

SUPPORTING CAREGIVERS OF PERSONS WITH DEMENTIA AT END-OF-LIFE

SUPPORTING CAREGIVERS OF PERSONS WITH DEMENTIA:
A PSYCHOEDUCATION PROGRAM AT END-OF-LIFE

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Lay Abstract

Family caregivers of persons with dementia can become depressed, anxious and isolated over time from caregiving. These feelings often do not go away even after the person with dementia has died. In this study, caregivers of people with advanced dementia or who had died, described how they felt about a new support and education program in a special unit of the hospital. Findings showed that caregivers believed the program helped them become: more balanced and part of a supportive community, empowered and prepared for end-of-life and occasionally frustrated. Caregivers whose family member had died felt the program gave them continued support, a chance to help others, and a place to continuing learning. Nurses should try to include caregivers in caring for people with dementia, learn about the program, become more involved, encourage people to attend, and help to begin the program in other areas of the hospital and long-term care.

Abstract

Informal caregivers (CG) of persons with dementia can experience increased negative effects and symptoms of burden as the disease progresses, with long-term effects into bereavement. The purpose of this study was to describe staff and attendees' perceptions of a unique CG psychoeducation program located in a Specialized Care Unit for persons with advanced dementia at end-of-life. This study used a qualitative descriptive design, which aimed to describe a natural experience. Sixteen individual interviews were conducted with current and bereaved CGs who jointly participated in the program, health care professionals (HCP) in the Specialized Care Unit and social work facilitators to understand experiences, perceived benefits and barriers of the program. Thematic content analysis was conducted with data collection following Hamilton Integrated Research Ethics Board approval. Final results indicate that the program was perceived positively, across all participant groups. Caregivers reported that the program contributed to improved emotional well-being, development of a close community, disease preparedness and empowerment. Participants also appreciated the open-ended, informal format of the program with continuity into bereavement. The study findings support the unique characteristics of this psychoeducation program compared to traditional education / support programs, which are closed to bereaved members and time-limited. This program model is translatable to multiple settings including long-term care. Moreover, study findings highlight the movement towards relationship-centered care for persons with dementia and their CGs. A future mixed-method study is warranted to measure quantitative outcomes, such as complicated grief, within CGs attending the program before and after bereavement.

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Abbreviations

CG	Caregiver
HCP	Health care professional
LTC	Long-term care home
Bereaved CG	Bereaved attending program caregiver participant
Non-Attending CG	Non-attending program caregiver participant
Program CG	Attending program caregiver participant
PHCP	Participant health care professional

Declaration of Academic Achievement

This thesis reports original research that I have conducted under the supervision of Dr. Sharon Kaasalainen, Dr. Sandra Carroll and Dr. Alexandra Papaioannou since September 2014. Committee members provided input regarding: the research proposal, design and methods (i.e. research questions, data collection and analysis), Hamilton Integrated Research Ethics Board application, and multiple drafts of the literature review, thesis chapters and entire thesis. I collected data from one site and completed all of the interviews. I completed transcription of audiorecordings.

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Chapter One

Introduction

In 2011, 747,000 Canadians were living with dementia and prevalence will rise to 1.4 million by 2031 (Alzheimer Society of Canada (ASC), 2012). Dementia is defined in the Diagnostic Statistical Manual of Mental Disorders (DSM-5) as a neurocognitive disorder, which can affect six cognitive domains including: complex attention, executive function, learning and memory, language, perceptual-motor function and social cognition (American Psychiatric Association (APA), 2013). Dementia is life-limiting and progressive, associated with multiple disorders, of which the most common of which is Alzheimer's Disease (Gauthier et al., 2012).

The impact of a dementia diagnosis can create negative effects suffered by caregivers. Informal caregivers (CGs) are defined as persons providing physical, emotional and financial care to a person with whom they have a relationship (i.e. spouse, adult-child, etc.) without pay (Schulz, 2013). These burdens increase as dementia progresses with up to 75% of CGs developing psychological illness and increases in mortality (Schulz, 2013; WHO, 2012). Therefore, the late-stage and end-of-life of a person with dementia represents a critical stage for CG intervention with long-term effects into bereavement (Romero, Ott, & Kelber, 2014; Schulz, 2013; Schulz, Boerner, Shear, Zhang, & Gitlin, 2006; Schulz, 2003). Both a systematic review of psychological interventions and a meta-analysis of support groups for CGs of persons with dementia reported improvements of well-being, social support and depressive symptoms within study participants (Elvish, Lever, Johnstone, Cawley, & Keady, 2013; Chien et al., 2011). This evidence supports the development of a new psychoeducational intervention program to provide emotional support and education for CGs of persons with dementia at end-of-life.

