Is There a Perceived Benefit For Familial Caregivers of Dementia Patients in Pre-Loss Counseling in Addressing the Feelings of Chronic Sorrow?
Is There a Perceived Benefit for Familial Caregivers of Patients in Pre-Loss Care? Addressing the Feelings
Is There a Perceived Benefit For Familial Caregivers of Dementia Patients in Pre-Loss Counseling in Addressing the Feelings of Chronic Sorrow? by Karen Ann Smith is licensed under a Creative Commons Attribution-NonCommercial-ShareAlike 3.0 Unported License.

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Abstract

This quantitative and qualitative study explores the importance of timing in the delivery of the support services that affect the psychosocial health of primary family caregivers of dementia patients. Caregivers’ narratives and survey responses reflect their feelings about the impact the experience of caregiving has on their emotional, physical, and mental health as they struggle to manage the stressors of dealing with a patient’s physical care, as well as the additional medical, legal, financial, spiritual, and emotional tasks associated with end-of-life issues. The purpose of exploring the importance of timing in the delivery of support services is to ascertain if the caregivers feel that they experience reductions in the negative emotional response (chronic sorrow) engendered by these stressors if they are provided with services early in the caregiving process. The participants in the study indicate that they feel it is important to receive support services early and often during the course of the caregiving process. Delaying the start of support is perceived as adversely affecting their feelings of self-efficacy during the
entirety of the caregiving experience. Three-fourths of this study’s participating caregivers report that the majority of their support and caregiving information is delivered through support group participation. They perceive that support group participation assists them in ameliorating some of the feelings associated with chronic sorrow.

Keywords: caregivers, chronic sorrow, support groups, information delivery

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Introduction

In 2009, the World Alzheimer Report estimated that 115.4 million people would be affected by dementia by 2050. The majority of these people (75%) will be cared for by an informal care system comprised of family and friends. Currently only about two per cent of the 5.1 million dementia sufferers in the United States are in formal care (long-term care) facilities. In the familial caregiving population approximately 69% of the caregivers are women. Familial caregivers who reside with dementia care recipients “spend 39.3 hours per week caring for that person” (National
Center on Caregiving, 2010). In 2009, this care was valued at $450 billion; of that amount, it is estimated that $144 billion was contributed by Alzheimer’s caregivers (Alzheimer’s Association, 2010).

Resources need to be provided if caregivers are to emerge from the caregiving process intact. Dementia caregivers provide care for one to four years longer than other caregivers. Levels of anxiety in dementia caregivers is higher than those found in the general population, as is depression (mean of 25% vs. 5.4% in the general population), and health problems (28% vs. 12%) remain for up to three years post the caregiving experience (National Center on Caregiving, 2010). Spousal caregivers older than 66 years who develop a chronic stress-related illness during caregiving experience a 63% higher mortality rate than similarly aged and ill non-caregivers (Rossheim & McAdams, 2010). The costs to caregivers are clearly delineated by the statistics that highlight their losses in mental and physical health and quality-of-life issues. The fiscal costs and medical treatment burdens associated with providing the caregivers with adequate after-the-fact care further strains families and the medical community as they struggle to stretch already strained resources. If this study provides some impetus to additional
research in the role timing plays in the introduction of support services to dementia caregivers then it may be possible to lessen the price of caregiving to both the caregiver personally and to society as a whole.

As the duration of the caregiving experience continues to increase due to advancing medical technology, skill and knowledge, the chronically or profoundly ill live longer lives post diagnosis. Because the duration of the caregiving event is now longer, studies find that “caregivers can be overwhelmed by these duties, their lives becoming consumed by endless tasks without boundaries and life-sustaining obligations without respite” (Rossheim, 2010). The caregiver reaction to these events has been described as chronic sorrow. “Chronic sorrow is a distinct grief reaction that occurs when loss is not final but continues to be present in the life of the griever” (Rossheim & McAdams, 2010, p. 477). The accepted linear model of normal grief responses used in most grief work does not apply to the chronic sorrow intervention process when working with informal dementia caregivers. It has only been in the past ten years or so that researchers and clinicians began to recognize the value of the chronic sorrow model in understanding the biopsychosocial effects familial
dementia caregivers’ experience during the care process.

The body of the research now being conducted regarding best practice models of care for dementia caregivers involves not just the affected individual caregiver, but the increasing size of this population within the general population as a whole. This vulnerable population will increase over the next thirty years as the baby-boomer cohort continues to age out; women, the majority stakeholders in the caregiving process, are already impacted by higher poverty rates than men and caregiving increases those rates. As social workers, we seek to make adequate medical care available to all members of society and fulfill our obligations to secure the best possible outcomes for entire client systems. We will need to act as change-agents so that public policies are framed to obtain parity for the caregiving population.

The specific research question in this study concerns the timing of the delivery of services to informal or familial caregivers. In specifically asking the caregivers about their perceptions of the value of pre-loss interventions the researcher hopes to be able to demonstrate that the impact of early interventions is beneficial. A secondary
aspect addressed during the interview segment of the study was “Does support help you resolve your feelings of chronic sorrow?” This question speaks to the process used by each individual to give meaning to (coping with) the burdens associated with caring for a dementia patient. The caregiver’s answers can aid researchers understanding of how some individual’s resiliency skills allow them to avoid the majority of the negative effects of being a caregiver. Additionally, the themes expressed by the participants in the study could echo those in the body of research that is beginning to fix on the efficacy of providing early and constant, idiographic responses to caregivers as the method best suited to a perceived reduction in stress and increase in the quality of life for those who undertake the caregiving experience.

This research study attempts to explore the current understanding of chronic sorrow by analyzing peer-reviewed articles. The core theory that informs current practices in interventions designed for informal or familial dementia caregivers is based on the demonstrable effects of the caregiving process, for example: high blood pressure, anxiety, social isolation, etc. Whereas there is a growing amount of research available dealing with the adverse biopsychosocial
effects dementia caregivers may experience, there is a corresponding lack of research dealing with the effect that timing plays in the efficacy of services provided to caregivers. The aim of this study is to open up a path for further consideration of early interventions in continuing caregiver research and the role that information plays in caregiver’s perceptions of preparedness in dealing with the issues presented by their experiencing chronic sorrow during the time they care for a loved one.

The limitations of this study do not allow a correlation between caregiver physical and mental health issues and early delivery of services to caregivers. Its limited sampling size precludes any general application of findings to the dementia caregiving population at large, as all of its participants were already attending a support group. The design of this study was exploratory in nature. As such, it was meant only as a tentative exploration regarding the matter of timing in chronic sorrow interventions and caregiver support.
Literature Review

In 1962, S. Olshansky first described the ongoing grief he observed in the parent-caregivers of children born with profound cognitive impairments. He referred to this cyclical and protracted grieving process as chronic sorrow. In this paper he “repeatedly asserts that chronic sorrow is a pervasive psychological reaction, a natural rather than a neurotic response to a tragic fact” (Teel, 1991, p. 1313). Olshansky recognized that a standard grief counseling protocol was not optimal in treating this particular population of caregivers. A standard grief work model is based on the precept that a physical death has already occurred in the life of the griever. With dementia, the person receiving the care is physically present to the caregiver, yet is no longer mentally or emotionally available to them. It needs to be understood that chronic sorrow is not complicated grief, but its own distinct emotional response by people experiencing a disparity between their reality and their idealized future. This grief is triggered periodically by re-experienced perceptions of loss (Peterson & Bredow, 2004). In 2000, Wilkinson proposed that clients experiencing chronic sorrow might also display behaviors associated with feelings of
“anger, being misunderstood, confusion, depression, disappointment, emptiness, fear, frustration, guilt/self-blame, helplessness, hopelessness, loneliness, low self-esteem, recurring loss, [and being] overwhelmed,” and that these feelings “may interfere with the clients ability to reach his/her highest level of personal and social well-being” (p. 443).

