RECRUITMENT FLYER

ASU College of Nursing & Health Innovation
ARIZONA STATE UNIVERSITY

Researchers at Arizona State University are seeking informal caregivers to share their experiences in self-care resources and activities promoting well-being.

Informal caregivers must be at least 45 years of age, caring for someone at least 60 years of age.

Participation is voluntary.

Participation will include:

- Attending a small group, audio-recorded discussion lasting one hour at Duet, Partner in Aging Community Center in North Phoenix or Scottsdale;
- Contributing to discussion about personal, social, and environmental resources that contribute to self-care, promoting well-being;
- Responding to questions regarding yourself and your caregiving
- Participants will be compensated with a $20 Target gift card. Light refreshments will be served.

INTERESTED?

Please call Laura Blank for further information at 480-648-8286.

APPENDIX E

PARTICIPANT INFORMED CONSENT FORM

Arizona State University, College of Nursing and Health Innovation

Research Study about Older Adult Caregivers and Self-Care Activities

As a PhD student in the College of Nursing and Health Innovation at Arizona State University under the mentorship and direction of Professor Julie Fleury, PhD, RN, FAAN, I invite your participation in research designed to better understand the experiences of older adult caregiver self-care resources and activities promoting well-being.

Your participation in this research will consist of a telephone screening to determine your eligibility, answering some questions about yourself and your caregiving, and an audio-recorded one-hour group discussion at the Duet, Partners in Health and Aging Community Center, with approximately 4-6 other caregivers. At the group discussion, Professor Fleury and I will ask general questions about your experiences with caregiving (how are you currently managing, what personal strengths you draw on for self-care to be successful, what community and social resources have you used to engage in self-care?).

To be eligible to participate, you must be a caregiver who is caring for someone over the age of 60, at least 45 years old yourself, able to provide information about yourself and your caregiving, and able to participate in a one-hour group discussion. You will receive a $20 gift card for your attendance at the group discussion, and refreshments will be served. You have the right not to answer any question asked in the group discussion, and to withdraw from participating in the group discussion at any time without penalty. Your participation in this research is voluntary.

There are no foreseeable risks or discomforts to your participation in this research, or in the group discussion. You may have an opportunity to better understand older adult caregiver self-care resources and activities promoting well-being.

Your name or identifying information will not be used during or after the audio-recorded group discussion. The results of this research may be used in research reports, presentations, or publications, but your name will not be used. Due to the nature of group discussions, complete confidentiality of your responses cannot be guaranteed.

The group discussion will be audio-recorded, to help me analyze and understand your responses after the meeting. Your consent to participate in this research includes the audio-recording of the group discussion.

This research will guide the development of programs designed to support older adult caregiver resources for engaging in self-care, promoting well-being.

For questions concerning this research study, please contact me at: Laura Blank, MSN, BSN, RN, CNE (or at 480-648-8286. You may also contact Professor Julie Fleury ( ). If you have questions about your rights as a participant in this research, or if you feel you have been placed at risk, you may contact the Chair of the Human Subjects Institutional Review Board, through the ASU Office of Research Integrity and Assurance, at (480) 965-6788.

By signing below you are agreeing to be part of this research.

Name:

Signature: Date:

Document Revision Date: October 23, 2017

APPENDIX F

PARTICIPANT QUESTIONNAIRE

Caregiver Questionnaire

Please provide the following information about yourself:

Age: ____

Number of years of education: ____

- ☐ Male
- ☐ Female

How would you rate your overall health?

- ☐ Good
- ☐ Fair
- ☐ Poor

Race/Ethnicity:

- ☐ White (Non-Hispanic)
- ☐ African American
- ☐ Asian American
- ☐ Hispanic
- ☐ Native American
- ☐ Other

How long have you been a caregiver?

- ☐ Less than 6 months
- ☐ 6 months to 1 year
- ☐ 1-4 years
- ☐ 5- 9 years
- ☐ 10 years or more

Do you currently have any of the following conditions? (mark all that apply)

- ☐ Diabetes
- ☐ Heart disease
- ☐ Arthritis
- ☐ High Blood pressure
- ☐ Other: ______

Please provide the following information on the person you care for:

Age: ___

- ☐ Male
- ☐ Female

Race/Ethnicity:

- ☐ White (Non-Hispanic)
- ☐ African American
- ☐ Asian American
- ☐ Hispanic
- ☐ Native American
- ☐ Other

Health condition(s) (mark all that apply):

- ☐ Alzheimer's/Dementia
- ☐ Parkinson's
- ☐ Cancer
- ☐ Stroke
- ☐ Diabetes
- ☐ Heart disease
- ☐ COPD
- ☐ Other: ______