Purpose

The purpose of this study was to describe the perceptions of CGs of persons with dementia regarding a unique psychoeducational intervention developed to meet CG needs during end-of-life and into bereavement, in order to understand outcomes, barriers and facilitators. The program had not been studied. Valuable descriptive data results can be used to tailor, clarify program objectives, content, understand feasibility and implementation in order to support CGs at end-of-life. The psychoeducational program can be translated to alternative settings including long-term care (LTC), which further supported the need for description of CG perceptions. The format of this paper is as follows: literature review, methodology, findings, discussion and recommendations.

Chapter Two

Literature Review

Literature Search Strategy

A comprehensive literature review aimed to discern the following questions to inform the proposed study:

1. What is the trajectory and symptomatology of advanced dementia?
2. What do caregivers experience during advanced dementia and end-of-life?
3. What pre-bereavement intervention studies have been conducted for CGs of persons with advanced dementia at end-of-life or in similar populations?

Searches of Embase, Medline, CINAHL, and PsychInfo were conducted for articles published between 2003 and May 2014 utilizing terms summarized in Table 1. Articles included in this review consisted of quantitative and qualitative studies of current or bereaved CGs providing care to: persons with moderate to late-stage dementia, adults receiving hospice/palliative end-of-life care or persons residing in LTC which suggested end-of-life. Studies were excluded involving CGs of persons with early-stage dementia or interventions without a group, face-to-face component. Long-term care homes are defined as residential facilities providing personal nursing care 24 hours per day. A thorough description of interventions aimed at CGs of persons with cancer receiving palliative care was beyond the scope of this review. Included study quality was assessed using Critical Appraisal Skills Program [CASP] tools last revised in 2014 and suggested as a resource for appraisal by the National Collaborating Centre for Methods and Tools at McMaster University (2011).

Table 1

Literature search terms

-
- 1) Dementia or Alzheimer's disease or palliative or terminal care or end-of-life *and*
 - 2) Caregiver or carer or family member or caregiving *and*
 - 3) Intervention study or experimental design or support group or psychoeducation or or counselling *and*
 - 4) Bereavement or bereavement support or grief or depression or complicated grief or personal loss
-

A summary of 14 articles providing the foundation for this review is provided in Appendix A. The search for intervention studies resulted in 295 English articles for review after 13 duplicates were removed. A search of grey literature utilizing Google Scholar was performed to identify reports from organizations such as the Alzheimer Society (a national non-profit education/support and resource organization) and the World Health Organization. Database results included 11 systematic reviews of interventions for CGs conducted between 2003 and 2014. Of these, seven systematic reviews focused on interventions for CGs of persons with dementia and four reviews focused on interventions for CGs of palliative persons at end-of-life. In this manuscript the terms 'end-of-life' and 'palliative' refer to persons nearing death (approximately one to two years life-expectancy or less) as these terms are used synonymously in the literature. Alternatively 'palliative approach to care' refers to a holistic approach to care of any persons with life-threatening illness through prevention/relief of suffering, aimed at improving quality of life (WHO, 2012).

Clinical Course of Dementia

The initial diagnosis of dementia can involve a prolonged, frustrating and stressful process for informal CGs often due to lack of physician knowledge and inconsistencies in diagnostic criteria (Prorok, Horgan, & Seitz, 2013). Complicating diagnosis is the variety of subtypes of dementia which exist including: Alzheimers, Lewy Body, Creutzfeldt-Jakob, Fronto-temporal, and Vascular (APA, 2013). Neuro-degeneration results in escalating functional dependence on CGs over time, often culminating with admission to LTC homes during moderate to advanced stages (Brown, Sampson, Jones, & Barron, 2012; Hennings, Froggatt, & Keady, 2010). Distressing symptoms of dementia include patterns of progressive, non-uniform behavioural and personality changes referred to as Behavioural and Psychological Symptoms of Dementia or BPSD, impaired memory and reasoning, eventual loss of speech, motor skills and awareness (APA, 2013; Gauthier et al., 2012; Mitchell et al., 2009). Challenging responsive behaviours can include wandering, agitation, apathy, resistance to care, hallucinations, paranoia and physical violence or aggression (Mitchell et al., 2009).