Teel (1991) proposes that understanding the difference between grief and chronic sorrow “requires a conceptual shift from the linear bereavement model of grief to a less restrictive, non-linear model of response to loss that is not temporarily circumscribed, but is ongoing and of extreme significance to a grieving person” and cites Brown & McCormick, 1988, Cook, 1988, VanRiper & Selder, 1998 (p. 1313). It is interesting to note that from 1962 to the mid 1990’s the application of a chronic sorrow model of grief work was almost exclusively applied in the treatment of parental caregivers of chronically ill and dying children. Roughly fifteen years ago the Nursing Consortium for Research on Chronic Sorrow (NCRCS) proposed the inclusion of family caregivers of the chronically ill as a population who experienced similar grief responses, as the caregivers met the criteria for a chronic sorrow diagnosis (Eakes, Burke &
Hainsworth, 1998). Studies began appearing about the same time that explored “The unique presentations of grief, depression, and anxiety associated with the chronic sorrow of long-term spousal caregivers” and their need of specialized therapy models (Rossheim & McAdams, 2010, p. 477).

Family-centered caregiving issues took a metaphorical backseat to patient focused outcomes in the formal care community until the early 1980’s. In 1979, one of the founders of the hospice and palliative care movement, Cicely Saunders, “wrote [to a colleague] about grief and the need to embrace not just the patient, but the patient’s caregiving family during the ‘struggle with long term or mortal illness. It has seemed to me that I should begin to try and learn how we can be more helpful at an earlier stage in, perhaps, preventing some of the later problems,’ ” (she stated in Clark, 2002, p. 81). In the past, the majority of studies involving chronic sorrow in caregivers emerged from researchers in the palliative and hospice communities. Caregivers were viewed as adjuncts to the medical process of caring for a patient. They were not deemed a separate population that required services shaped to their own specific needs. Current studies are emerging from the gerontology, mental health, and social work communities.
As we come to understand that a caregiver’s biopsychosocial well-being is impacted by the caregiving experience, intervention models need to be developed that serve their recognized needs.

Before an intervention should be implemented in any given population there must be in place a way to measure not only the need for that particular intervention, but also the perceived and proven efficacy of that intervention. Studies that illuminate the need for assessment instruments for the dementia caregiving population began about ten years ago. Hudson et al. (2010) produced a meta-analysis regarding the consistency of the assessments of the needs of familial caregivers in general and subsequent interventions. It pointed up the lack of longitudinal studies centered on caregiver issues and the scarcity of evidence-based interventions serving this population’s needs. “Support for family caregivers is often provided in an ad-hoc manner. Family caregivers confronted by significant psychosocial distress should be targeted for interventions. However, a suitable means for assessing and measuring distress and well being in this population has not yet been identified” (Hudson et al., 2010, pp. 1-2). In the United States, AARP and the Family Caregiver Alliance are
collaborating in conducting a meta-analysis of “caregiver assessment tools, protocols, and best practices within Medicaid home and community-based services waiver programs [because] effectively supporting caregivers can reduce burdens and health risks that can impede a caregiver’s ability to provide effective care” (AARP Public Policy Institute, 2012).

Family caregivers represent the largest segment of the stakeholders in the long-term-services and supports system (LTSS) of in-home care for those with chronic and health problems or cognitive functional limitations. The National Institute of Health funded multiple studies with hopes of identifying and developing a brief screening instrument capable of producing a validated assessment tool. During the REACH II trials caregivers who were provided with “education, support, and skills-building in both home visits and by telephone showed significant improvement in burden, depression, health and self-care, social support, and management of patient behaviors” (Nichols, Martindale-Adams, Burns, Graney & Zuber, 2011, p. 1). These protocols were later translated from clinical trials to a real-world application by the Veterans Administration (REACH VA) in a trial that lasted from 2007-2009. In 2011,
the American Medical Association reported that caregivers who participated in both REACH II and REACH VA had contacted them “to report that they continue to use behavioral strategies, stress reduction exercises, and problem solving to take on new challenges” (Nichols et al., 2011).

REACH, Risk Appraisal Measure (RAM), is based on the data obtained from “Resources for Enhancing Alzheimer’s Caregiver Health (REACH II) a multi-site, randomized, clinical trial. The measure was found to have both acceptable internal consistency and concurrent validity for each ethnic and racial group.” (Czaja et al., 2009, p. 3).

A literature review in 2011 by Van Mierlo, Meiland, Van der Roest & Droes resulted in 269 possible reviews of intervention studies, 26 of which met the inclusion criteria of describing effective interventions for dementia caregivers. Their study sought to define the outcomes of effective interventions for dementia caregivers. They concluded that the most effective psychosocial interventions for dementia caregivers were information-based. This led them to observe that “Caregiver needs often include the unmet need for information. Effective and efficient support, tailored to individual (unmet) needs, therefore seems
highly relevant. Such knowledge will be very useful for healthcare professionals who offer support to caregivers…it will help them provide tailored advice attuned to the needs of the individual carers.” Ducharme et al. (2011) reported their experimental study tested the “efficacy of a psychoeducational individual program” that was designed to aid family caregivers of newly diagnosed Alzheimer’s patients. They found that those caregivers in the experimental group:

were more confident in dealing with caregiving situations, perceived themselves to be better prepared to provide care and more efficacious in their caregiver role, were better able to plan for the future care of their relative, had better knowledge of available services and made frequent use of coping strategies of problem solving and reframing. This program underscores that a proactive intervention approach from the onset of the care trajectory is key in fostering caregiver adaptation (Ducharme et al., p. 484).

Van Mierlo et al. (2011) reported the positive effects in their intervention studies review were most often related to the outcome categories “competence and self-
efficacy and mental health.” The authors of this review confirm the merit of individualized interventions based on the needs of a particular sub-group of caregivers. They recognize that interventions that are framed using this model are justified by their demonstrably successful outcomes. These findings would seem to indicate that informational services could play a critical role in caregiver coping strategies. Yet, Carpenter & Dave (2004) and Robinson, Clare, & Evans (2005) authored “empirical studies [that] revealed that at the time of the diagnostic disclosure, caregivers received little information about dementia and prognosis” (as cited in Ducharme et al., 2011, p. 485).

If we consider the feelings attributed by Wilkinson (2000) to those clients displaying signs of chronic sorrow, we can begin to understand how providing clients with information about the care-receiver’s ongoing medical needs/behavioral deficits, legal and financial matters, or the possible biopsychosocial injuries associated with caregiver burden, could help reduce the stress associated with a loss of an internal locus of control. Feelings such as anger, confusion, fear, helplessness, low self-esteem, and being misunderstood occur cyclically during the multiple and ongoing
losses triggered by events during caregiving, all of which can affect an individual’s feeling of self-efficacy. Information allows caregivers to consider multiple options when making decisions for their care-recipient; that in turn lessens their fear of making a choice with a bad outcome. Information gives them access to, and an understanding of, the vocabulary that they need when communicating with medical professionals regarding their loved one’s care. The ability to communicate clearly empowers them as they act as their family member’s advocate during the disease process. Empowerment leads to a reduction in stress and an increase in perceptions of parity.

Transactional models of stress can be used to describe the experience of caring for a dementia patient by a family caregiver. “Stress is defined as a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and as endangering well-being” (Barbosa, Figueiredo, Sousa & Demain, 2010, p. 491). The two processes of this theory that are of particular value to successful outcomes for dementia caregivers are cognitive appraisal and coping. Coping is definable as the skills that people rely on to “master, tolerate, reduce or minimize stressful events” that
enable them to reduce self-harm in stress-related psychosocial events (Taylor & Stratton, 2007). Barbosa et al. (2010) cites multiple authors who have reported that caregivers given improved coping tools receive greater benefits from using those tools than just “dealing with the consequences of stress” (Figueiredo, 2007; Kuuppelomaumlki, Sasaki, Yamada, Asakawa & Shimaanouchi, 2004; Lundh, 1999; Nolan Ingram & Watson, 2002; Nolan, Grant & Keady, 1996; Salin, Kaunonen & Astedt-Kurki, 2009).

These cited studies, REACH II (2004), REACH VA (2009), Van Meirlo et al. (2011), Barbosa et al. (2010), and Ducharme et al. (2011) all indicate that positive outcomes can be achieved if sub-group specific interventions are delivered to primary family caregivers. Additionally, the AMA study (2011) points out caregivers self-report that they continue to use the coping skills and information provided to them during their interventions in subsequent stressful situations for years post-delivery of intervention services. There is a limited amount of literature available to researchers at this time that clarifies the
concept of how an improved longitudinal flow of information and services could be of benefit to familial caregivers as they seek to develop greater resiliency and improved coping skills. This is a gap that I hope my work helps to close.

The body of the research being done on familial caregivers of dementia patients recognizes the burdens that caregiving places on the biopsychosocial lives of the caregivers. It acknowledges the need for interventions that reduce these burdens so that the caregivers themselves do not prematurely require medical or psychological services in higher percentages than their non-caregiving cohort members. It recognizes the need for assessment instruments that enable researchers to fine tune the interventions needed to appropriately provide service to individual caregivers. But, as in any process, timing is everything. Researchers such as Charlesworth, (2001) and Clark, Chaston, & Grant, (2003) believe that interventions “appear to be offered too late and recommend taking a proactive approach, that is, offering early intervention at the onset of the care trajectory, rather than a reactive approach” (as cited in Ducharme et al., 2011, p. 485).
Research studying the timing of counseling/interventions designed for dementia caregivers has not yet merited a meta-analytical study of its own because of a current paucity of such studies on which to draw. A paradigm shift in caregiver care theory is needed to move the focus of that care from those who are already in the midst of the journey to those caregivers that are just beginning it. Ducharme et al. 2011, points out that interventions introduced to long serving caregivers after their care-receiver is already experiencing severe dementia symptoms carry few benefits to the caregivers. He reports “Analyses have shown that these interventions have relatively modest effects on various indicators of caregiver health and quality of life” (p. 485). Withholding information from a new caregiver prevents them from being a full participant in what will arguably be the focus of their life for the next six to ten years, and as the referenced studies have indicated, lessen their chances to develop better coping and self-efficacy skills over the duration of the event.

Clinicians have long accepted that a person-centered systems model is one that empowers a client to draw on all of their resources in order to meet life’s challenges. Social workers believe that information and
knowledge are power. I believe that this study will indicate that caregivers are best served by an early delivery of information during the caregiving process and I hope that this aspect of service delivery becomes an accepted part of a best practice model in caring for caregivers.

The final readings involved in this literature review address the importance of researcher reflexivity in the analysis of qualitative data obtained during one-on-one interactions with interview participants. Gemignani (2011) writes “Investigators who are engaged in the field are likely to develop a rapport with the researched that is meaningful not just to the inquiry but also to the development of their own social and personal identities” (p. 705). Finlay (2002) adds her voice to the chorus when she speaks of “the richness of reflexivity” in the evaluation of intersubjective elements by researchers who are personally moved by their research participant’s narrative data. “Social scientists observe, interact with, transform, and are transformed by other human beings. Thus, we have the task of figuring out how to represent ourselves and other human beings in the most full and accurate way possible” (Gilgun, 2005, p. 260). I viscerally respond to the power of a caregiver’s narrative, even as I continue to
recognize the need of the researcher to maintain the ability to subjectively analyze the spoken word of a study participant. For the duration of this study I represent both communities. Nine years ago I became a dementia caregiver for my life-partner. The stories of the caregivers who participated in this study may not be spoken with my voice, but they echo in my heart.

**Intent of the Study**

The primary purpose of this non-experimental, cross-sectional, exploratory study is to expand the discussion regarding the perceived feelings of familial dementia caregivers regarding the value of the information (counseling) they receive during their caregiving process; and if they judge that information or support to be of such a quality that they feel prepared to meet the biopsychosocial challenges presented during their caregiving experience. The secondary field of interest is the participants’ subjective responses to the importance of timing in the delivery of information based interventions as disclosed to the researcher during the interview process.
Research Design

This mixed method research study uses an exploratory platform and is based on cross-sectional survey design by Grinnell, Williams, & Unrau, 2012. Cross-sectional surveys can use any mode of data collection. The quantitative data obtained from the survey is represented as numerically weighted information, which is then statistically analyzed in a manner that allows each variable to represent a measurable response to a question. The source of the qualitative data are the participants’ responses to the interviewer’s questions. Text analysis has been performed on annotated transcriptions of the interviews, and the data analyzed according to themes. In the context of this research study the dependent variable is the feeling of preparedness expressed by the caregivers regarding the total caregiving event. The element of timing in the delivery of information to caregivers represents the independent variable.
Recruitment and Study Participants

A purposive sample was recruited from six Alzheimer’s Support Groups. The groups meet weekly, bi-weekly, or once a month. Before approaching a group, permission was sought from the Rhode Island chapter of the Alzheimer’s Organization, which sponsors the groups. Subsequent permission was solicited from the individual support group facilitators to approach their groups about volunteering for the study. Copies of the study abstract, the survey instrument, and the Rhode Island College IRB approval document were provided to the group’s facilitator if requested. The groups meet in two senior centers, three churches, and a private dementia care center. The meetings are held at different times of the day and evenings throughout the state. The communities range from urban (North Providence), suburban (Middletown), to rural (Greenville). The groups represent communities that span diverse economic populations, from median household incomes of $41,285 in Warren up to $170,062 in East Greenwich. The median household income in Rhode Island is $55,975 (U.S. Census Bureau, 2010). Support group members range in age from
their early thirties to late eighties, and are/were care providers to parents, partners, and siblings. Caregivers whose care-recipients died before, or during, the study were included in the possible participant pool. Thirty-five possible participants attended the six meetings (N=35). Seven people declined to participate in the study. A total of 28 volunteers, or 80% of the available pool, agreed to participate in the survey. Thirty-two per cent of the individuals were male caregivers, which is only two per cent less than the male caregiver national mean of 34% (Family Caregiver Alliance, 2012). Sixty-four per cent of the survey responders (n=18) agreed to further participate in the interview segment of the study. Five people (18% of the respondents) who agreed to be interviewed were selected: 2 men and 3 women. This gender ratio was deliberate, as the researcher sought to use an approximation of both the full group and the national caregivers. The groups appeared to be all Caucasian in composition, as on the days the survey was completed there were no Latinos, African-Americans, or Asians present.
Data Collection

Original data collection took place between October 2012 and March 2013. Each participant signed a consent document before filling out the survey instrument. For those who participated in recorded interviews, an additional consent form was used. There is no identifying information to link instruments to consent information. Instruments, consent forms, and the transcripts of the taped interviews are kept in a locked file cabinet. Every effort was made to ensure the protection of participants’ identities and information. The methodology was approved by the RIC IRB.

Data were entered into an SSPS file under the supervision of Dr. Daniel Weisman. Dr. Weisman and Dr. Mildred Bates, both faculty members of Rhode Island College, and the researcher, Karen Smith, have access to the protected information; all three individuals are CITI certified. The primary researcher, Karen Smith, acquired the data presented during the narrative interviews. The interview format was semi-structured and the discussion was based on fifteen IRB-approved questions. A professional transcribed the interviews; the interviewer using field notes written directly
after the interview has annotated the transcripts.

**Instruments:**

The researcher developed the non-standardized survey (Appendix A) under the supervision of Dr. Weisman. The majority of the questions were framed to assess the participants’ perceptions of their emotional responses to the assistance they receive/received from both informal and formal caregiver support providers during the caregiving event. Other questions sought information about the duration of, and time commitment to, the caregiving experience. Questions included the sources of the delivery of care-related information and caregiver support mechanisms. Additional data concerning when participants were provided with information was solicited during the interview segment of the study.

The variables in the survey were scored using an ordinal value (1-5) Likert scale, in order to compare individual participant responses between two variables, and cohort responses between two variables. This survey is designed to capture the participants’ responses to an ongoing and evolving event and their subjective
responses to a variable at a single point in time.

The interview questions were developed by the researcher in order to give voice to individual caregivers. (Appendix B). The researcher was the only interviewer and annotator. The transcripts are analyzed by exploring the themes that emerge from the participants’ narratives.

**Operational definitions:**

**Chronic sorrow**: an ongoing event centering on the caregiver’s loss of relationship with a dementia care-recipient due to the disease trajectory.