The trajectory of dementia varies and is unique from other terminal diagnoses with mortality ranging from six months to greater than 20 years depending on classification and age of onset (WHO, 2012). Diagnosis is often delayed two to three years following symptom appearance and available prognostic tools remain unsatisfactory in their ability to predict mortality, decreasing CG's ability to anticipate and plan for end-of-life (Brown et al., 2012; Hennings et al., 2010; Mitchell et al., 2012; Sanderse & Cochrane, 2014). Furthermore, persons with dementia are often not recognized to be dying by health care professionals (HCP) and family members, diminishing the provision of end-of-life care (Hennings et al., 2010).

The Global Deterioration Scale is utilized internationally to measure or categorize progression of dementia into seven stages (Mitchell et al., 2009). Advanced dementia is defined as stage seven criteria with personal characteristics of: extreme cognitive deficits including lack of recognition of family members, absolute functional dependence, incontinence of bladder and bowel, lack of ability to mobilize independently and minimal communication through speech (Mitchell et al., 2009). The large, prospective, ongoing longitudinal study ‘Choices, Attitudes, and Strategies for Care of Advanced Dementia at the End-of-Life’ (CASCADE) provides insight into the clinical course of advanced dementia (Mitchell et al., 2009).

Mitchell and colleagues (2009) reviewed 323 charts of residents with advanced dementia over 18 months in 22 LTC homes, identifying probability of experiencing pneumonia as 41%, febrile episodes 44%, eating difficulties 38% and distressing symptoms such as pain 39% and dyspnea 46%. Agitation and urinary tract infections were also common (Sampson, 2010). Symptoms of dementia progressively increase during end-of-life (Mitchell et al., 2009). An integrative literature review performed by Sampson (2010) cited infection and febrile episode as the cause for 71% of deaths in persons with advanced dementia. The percentage of persons with dementia that die in LTC in the United States is similar to Canada and is approximately 70% (Hennings et al., 2010).

High levels of controversial invasive treatments such as insertion of feeding tubes and transfer from LTC to acute care hospital for treatments of infections, fractures and critical events are reported particularly during the last three months of life (Mitchell et al., 2009, Mitchell et al., 2012; Sampson, 2010). A systematic review of palliative care content within current, international clinical practice guidelines for dementia care revealed that only 67% of guidelines had moderate end-of-life care content, 22% possessed minimal content and 11% did not address

end-of-life care at all (Durepos et al., In Preparation, 2016). Poor prognostication, lack of clinical guidance and recommendations for HCPs regarding quality end-of-life care, minimal conversation surrounding end-of-life, and non-observance of advance care directives even when in place may result in burdensome interventions, diminishing quality of life with questionable efficacy in extending life (Durepos et al., In Preparation, 2016; Mitchell et al., 2009). These factors contribute to perceived gaps and disparities in the quality of end-of-life care for persons with dementia and their families (Mitchell et al., 2012; Hennings et al., 2010; Sampson, 2010). The unfortunate, distressing symptoms and complications experienced by persons with dementia are experienced and observed by CGs.

Caregiver Burden

Advanced dementia can cause CG burden, defined as negative physical, psychological, social and financial effects of caregiving (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Bass et al., 2012; Beinart, Weinman, Wade, & Brady, 2012). Despite high levels of burden, CGs also perceive positive effects of caregiving including: companionship, enjoyment and reward (Beinart et al., 2012). In 2011, Canadian CGs spent over 444 million hours without pay caring for persons with cognitive impairments like dementia, illustrating the high demand (ASC, 2012). Over 75% of CGs experience psychological illnesses, and between 15 to 32% develop depression as a result of their role (ASC, 2012). Negative effects related to providing care to persons with dementia include: anxiety, high levels of stress, decreased well-being and decreased self-efficacy (Bass et al., 2012; Papastravrou, Kalokerinou, Papcostas, Tsangari, & Sourtzi, 2007; Sorensen & Conwell, 2011). Caregivers can also develop increased morbidity (i.e. increased likelihood of developing health problems) such as cancer, low immunity and cardiovascular problems (Brodaty & Donkin, 2009).