**Full time caregiver**: provider of a minimum of 33 hours per week of care for the dementia patient.

**Perceived support**: when a responder feels satisfied with the level of support shown to them regardless of the actual level of support tendered.

**Caregiver stress/stressors**: the aggregate of the negative biopsychosocial responses to the care-giving experience. The symptoms presented may include: high blood pressure, diabetes,
sleep disturbances, chronic exhaustion, weight gain or loss, anxiety, depression, uncontrolled anger, social isolation, inappropriate social responses, and substance abuse.

**Informational interventions or counseling:** The process of providing caregivers with the information/assistance they require to best perform their caregiving and self-care responsibilities.

**Limitations and Issues of the Study:**

The limited sampling size of the study precludes generalization of the results. The study participants were drawn from a non-random sample of individuals who were already participating in dementia caregiver’s support groups. Caregivers who are not receiving the benefits of support group systems were not included in the sample. This study cannot test the efficacy of early information interventions on caregivers’ biopsychosocial lives because the design and methodology were exploratory. There was no testing done on the reliability and validity of the instruments or the variables. As all of the volunteers were aware of my dual roles of dementia caregiver and researcher, the reactive effect could have influenced
participants’ responses during the interviews. Still, the questions the study explores concerning the perceived value of proactive dissemination of information to caregivers may be of use to social workers and medical professionals researching caregiver support systems.

Quantitative Analysis

Descriptive Statistics of caregivers:

In the quantitative portion of this study 28 surveys were returned. Sixty-eight per cent (n=19) of the caregivers self-identified as full time caregivers. Their caregiving experience ranged from eight months to 21 years, with a mean of 50 months and a median of 36 months. Thirty-two percent of the participants (n=9) had participated in a support group for less than one year, 50% (n=14) had participated 1-5 years, and 14% (n=4) had participated for 6-21 years. Forty-six percent of the caregivers (n=13) joined a caregiving group within one year of the onset of their caregiving experience. Of those who joined within one year seven joined immediately upon becoming caregivers. Of those who waited more than one year to join a support group the interval
ranged from 18-60 months, with a mean of 44 months.

**Caregiver’s information acquisition experiences**

Only 7% (n=2) of the caregivers had a case manager to oversee their caregiving experience, but 46 % (n=12) of them felt that a caseworker could benefit them in meeting some of the emotional demands of caregiving. When asked if a medical professional had discussed the topic of either anticipatory grief or chronic sorrow with them, 78% (n=22) said no. When asked about end-of-life issues 85% (n=22) agreed that they felt at least somewhat sad when thinking about them and 66% (n=18) felt some degree of being overwhelmed by the issue. Forty-six percent (n=13) felt prepared for the coming loss; 21% (n=6) felt unprepared. When queried about what areas of knowledge they wanted more information about, the top three choices were: information concerning caregiver’s emotional stress 68% (n=19), information concerning healthcare issues affecting caregivers 63% (n=18), and information about legal matters 53% (n=14). (Appendix C).
Caregivers’ perceptions of external supports

One hundred percent of the caregivers (N=28) responded positively to the question regarding the desirability of discussing the emotional aspects of caregiving. This response is reflected in the “very satisfied” ranking expressed by 61% (n=17) of the participants with the local caregiver programs (support groups) they attended. The overall percentage expressing satisfaction with their local support group was 79% (n=22). This question was part of a series of variables framed to elicit information about the degree of support they felt from various natural support systems in their lives. The support of friends received the highest overall satisfaction ranking (82%). The overall satisfaction rate with medical providers ranked third (75%). Extended families (61%) was fourth, and fifth was their faith communities (52%). The least positive score was the respite care system at a 3.5% (n=1) satisfaction rating, which is also the support service that respondents appear to have the least interaction with. Fifty-four percent (n=15) answered “don’t know” to a question about support satisfaction regarding respite care. No other variable scored higher
in “Don’t know” responses than the respite issue.

Caregivers feel supported regarding the decisions they make about their loved one’s care: 21% (n=6) report they are “very satisfied” with support received. They feel slightly less supported in the decisions they make for their post caregiving life with 11% (n=3) reporting “very satisfied” with support they receive. Overall, 84% of the participants are satisfied with the support they receive in making decisions for their care-recipients and 48% are satisfied with the support in making decisions for themselves.

**Caregivers’ Perceptions of Self-efficacy**

Ninety two per cent (n=25) of survey respondents feel prepared to deal with their own healthcare needs, 64% (n=18) understand how their life will change when caregiving ends, 61% (n=17) feel prepared to make decisions about their loved one’s care and 46% (n=13) feel they can face the loss of the care-recipient. When asked about feeling prepared to face the changes in their life while dealing with end-of-life issues only one participant strongly agreed with that statement. That respondent was the
participant with the greatest number of years of caregiving experience (21).

Bivariate analyses were performed on the data which tested the correlations between the dependent and independent variables. The data show no relationship between those who answered **YES** to question (9) “Has a medical professional such as a nurse, doctor, or hospice worker ever discussed either chronic sorrow or anticipatory grief with you?” and responses to questions that dealt with participants’ perceptions of competency, preparedness, or feelings of support.

Comparing the length of time spent caregiving (Variable 11) produced the following results:
<table>
<thead>
<tr>
<th>Variable 1c.</th>
<th>I feel prepared in making decisions regarding my loved one’s care.</th>
</tr>
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<tbody>
<tr>
<td>Variable 9.</td>
<td>A medical professional such as a nurse, doctor, or hospice worker <strong>never</strong> discussed chronic sorrow or anticipatory grief with me.</td>
</tr>
<tr>
<td>Variable 10b.</td>
<td>When I think about end-of-life issues I feel prepared to face the changes in my life.</td>
</tr>
<tr>
<td>Variable 14g.</td>
<td>When I think about the time I have been a caregiver I am satisfied about the way I have been supported in the decisions I make for my loved one’s care.</td>
</tr>
<tr>
<td>Variable 14h.</td>
<td>When I think about the time I have been a caregiver I am satisfied about the way I have been supported in the decisions I make for my post-caregiving life.</td>
</tr>
</tbody>
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When comparing the participants who joined a support group within a year of the onset of the caregiving event (n=13), to caregivers who waited a year or more to join (n=13), the responses to questions that concerned their perceived skill levels in making decisions for their care-recipients and themselves reflects their perceptions of their ability to face changes in their post-caregiving life. What the data indicates is that the participants in the survey who joined within a year scored lower in feeling prepared than those who waited two or more years to join a support group. The length of the total caregiving experience appears to affect perceptions of competency for many of the participants.

When asked about the support they received when they made the decisions regarding their loved ones, the group that joined a support group quickly was more likely to feel supported (92% vs. 60%) than those who waited to join. When asked about the support received for the “decisions you make for your post caregiving life (V.14.h)” the group who had delayed joining a support organization was more likely (60% vs. 31%) to feel supported. This last variable’s response analysis could be skewed by the large number of “Don’t know” responses
(54%) from the group that joined a support group quickly.

**Quantitative summary**

When caregivers were sorted into three groups based on the duration of caregiving experience the data indicate that the newest caregivers (those with three years or less caregiving experience), are the most likely to have discussed chronic sorrow or anticipatory grief with a medical professional. Those with three years of experience (the participant mean and mode of years of caregiving experience) reported that 22% had discussed the topics. Participants with three years or more of caregiving experience reported 11% had discussed these topics with medical personnel. When asked if they felt prepared to face the changes in their lives, no one with less than three years of experience felt prepared. In all the groups the majority of the caregivers felt supported in the decisions they made regarding their loved ones.

The twenty-two participants in the survey that indicated they were satisfied with the support they received from their local support groups represented 75% of those who indicated overall satisfaction with their
skills in making decisions for themselves and their caregivers. There appears to be a positive correlation between support and feelings of self-efficacy, as the same twenty-two individuals also accounted for 73% of those responders who were satisfied with the support they received in making decisions for their loved ones care, and they accounted for 93% of those who answered that they felt prepared to face the changes in their life in regards to end-of-life issues.

**Qualitative Data Analysis**

One qualitative question was asked on the research instrument (“What one thought would you share with someone who had just begun their caregiving experience?”). Twenty-six of the twenty-eight participants answered this question. Two major themes emerged: 11 of the responders would urge people to join a support group and 9 participants would advise caregivers to be patient and kind to both themselves and their care-recipient. Two of the writers simply said, “Forgive yourself.” One wrote, “Be strong. Be kind.” Some advised people to “have a sense of humor” or to “be persistent.” The most poignant response came from a participant who has been caregiving for two years and who was attending their first support group
meeting. He or she wrote, “I don’t know yet.”

Five interviews were conducted during a two-week period. Five individuals were selected to reflect the differing voices within the caregiving community, as well as the different geographic and socio-economic levels represented in the population sample. In keeping with the gender ratio reflected in the participant pool I made the decision to interview two males and three females. This gender ratio is also in keeping with the national standard for caregivers. The one gay male caregiver was specifically chosen but the other four interview participants were selected at random.
Three of the interviews were conducted in the homes of the participants (Lisa, John and Bart), and two were conducted in public spaces (Connie and Diane). The interviewees chose the time and place of our meetings. The care recipients of both John and Diane were in the home, but not in the room at the time of the interview. Bart’s wife died in hospice in 2010, thus we had complete privacy during the interview. All of the interviews were taped with no editing before transcription.

<table>
<thead>
<tr>
<th>Caregiver</th>
<th>Gender</th>
<th>Age (years)</th>
<th>Home location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Connie *</td>
<td>Female</td>
<td>32</td>
<td>+5</td>
</tr>
<tr>
<td>Diane *</td>
<td>Female</td>
<td>52</td>
<td>+5</td>
</tr>
<tr>
<td>Lisa *</td>
<td>Female</td>
<td>67</td>
<td>-$</td>
</tr>
<tr>
<td>John *</td>
<td>Male</td>
<td>83</td>
<td>+5</td>
</tr>
<tr>
<td>Bart *</td>
<td>Male</td>
<td>88</td>
<td>+5</td>
</tr>
</tbody>
</table>

*Names are changed.*
The study participants were aware of my dual roles as caregiver and researcher. I believe this duality allowed for a tacit understanding between researcher and participant that encouraged the participants to answer the questions in a particularly unselfconscious manner. They also felt free to ask me questions about my caregiving experience. I believe that these shared experiences and emotions allowed the participant and researcher a certain level of comfort during the interview. Research rapport can be seductive to both the researcher and the participant. Too much intimate information, shared quickly, can shut down communication rather than enhance it. I was careful during the interview to use reflective listening and narrative reframing skills so that I could be relatively sure that I was “hearing” the caregivers voices, not my own. I waited for a participant to introduce a topic for discussion before I entered into a conversation with them concerning that particular theme. I tried to account for the possibility of a reactive effect due to selection and researcher bias during the interview process.

After the interviews were completed it appeared that four major themes were shared by the participants. These were also the
themes that I observed being discussed when I attended the support group meetings prior to administering the research instrument.

**Table 3 Core themes and sub-themes**

<table>
<thead>
<tr>
<th>Core themes</th>
<th>Sub-themes</th>
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<tbody>
<tr>
<td>Theme 1</td>
<td></td>
</tr>
<tr>
<td>Caregiver challenges</td>
<td>Physical</td>
</tr>
<tr>
<td>Theme 2</td>
<td></td>
</tr>
<tr>
<td>Coping adaptations</td>
<td>Internal, Acquired</td>
</tr>
<tr>
<td>Theme 3</td>
<td></td>
</tr>
<tr>
<td>Support structures</td>
<td>Support, Friend</td>
</tr>
<tr>
<td>Theme 4</td>
<td></td>
</tr>
<tr>
<td>Need for better caregiver supports</td>
<td>Formal, Informal</td>
</tr>
</tbody>
</table>

_Challenges of caregiving: Physical, emotional, and social costs._

This theme emerged as the dominant concern among the five caregivers interviewed. They described the key challenges as obstacles that had to be
learned and mastered so that they could meet the demands of caregiving as they continued to increase due to the cognitive and physical decline of the care recipient. While not all of the caregivers found the caregiving role to be physically exhausting, most acknowledge that the additional burden of being physically responsible for all of the aspects of their care recipient’s environment was tiring. John, an eighty-three year-old retired college professor with a heart condition, cares for his partner. He describes his typical day:

I get up to take Thor (their dog), for a walk around six. I don’t get back in bed, I stay up. Then Peter gets up anywhere between 7:30 and 8:30 and I’ll make breakfast. And then he’ll go in and watch the TV, I’ll clean up the dishes and make coffee. I get coffee for him a couple of three times a day. Then I take Thor out. I do all the laundry, not everyday, but I do our laundry. He has crazy accidents, he was standing in front of the TV and he peed on the damn table. Then one time there was poop in his bedroom, all over the floor in his bathroom and down the hall into my room. I spent almost the whole day just scrubbing and scrubbing. I do all the housekeeping. It is beginning to get
to me, I mean it’s getting to where I’m glad to go to bed at night.

During the interview John mentions the chores associated with taking physical care of Peter multiple times. Both his body language and his voice clearly indicate that he finds this aspect of caregiving difficult. He does not contemplate seeking assistance for this aspect of caregiving even though it distresses him, but he does consider finding help in keeping the house clean.

Connie is a thirty-two year-old single mom and is the caregiver for three people. She has a three year-old daughter who suffers from autism, a sibling who receives 34 hours a week of in home care due to Grand-mal epilepsy, and her mother who was diagnosed nine months ago with a progressive dementia. She also maintains the family home that she shares with her father, daughter, mother, and brother. In addition to maintaining the family’s physical environment, she schedules her brother’s caregivers, manages everyone’s medication needs, and shares financial duties with her father. Connie also assists her daughter’s therapist with a very demanding physical therapy protocol. Her days are tightly structured. She told me they have to be in order for everyone’s needs to be met. “It’s
important that my daughter keeps her routine, ‘cause that really messes things up for her. So my timing has to be pretty much just right.” Her only time to do household chores is at night after the care-recipients are in bed. The result of this schedule is that she rarely sleeps more than 5-6 hours a night and since she began caregiving she has developed high-blood pressure.

Diane and Lisa both work outside the home, and both have spouses who assist with caregiving. Diane further shares her caregiving duties with two older sisters. She goes to her parents’ home directly from work 3-4 days a week. She stays for several hours and leaves after she has bathed her mother, and put her to bed. The sister that had been taking care of her parents’ physical environment is having medical issues herself, so Diane is now carrying an increased share of that burden as well as the role of medication manager. She also hopes that in the very near future formal physical care supports can be put in place to care for her mother. Her caregiving duties are further complicated by the cognitive and behavioral changes displayed by her father, after a life-threatening illness two years ago.

Lisa’s mother lives with her and at this time she is able to physically care for herself.
Lisa’s caregiving actually began when her father was taken ill: at that time her parents had their own apartment. As the level of caregiving increased, so did Lisa’s stress. Lisa’s solution, with the support of her spouse, was to move her parents to her home to care for them. This move meant that she was responsible for maintaining only a single environment. Bart’s spouse died three years ago. When Bart was a full time caregiver, and 85 years old, he did get help in caring for his home. He preferred to get help with cleaning chores rather than with his caregiving duties. The physical aspects of caregiving often bleed into the emotional and social areas of the caregiver’s life. Time devoted to the needs of a partner, parent, or sibling will mean less time available to interact with a child, lover, or friends. Time, or more specifically the lack of it, becomes a driving concern and stressor for many caregivers.

All five of the caregivers suffer from illnesses that have recognized linkages to prolonged periods of exposure to stress-filled environments: high-blood pressure (n=2), diabetes (n=2), heart ailments (n=2), and anxiety (n=2). Two of the caregivers are currently seeing therapists to discuss their feelings about caregiving. The two male caregivers suffer from cardiac conditions.
They are reluctant to name caregiver stress as the direct cause of their health problems and both appear to be more comfortable identifying their heart disease as a result of the natural aging process complicated by stress. Two of the women feel that their health issues are a direct result of caregiver stress. The remaining woman does not believe that caregiving caused her illnesses, but she does feel that it exacerbates them.