The progressive psychological and behavioural symptoms of persons with dementia can increase CG burden during advanced stages and end-of-life (Bass et al., 2012; Beinart et al., 2012; Papastravrou et al., 2007). Burden is not eliminated when care recipients are transitioned into LTC. Previous caregiving tasks are maintained including feeding, grooming, shopping and managing money, and new psychological distress related to advocacy or interactions with LTC staff and decision-making tasks are placed upon CGs (Peacock, 2013; Papastravrou et al., 2007; Givens, Lopez, Mazor, & Mitchell, 2011; Shanley, Russell, Middleton, & Simpson-Young, 2011; Schulz et al., 2014). CGs can experience feelings of guilt, regret, failure and anxiety over ‘losing’ their role and assuming new responsibilities (Adelman et al., 2014; Givens et al., 2011; Peacock, 2013; Shanley et al., 2011).

Groups at higher risk for detrimental effects from caregiving include spouses, women and persons with lower socioeconomic status (Adelman et al., 2014; Papastavrou et al., 2007; Sorensen & Conwell, 2011). These subgroups (i.e. female spouses) represent the majority of CGs worldwide and should be targeted for intervention, however unmet needs including lack of social support and isolation persist (Bass et al., 2012; Prince & Jackson, 2009; Shanley et al., 2011). Due to the long, uncertain trajectory of dementia and specific behavioral symptoms such as loss of familial recognition dementia, CGs experience higher levels of burden and depression than other CGs and should be the target of evidence-based interventions (Kim & Schulz, 2008; Sorenson & Conwell, 2011).

Caregiving During End-of-Life

The increasing level of burden experienced by CGs throughout the caregiving journey cumulates during advanced stages of dementia and end-of-life, when resources may be depleted (Chan, Livingstone, Jones & Sampson, 2013). This final stage of caregiving impacts adjustment

during bereavement (Schulz et al., 2003). Few intervention studies have examined the experience of CGs of persons with dementia during end-of-life despite recognition of heightened, unmet needs and distress. The inconsistent provision of evidence-informed, high quality end-of-life care for persons dying from dementia also impacts CGs' immediate and long-term well-being (Schulz et al., 2003).

A rigorous systematic review of 13 electronic databases conducted by Hennings, Froggatt and Keady (2010) synthesized 10 high quality studies of CGs' experiences of persons dying with dementia in LTC. Constant comparative analysis identified themes including grief, difficult decision-making, and unmet needs such as communication and information about death (Hennings et al., 2010). Additional reviews conducted by Davies, Maio, Rait and Iliffe (2014) and by Peacock (2013) confirmed the themes of challenging decision-making and grief for CGs during end-of-life. A unique phenomenological study of CG's experiences of caring for dying persons with dementia also provided deeper insight into factors influencing the experience (Peacock, Duggleby, & Koop, 2014). The over-arching themes of difficult decision-making and feelings of grief, as well essences of the lived experience of CGs with influencing factors will be summarized.

Decision-making.

Increased distress related to end-of-life decision-making is an over-arching theme within the literature (Davies et al., 2014; Hennings et al., 2010, Peacock, 2013; Raymond, Warner, Davies & Iliffe, 2014). Raymond and colleagues (2014) searched 13 databases and selected 12 papers regarding family and professional CG's experiences during end-of-life to inform a study of quality indicators of palliative care for persons with dementia. Lack of preparedness for end-of-life associated with gaps of knowledge and communication with HCPs are described by CGs

and emulated in further studies (Davies et al., 2014; Hebert, Dang, & Schulz, 2006; Peacock, 2013; Raymond et al., 2014).