In the interviews I conducted for this study and in the support group meetings I attended, the most painful aspect of the caretaking experience appeared to be the loss of the relationship shared by the caregiver and the care-recipient. Talking about the loss of the former relationship often brings the participants to the edge of tears. When Connie speaks about her mother she says:

It’s just…sometimes it’s like being my mom, to my mom. I think that is one of the bigger things I had to learn. I also had to learn that taking things personal from her really needs to be on my back burner. Because… there are days I cry, every day. ‘Cause she wasn’t nice. She wasn’t my mom. When Diane was asked about her emotional response to caregiving she weepily told me “I see those commercials…”
I just want to be a daughter again.” When I hear Connie and Diane speak of missing the person who once was, I consider the universality of those feelings among caregivers. It is so poignantly human to define ourselves in the reflection of a loved one’s eyes. When those eyes no longer reflect us, who are we? These women speak to the heart of chronic sorrow, the time when “loss is not final.” Every caregiver I interviewed spoke of “missing” the person their loved one once was and how they struggle to hold on to that image of their loved one. All of them also talk about their feelings of anger; sometimes it is directed towards the actions of the care-recipients, but more often it is directed at the disease itself. Bart’s anger is reserved for doctors who say that “No one dies from Alzheimer’s.”

Several of the caregivers mentioned that the loss of speech was a particularly hard blow. When the ability to freely communicate with their loved one was lost the caregiver quickly felt the loss of companionship as well. A woman at one of the support group meetings said, “It’s like living with a ghost.” A quick loss of language was one of the hallmarks of my partner’s presentation of his dementia, and hearing others speak of their sadness reminded me of my own
feelings of loss when David became silent. John and Bart both commented on their partners’ loss of speech with great sadness in their voices. This absence of free communication affects the caregiver and care-recipient on an emotional level. Yet, communication does not just reside in the ability to speak. As long as two people are able to convey an emotion or an intent to one another, communication exists. Bart relates that his wife used to love to dance. One day, long after she lost her ability to hold a conversation, it was discovered that she remembered how to dance. “One time they had music playing and she got up and started dancing. And you could see in her face and in her action that she knew. She would just be so beautiful.” Bart thinks that dancing with him was his wife’s way of telling him that she remembered him and their life together. John feels that his partner communicates with him when he kisses him on top of his head. I, myself, am certain that when my husband laughs after I call him “banana nose” he is remembering me. As the disease worsens even these moments of perceived connection are lost, feelings of isolation are a natural response to the loss of even these faint touches.
When caregivers speak of their sense of social isolation it may be related to the time constraints produced by the multitude of physical tasks associated with the caregiving process. But more often it is the loss of association with previously close friends or family that conveys to them a sense of isolation. Very rarely do caregivers use respite services (the cost is $25-$50 an hour) that could provide them with an appreciable amount of time for socializing. John is looking for state assistance in obtaining respite care because of the expense. He reports “A registered nurse came out on late notice to provide five hours of care so I could go to my granddaughter’s birthday party. It was $25 per hour. Last Christmas it was going to be $48 per hour, so I canceled it.” The cost, coupled with the guilt many caregivers feel when leaving their care-recipients in another’s care, means that caregivers often feel trapped into remaining in close proximity to the dementia patient. John said he felt that using a paid respite caregiver was comparable to “leaving him alone.” Bart also felt he was failing in his caregiving duties when he placed his wife in a respite day program. Some support groups provide a separate room in their meeting facility; there care-recipients are watched by a volunteer in
order to provide the caregiver with an opportunity to be fully present to the group. But more than a few caregivers admit that they leave their loved one home alone.

Visitors may be uncomfortable when they are exposed to what they perceive of as a “mental illness” and are reluctant to visit when they could witness behaviors that are socially taboo, such as incontinence and the un-filtered speech that the dementia sufferers often display. Bart talks about his experiences with no one coming to visit his wife, not even people from their church. We discussed how bad it made us feel when people failed us at the time we feel we most need them. That conversation prompted him to confess his own bad behavior:

I can tell the story; my best friend was my brother-in-law who also happened to be Jean’s cousin. And he had Alzheimer’s. And he, ah, stayed at home much too long. Much, much, too long. And when he finally got into a nursing home, I think I went to see him twice. I couldn’t do it. And you know, we were very close. Couldn’t do it. No. So I don’t cast any bad stones at people, if people can’t do it. I understand why they can’t do it. I’ve been there.
This perception of isolation, though much discussed in the support groups I attended, was addressed during the interviews only by spousal caregivers. If you are a caregiver who has a supportive relationship with a sibling, father, or spouse, the support appears to lessen the caregiver’s feelings of isolation.

Of the five interviewees, the two presently with the highest physical degree of caregiver burden John and Connie, are also the ones that expressed the strongest feelings of isolation. Connie simply has an extremely limited window of opportunity in which to pursue social relationships, but she does have her father to assist her periodically in a few of the physical and fiscal tasks associated with caregiving. She has a therapist she visits bi-monthly and a friend she sees 3 hours a week. John, on the other hand, has remained fairly active in the community but he is doing all of the fiscal and environmental tasks as well as his caregiving duties on his own. Bart is no longer an active caregiver; Lisa and Diane are part-time caregivers and they both have family members to support them.
**Coping adaptations: Internal locus of control and new skills.**

All of the interviewees identified the number one skill they developed during their caregiving experience as *patience*. Patience with the emerging behaviors displayed by their loved ones, patience with the loss of the care-receiver’s capabilities, patience with the lack of support for both themselves and their loved ones and patience with their own perceived failings as a caregiver. They all acknowledge that the behaviors exhibited by their loved ones are the effects of the dementia. They also recognize that their anger is in response to the situation caused by those behaviors, not toward the person that initiates the response. Connie speaks about her mother’s illness as “going in cycles” and how she has taught herself to see the behaviors as events that occur in encapsulated periods of time. Several times she talked of “building walls around herself” in order to minimize her emotional response to her mother’s outbursts. “It was earlier in the day, you know. I can help her right now. ‘Cause if not, I hold on to it, and that doesn’t make any sense.” Diane finds that her patience is tested not by the dementia sufferer, but by her father. His need to direct her mother’s care often conflicts with Diane’s ability to
accomplish the task. She reports, ”So I guess it’s more for him…because I can understand the disease, and I can deal with that part.” Lisa, whose 93 year-old mother is still verbal, admitted, “ My, my big thing is patience. That’s what I deal with the most, because I just despise repetition and what am I doing but repeating over and over again.”

When these caregivers identify a needed skill and then master that skill, they indicate that learning and using the skill helps them adapt positively to their caregiving. Using the new skill positively impacts their sense of self-efficacy. Both of the males remarked on their improved cooking skills. They used the resulting skills to entertain friends during the early stages of the caregiving experience. Connie spoke with satisfaction about the skills she and her father developed in order to manage the family finances and the fact that they now worked as a team to do so. Diane reported that learning how to share caregiving duties with her two sisters led to closeness between the three of them that had not been present since childhood.

The acquisition of new skills by caregivers cannot negate the stresses of the caregiving experience. The caregivers feel
that every time they learn a new skill, a new need arises for yet another skill. Connie tells of her mother’s arrest for shoplifting at the local grocery store. Connie says she “had to learn to shop efficiently. My mother had time, apparently, to go three times a day to the same Stop & Shop. I don’t have that time.” She does not view food shopping as an asset; she views it as a deficit, just one more chore in an already task laden environment. She identifies her new “efficient shopping” ability as one of the costs of the natural progression of her mother’s dementia.

Each newly acquired skill may represent a newly recognized deficit presented by their loved one. While in his late seventies, Bart realized he needed to re-learn how to ride a bike. In order to allow his wife her personal freedom to go walking, he needed the means to covertly observe her in order to keep her safe (from stray dogs, traffic, or getting lost). When Bart tells me this story there is a mix of amusement and pain in his voice:

She wanted to go for a walk and she wouldn’t let me go with her. And I wouldn’t let her go alone. So I was following her and she saw me. She was outraged, absolutely outraged, but that
is what I had to do. I had to keep her safe.