Family members felt they lacked discussion for decision-making and planning during end-stage dementia, which led to unwanted invasive procedures (Davies et al., 2014; Peacock, 2013; Raymond et al., 2014). Specifically decisions regarding treatment of progressive symptoms and complications of dementia including impaired swallowing and pneumonia were described as distressing (Davies et al., 2014; Hennings et al., 2010; Peacock, 2013).

Families have also expressed concern over HCP perceptions of their decisions as either ‘hastening’ death or being inappropriate, adding another dimension of CG stress (Davies et al., 2014; Raymond et al., 2014). Overall, the negative emotions of fear, anxiety, guilt and uncertainty expressed by CGs during decision-making and end-of-life warrants the need for research into interventions during this stage (Hennings et al., 2010; Davies et al., 2014; Peacock, 2013; Raymond et al., 2014).

Anticipatory grief.

Both anticipatory and after-death grief are addressed in a systematic review of dementia CG grief reactions conducted by Chan, Livingston, Jones and Sampson (2013). Spousal CGs demonstrated patterns of progressive grief with sadness, bitterness, helplessness during end-of-life compared to adult children CGs who experience peak levels of grief during mid-stage dementia (Chan et al., 2013; Meuser & Marwit, 2001). Severe grief often leads to functional impairment in carers (Chan et al., 2013). Specific to dementia, CG grief is affected by the loss of recognition of loved ones, behavioural symptoms and feeling of multiplicity of loss from time of diagnosis (Chan et al., 2013; Raymond et al., 2014). Surprisingly, two studies reviewed by Peacock (2013) found that anticipatory grief did not lessen levels of after-death grief (Meuser &

Marwit, 2001; Schulz et al, 2006). Heightened levels of pre-death grief, depression and burden have been linked to complicated grief (intrusive and inhibitive of function) during bereavement, demonstrating the need for study of CG interventions focused during end-of-life (Romero et al., 2014; Schulz et al., 2003).

Essence of the experience.

A unique interpretive phenomenological study of CG lived experiences of providing end-of-life care to family members in LTC, was conducted by Peacock, Duggleby and Koop (2014). The essences ‘being-with’ and ‘being-there’ emerged from open-ended interviews conducted with 11 bereaved CGs of persons with dementia who had died during the past year (Peacock et al., 2014). ‘Being-with’ conveyed the feeling of connection and closeness that CGs felt to their loved ones, while ‘Being-there’ referred to the CG’s need to be physically present, keeping vigil, providing and supervising care during death. ‘Being-with’ and ‘being-there’ brought CGs comfort and were seen as essential aspects to the final journey of end-of-life. Health care professionals have the ability to facilitate CGs’ ability to ‘be-with’ and ‘be-there’ in order to promote a positive experience.

Four life worlds emerged from Peacock and colleague’s (2014) data, which affected CGs’ experience including: spatiality (the space end-of-life took place in), temporality (sense of time passing), corporeality (impact of caregiving on the physical and emotional state) and relationability (interactions between carers and staff, and others). Each factor is amenable to HCP intervention (Peacock et al., 2014). Health care professionals should be aware of these factors in order to promote and facilitate satisfying, meaningful experiences for CGs. Each of these factors can also inform programming and content of supportive interventions for CGs.

Caregiver Bereavement

High levels of CG burden and low satisfaction with end-of-life care are linked to poor adjustment and complicated grief during bereavement (Garrido & Prigerson, 2014; Romero et al., 2014; Schulz et al., 2006; Schulz, 2013). Complicated grief, characterized by profound, incapacitating sadness, intense longing and intruding thoughts of the deceased is experienced by 10 to 20 percent of CGs of persons with dementia (Boerner & Schulz, 2009; Schulz et al., 2006). Caregiver intervention prior to bereavement can decrease likelihood of chronic depression (Haley et al., 2008). Evidence of the association between levels of pre-death burden and long-term outcomes implicates need for targeted, pre-bereavement interventions (Garrido & Prigerson, 2014; Schulz, 2013).

Care Guidelines for Caregivers of Persons with Dementia

The implementation of clinical guidelines and tools can facilitate high quality, evidence-based care by HCPs for CGs (Hudson et al., 2012). Canadian guidelines for treatment and management of dementia are inclusive of recommendations for general pre-bereavement care for CGs across the disease trajectory (Hermann & Gauthier, 2008). Health care professionals are encouraged to provide referral at time of diagnosis to the Alzheimer's Society 'First Link' program and continuously assess CGs' degree of stress (McCainey, Hillier, Stolee, Harvey & Michael, 2012; Hermann & Gauthier, 2008). The Alzheimer's Society is a national non-profit organization providing support and education, as well as funding research into dementia. Evaluation of the 'First Link' program, found participants reported more knowledge about dementia and community resources and supports than those outside the program (McAiney et al., 2012).

Daycare programs, respite, homecare and education surrounding dementia are cited as possibly helpful to CGs (Hermann & Gauthier, 2008). Unfortunately, graded evidence of the effectiveness of CGs interventions is lacking in the Canadian guidelines and the recommendations are vague in terms of dosage, timing and details of evaluated programs. The national Canadian guidelines also do not speak to the unique needs experienced by CGs during institutionalization of the persons with dementia, advanced stage, or end-of-life. Gaps in recommendations for spiritual, end-of-life, and loss or grief care were illuminated by the systematic review of palliative content within Canadian and international guidelines (Durepos et al., In Preparation, 2016).

Specific guidelines for the psychosocial and bereavement support of CGs of palliative or end-of-life patients developed by Hudson and colleagues (2012) include recommendations applicable to CGs of advanced stage persons with dementia. A summary of 20 principles includes recommendations to: assess CG health, assist CG in preparation for the patient's decline through education on signs of death, and assess CG emotional preparedness for death (Hudson et al., 2012). Caregivers whom critiqued these guidelines noted there remains a lack of evidence of detailed interventions and programs, as well as clinical examples (Hudson et al., 2012).

Interventions for Caregivers of Persons with Dementia or in Palliative Care

The following section summarizes psychological intervention studies for CGs of persons with dementia or 'palliative' persons with varied diagnoses receiving end-of-life care. Generalized studies of CGs of persons in palliative care (referring to end-of-life) may inform provide evidence for interventions useful to CGs of persons with dementia. Evidence exists surrounding benefit of psychological interventions for CGs, and while largely unfocused on end-of-life, interventional studies have increased during the past years (Harding, List, Epiphaniou, &

Jones, 2011; Elvish, Lever, Johnstone, Cawley, & Keady, 2013). Psychological interventions aim to change behaviour, emotional state or feelings (Elvish et al., 2013). A large number of CG interventions are classified as ‘psychological’ or as multicomponent ‘psychoeducational’ structured programs primarily providing information about the dementia disease process, and resources or training to assist CGs in responding effectively to disease-related problems (Elvish et al., 2013). The term ‘support group’ can refer to open or closed membership, time-limited or unending duration meetings, which may include interaction and sharing, formal manual-directed cognitive-behaviour training or stress management (Hornillos & Crespo, 2011).

Psychoeducational programs combine support with educational content, beyond participant sharing, differentiating these programs from strict support groups (Elvish et al., 2013).

Psychological interventions are composed of three primary elements of varying levels: 1) information or education, 2) support and 3) skill-building (Elvish et al., 2013). While the majority of interventions resist strict classification, delineation assists in determining the most effective components. Interventions are classified by researchers as: psychoeducational-skill building, psychotherapy-counseling, multicomponent or technology-based (Gallagher-Thompson & Coon, 2007; Elvish et al., 2013). Psychoeducational-skill building interventions attempt to increase disease knowledge, coping and management skills. Psychotherapy-counseling is provided by HCPs educated in psychological theory including Gestalt and cognitive-behavior training (Gallagher-Thompson & Coon, 2007; Elvish et al., 2013). Multicomponent and technology-based programs provide either telephone or computer-based services (Elvish et al., 2013).

The Alzheimer’s Society is recognized as a leader in the provision of interventions for persons at all stages of dementia and their CGs, who are typically referred to the Society at time

of diagnosis through the ‘First Link’ program (Brodaty & Donkin, 2009). The Alzheimer’s Society of British Columbia evaluated their CG support group program, described as a model of information and mutual support, using questionnaires from 424 CGs and group facilitators, group observations and interviews with stakeholders across the province (ASC, 2014). Ninety-two percent of CGs were satisfied or greatly satisfied with their support group. A formal stage-specific series of educational seminars for CGs is also provided by Alzheimer’s Society and includes topics pertinent to end-of-life like pain, distress and grief (ASC, 2014).