This ongoing need for new skills and the information needed to foresee and develop those skills, coupled with the uncertainty of the disease timeline may affect their feelings of control and resiliency. John is frightened that “I may be getting close to my limits, and there is more than that; it could start taking me down hill.” Diane, in talking about her father and his reluctance to put in writing who will make decisions for himself and her mother, reflects that “if something happens to my father, whoever he chooses worries me more. Because you know, you have to have someone that will be able to make choices for her.” Connie is very agitated when she discusses the eventual need to place her mother in a care facility:

I don’t know that there is ever going to be a day that my father would be willing to have my mom in a facility. I don’t know. I think that is a reality, and I think he probably should have started yesterday thinking about this, because it will take a long time to do that. It is going to be a kind of issue in our household, and I don’t want it to [be].
These three caregivers all recognize that eventually the disease will remove their loved ones from their care, either because of the presentation of the illness itself, or their own inability to continue the caregiving process. Once again time becomes an issue. John’s fear is that his growing older, coupled with the ever-increasing physical burden of caregiving, will necessitate surrendering his partner to paid care. He equates this scenario with his partner “being left alone.” Diane sees her father’s increasing cognitive deficits as a threat to her mother’s future and her ability to care for her. Connie worries that the current partnership between her and her father will be affected as her caregiving burden increases apace with her mother’s dementia. She fears the time when she will have to make a choice between her mother’s needs and her daughter’s care. Time and the vagaries of the disease trajectory have robbed these caregivers of their sense of control over their own future and that of their loved ones.

**Support structures: Support groups, family, friends**

This theme revealed that the major transfer of information to caregivers occurred in the support groups they used. Only one
Interviewee, Connie, the youngest and newest participant in caregiving, does not maintain a membership in a support group. The remaining four participants credited support group members with providing them with information that ran the gamut: from bathing tips to what legal documents would be needed and how to procure them, from the stages of dementia and the possible behaviors presented in those stages to how to learn to forgive yourself when you felt you failed as a caregiver. Diane suggests that “It does help listening to what they go through, how they handle it, different ways they handle it.” Bart admits that he never went to a support group until he used a day-care respite program for his wife. The women there encouraged him to go:

“I’ve never been to a support group in my life. Go to a support group—what are you out of your mind? I’m not going to a support group. I respected them…so obviously I must have been displaying stress, and so I said okay, I will give it a try. So I went and I’ve never stopped going.

Lisa reports that her mother’s gerontologist doesn’t talk to her about the trajectory of the dementia. At this time he appears more
concerned with her mom’s physical health and she is satisfied with his services. When asked where she gets her information about the dementia she replied, “I get it from, from the support group, you know, [I learn] how things are going to be progressing from the other people. That’s how I started to get information.” John is now involved in a LGBT caregivers support group, but it is just beginning and some days he and the facilitator are the only ones present. Yet he still feels that the facilitator, “has been very helpful. And that will enable me to avail myself of outside help.” He wishes that he had known about support groups sooner because he feels he would not have waited so long to get the legal documents he needed to better care for his partner.

Within support groups the lack of familial support is often discussed and the members talk about family not wanting to “see” the evidence of the dementia. It is not uncommon for the caregiver to be told they are exaggerating the decline of the care-recipient or even that the care-recipient is showing improvement. The most common form of familial support provided to the primary caregiver is verbal. On some occasions there may be limited periods of respite time offered to the caregiver, perhaps two or three hours per month. Daily physical
relief and support from caregiving duties is rarely tendered.

Diane is part of a triad of sibling caregivers involved with the care of her mother (and in reality her father too). She is the only caregiver interviewed that has consistent familial support. Connie’s mother receives no support from her parents or siblings even though they live less than ten miles away. Bart had four children, and the longest period of respite support they offered him during his caregiving occurred when he had to have major surgery. Each child returned home and provided care in one-week shifts. As parts of a familial unit they cared for both parents for one month. It is clear that this show of support meant the world to Bart, as he had to pause in the telling to wipe his eyes. He described the experience as being “very beautiful.” Lisa has one sister and she is not involved in their mother’s care. John and Peter had previously been married to women; both of their former spouses are still alive. From those marriages they each have two sons and the sons are not involved in the caregiving process. The interviewees and the support group members I visited with during my field research agree that it is very unusual to have a truly shared caregiving experience within a familial system.
Support from friends during caregiving very rarely consists of physical support in regards to the needs of the care-recipient. Their support is directed at the caregiver and it usually consists of a phone call, a lunch out, or the occasional card or email. Bart expressed it well when he admitted:

It’s kind of interesting because I received very little help. I received help from my friends who are members of the same church. Not coming here and doing stuff, but they were very aware of what I was going through. But from my church and people going to see Jean…zero.

**Need for better caregiver supports:**
**Formal supports, information delivery**

The caregivers themselves reveal the need for improved support systems. Caregivers want more and better information at all points during the caregiving event. They recognize there are common experiences shared during caregiving, but they also feel the need for specific, individual support. Connie is thirty-two. The support group where I met her three months ago, was the first and only time she attended a support group meeting. My reaction to support groups mirrored Connie’s and in this
instance her voice could have been mine. She feels that between her mother’s doctor and the Internet, she has plenty of information on the trajectory of her mom’s dementia. What she lacks is support from a group that looks like her:

I think it’s helpful for someone in my position, where I am younger, my mom was diagnosed younger, and I think it is so helpful to have a younger person to relate to. I think you don’t find that [in support groups]. But I think that you know looking at things now, I’d love to hear from another thirty something-year old. I’m going through this, and it happened so quickly. I want someone to be there and say you know what, I cried myself to sleep for nights because I just couldn’t know how to deal, that my Mom was, fifty-four, or whatever. You know I think that for me would be more helpful. I think that’s what I long for, it’s that age kind of peer stuff.

Receiving support is clearly important to all of the interview participants and it appears to be critical in easing the feelings of isolation that caregivers so often allude to. That the majority of this perceived support is derived from sharing the experience with other caregivers is attested to by the
caregivers’ own words. Bart neatly summed up the value of a support group to caregivers:

I knew what the end result was going to be, but I didn’t know all the little bumps on the way there. And you learn those as you go along. You know where you’re going to end up, but you don’t know what the road is till the finish line. And ah, it’s hard.

**Qualitative summary**

There were four core themes that emerged during the interviews and from my observations at the support groups I visited. The themes are: the biopsychosocial challenges of caregiving, caregiver coping skills, caregiver supports, and the need for better supports. Caregivers speak of being overwhelmed by the myriad of tasks they need to perform in order to care for their care-recipients and their other family members. They spoke with one voice when asked if they valued discussions concerning the emotional aspects of caregiving. They expressed a need for information on health and emotional issues that affect caregivers. The feelings of the interviewees on these issues reflects the results obtained from
analyzing the quantitative data gathered from the survey instrument.

They shared their feelings of loss when the disease process altered their loved ones. The majority of them reported that they felt sad and overwhelmed when contemplating their loved ones’ end-of-life issues. They talk at support meetings about their loneliness and feelings of being separated from social interactions because of their caregiving duties.

The coping skills of all of the participants seem to begin with the need to learn patience. Patience with their care-recipient, family members, friends, doctors, and, most importantly, with themselves. At times their newly acquired skills increase their feelings of mastery and self-efficacy. But some new skills may also serve as a reminder of the continuing losses experienced by their loved one. Or they may actively reinforce a caregiver’s fear that the remaining skills needed to care for a loved one may lie beyond their abilities.

Caregivers who participate in support groups see the groups as their best chance of accessing “real world” information and personal support. The support offered by family and friends is viewed as sporadic and
appears tenuous according to some of the study’s participants. Those interviewed indicated that their doctors and their care-recipient’s doctors, did provide them with satisfactory medical care. But the doctors did not always give them the information they needed to address the emotional and social burdens that arise during caregiving.

The caregivers who voiced the most satisfaction with their support group were the ones that attend the only weekly support group I visited. Participating members of the other groups that met bi-weekly or monthly also expressed feeling supported, but not to the degree of those attending the weekly group meeting. The interviewee who only attended one support group meeting felt that she needed to find a support group where the members were closer to her demographic descriptors in order to feel a part of the group, rather than apart from the group.

**Discussion**

This study describes the value that information and support hold for family caregivers of dementia patients. It indicates that a support group serves a dual purpose; it
functions as a primary support mechanism, and it serves as an information delivery site for its members. Each meeting that an individual participates in is in essence an intervention. It also suggests that the timing of information delivery by formal support systems may not be critical to caregivers’ overall perceptions of support. Though it does appear that the primary health providers of both the caregiver and the dementia patient have a role to play in a caregiver’s perception of support, that role does not appear to be substantive if a caregiver has a sustained, supportive relationship outside of the medical community. The data from the quantitative research section of the study would appear to buttress the current research that indicates it is better to take a proactive approach rather than a reactive approach in introducing supports and information to caregiver systems. Since participants indicate that the majority of their caregiving information is obtained from support groups, as well as the majority of their personal feelings of support, the sooner they are introduced to a support group the more empowered they will feel. The perceived importance of the availability of support systems that reflect the differing needs of specific sub-systems within the evolving caregiving population is voiced in the
interviews and at the support groups I visited. Idiographic (individual) interventions for these sub-sets of caregivers should be considered if there are no local support groups that reflect their cohort demographics.

One of the support groups has a member who is experiencing her twenty-first year of caregiving. Her feeling of self-efficacy is firmly centered and she feels supported in all her decisions, yet she too reports feeling sad and overwhelmed when thinking about her loved one’s end-of-life issues. Other members continue to attend meetings even though their loved ones died years ago. This indicates the need for emotional support appears to remain constant throughout the caregiving event, and beyond. Just as the health deficits remain for caregivers 1-3 years post caregiving experience; the emotional burden may remain even longer. The self-identification as a caregiver may not end when the loved one is placed into a long-term care facility or hospice, nor even with their death. This suggests that we may need to see chronic sorrow as a process that has to complete its final cycle before the more linear presentation of normal grieving begins.
In my observations of the support groups that I visited, the group that appears to be the most strongly self-sustaining and highly functioning was also the only one that met once a week. Within the state are caregivers who travel from meeting to meeting in order to obtain the level of support they perceive they need. It appears that gathering monthly, or even bi-monthly, is not optimum in meeting caregiver needs. Several groups also provided caregiving services to the dementia patients at the meeting sites of the support group. This service provides the caregivers with the opportunity for undistracted participation in the support group meeting. One of the most basic needs of caregiver support is respite care. The lack of available, affordable respite care prevents many caregivers from having the time needed to involve themselves in activities outside of their caregiving experience. The psychosocial benefit of being able to step away from unceasing care duties for a few hours or days, could add much to a caregiver’s quality of life.

Caregiver guilt is a recognized phenomenon and it can manifest itself in real-time fantasies of the loved one’s death, an inability to sleep through the night post placement of the care-receiver in a formal
care environment, or a refusal to return to previously pleasurable personal pursuits after the loved one’s death. It would appear that for most familial caregivers the caregiving experience defines their life during the period of caregiving and for some time after it ends. Its effects should to be given the attention that they deserve when considering the total lifespan costs caregivers appear to pay in fulfilling their duties. These costs are not confined to only the biological and psychological burdens borne by the caregiver because fiscal costs are also part of caregiving burden. Caregiving costs for Alzheimer’s caregivers were $144 billion in 2009. Sixty-nine percent of those caregivers were women. Women, who are already economically damaged because of lower wages, often need to give up outside jobs in order to fulfill their caregiving duties. A few states recognize these fiscal costs to familial caregivers and they provide the caregivers with a small stipend for their duties. If this program was universal the financial burdens placed on caregiving families in general, and women in particular, could be ameliorated.

The testimonies of the study participants are clearly heard during the interview process and during support group meetings when, as one woman wrote, the need is to “share the
journey, so we can walk it together.” Or when Connie speaks vehemently of her longing for “someone who looks like me, a younger person to relate to. To be really clear, to be out there. Let’s not mince words, this is how it is.” It could be posited that in order for an individual to recognize the validity of a group they must be able to see themselves as being a recognizable member of the group. The demographics of familial caregivers are inexorably changing, and as social workers we should shape our responses to meet the changing needs of 21st century caregivers. There are both demographic and cultural implications that need to be addressed when implementing support groups for certain sub-systems of the caregiving population. A dementia support group should mirror the reflections of the caregivers, not those of the care-recipients.

Caregivers perform multiple tasks, many of which are based on skill sets they are forced to quickly master during the course of their caregiving event. Caregivers express a desire for a proactive approach in information delivery, and it appears that the most effective way to disperse the information needed to build those skills may be through support group participation. Caregivers perceive that support groups
offer them a place to speak without filters, a
place to cry without apology, and a venue in
which the sacrifices required by their
caregiving experience are both valued and
understood. The support groups offer them a
place to address emotions that are associated
with chronic sorrow: anger, confusion,
helplessness, guilt, self-blame, and feelings
of being overwhelmed. In sharing their
stories, their social currency is earned by the
knowledge and skills they have acquired
during their caregiving event, and
reciprocity in social interactions is in the
free exchange of information during
meetings.

Implications

>When I began this study I expected to be
able to indicate that early interventions
would be perceived as valuable by
caregivers in dealing with the feelings
associated with chronic sorrow. I did find
that caregivers value information and that
they expressed the opinion (in sufficient
numbers) that timing in information delivery
is important to their feelings of
preparedness to face their ongoing
caregiving challenges. However, I had
thought that the information was of
paramount importance. I was unprepared to
find that it was the perception of support that was of paramount importance. Caregivers are so desirous of support that they are willing to acknowledge support as being the idea that someone may be thinking of them as a gesture of concern. What does it say about familial support when caregivers feel less supported by family than they do by doctors or friends? Participants in this study who feel supported report they derive the majority of that support from their caregivers’ group; friends were rarely mentioned by other primary caregivers. This is an interesting omission considering that the quantitative data indicates that 82% of participants feel satisfied with the support they receive from friends. Could the caregiver’s interpretation of the term “friends” include their support group cohort? When asked about their satisfaction level with support groups, 79% of the participants responded positively, yet during the time I spent in support groups throughout the state, friends were mentioned only if they were serving as the primary caregiver.

As those born post World War II move into the caregiving forefront, the ease of online information acquisition could be one of the primary forces that reshape caregiving dynamics during the next two decades.
Younger caregivers are comfortable with acquiring information about illnesses from online sources. Older caregivers may be less trusting of online information and may not have ready access to computers. They, and those caregivers who may not have the economic resources to support a computer or online provider, will need to continue to receive primary information support from their physicians or case managers. And while there are online support groups that may offer some comfort, I think that the need for the human connection has been addressed again and again by the participants in my study.

The issue of support is one that speaks strongly to social workers. It is the focal point of one of our six core values, that of “Service: Providing help, resources, and benefits so people can achieve their maximum potential” (Kirst-Ashman, 2010, p. 31). Caregivers have needs that require a complex interweaving of multiple formal and natural support systems in order to assist them through a caregiving event that can last for years or even decades. Specifically, we need to consider the importance of establishing a strong presence in local community caregiver support groups. Our skills in mezzo work coupled with our respect for cultural diversity could enable us
to form support groups that address the needs of particular sub-systems of dementia caregivers. Respite care, fiscal funding for familial caregivers, and case management for caregiving families are issues that pertain to system changes. Well supported caregivers may be more able develop coping skills that allow them to effectively process the physical and emotional impacts of caregiving, such as chronic sorrow, with less cost to themselves. The ability to address those needs could benefit not just the individual caregivers and their families, but also lessen the societal impact of caregivers becoming premature care-recipients.

I believe that this study has raised two interesting questions for social researchers. One question pertains to the apparent expansion of the role support groups play in caregivers’ lives to include that of friendship. Does this perception of “friendship” with other support group members exist outside the confines of the support group structure? Clearly, support groups fill many caregiver needs: for information, for support, and perhaps for friendship. But I believe that the primary question concerns the role information technology will play in a 21st century familial caregiver’s support system. How will the answer to that question shape future
support groups’ ability to reflect a caregiver’s need for “Someone who looks like me.”

1

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