Systematic reviews of psychological interventions for caregivers.

Multiple systematic reviews of psychological intervention studies for CGs of persons with dementia have attempted to assess efficacy of varying programs evaluated through experimental, quasi-experimental, observational and qualitative designs (Elvish et al., 2013). Psychological interventions made up the highest proportion of intervention classes with content focused on increasing CG preparedness, self-efficacy, support, perceived reward of role and decreasing uncertainty (Harding et al., 2011). Four summarized education and training programs promoted problem-solving for symptom management, coping, self-care and effective communication with HCPs. Hudson, Remedios and Thomas (2010) detailed similar themes in a systematic review of psychosocial interventions for CGs of palliative/end-of-life care patients. All study designs of varying psychosocial interventions had positive, although not always statistically significant impacts on CG outcomes (Hudson et al., 2010). A lack of qualitative descriptive studies prevents insight into the perceptions of intervention for CGs of persons with dementia before and after bereavement beyond quantitative measure.

A rigorous systematic review of psychological interventions for CGs of persons with dementia performed by Elvish and colleagues (2013) expanded upon two previous reviews

demonstrating rising interest and awareness of CG health. Previously, Pinquart and Sorensen (2006) synthesized 127 studies of interventions for CGs of persons with dementia while Gallagher-Thompson and Coon (2007) examined 19 intervention studies of CGs of older adults based on psychological theories of change (Elvish et al., 2013). The updated review included three additional qualitative and 17 quantitative high quality studies of psychological interventions for CGs of persons with dementia conducted between 2005 and 2011 (Elvish et al., 2013). Mild to moderate effects in CG outcomes were reported including improved levels of depression, well-being, social support, perceived burden, knowledge, quality of life, attitude to caregiving and anxiety post intervention (Elvish et al., 2013). Follow-up into bereavement to assess the value of pre-loss intervention did not occur demonstrating a gap in research.

The incorporation of theoretical models, intensity and duration of support meetings longer than eight sessions or 16 hours further impacted well-being and depression effects (Chien et al., 2011). Additional factors increasing effect size included: group size of six to ten members, use of a manual, professional facilitation and advanced stage of the persons with dementia (Chien et al., 2011). The increasing number of quality studies into caregiving is consistent with the rising awareness that CG health impacts the health of persons with dementia and the health of the national economy (ASC, 2015). However, CG perceptions of interventions have not been adequately studied.

Two specific intervention programs were identified in the literature targeting CGs of persons with dementia at end-of-life, which are shared attributes of the program of study. Additional characteristics and outcomes associated with these programs will be outlined to illustrate current knowledge.

‘Taking Care of Myself’ program.

A psychoeducational intervention entitled ‘Taking Care of Myself’ studied by researchers at McGill University in Montreal targeted CGs of persons admitted to LTC, many of whom had dementia (Ducharme, 2014). Some of the sessions of this innovative, psychoeducational program included: effective communication with staff, enjoying time with the care recipient, dealing with loss and the eventual loss of the care recipient and reorganization of CG life after LTC placement (Ducharme, 2014).

Evaluation of the ‘Taking Care of Myself’ program found improved CG quality of life related to competence dealing with staff and perceived challenge of CG role when compared to a control group (Ducharme, 2014). Researchers attributed success to program roots in empowerment, stress and coping theory (Ducharme, 2014). Additional qualitative outcomes would have provided depth to the data and allowed discernment of the value of the program as perceived by its members.

‘Resources for Enhancing Alzheimer’s Caregiver Health’ (REACH).

The REACH study was a ground-breaking randomized control trial (RCT) conducted by Schulz and researchers in 2003. This study was the first to investigate the impact of pre-bereavement interventions for the unique population of CGs of persons with dementia on post-bereavement outcomes (Stroebe & Boerner, 2015). The sample included 217 CGs of persons with dementia at six sites in the United States, assessed over time at six, 12, and 18 months (Schulz et al., 2006). Higher rates of pre-loss depression, pre-loss anxiety and pre-loss burden were associated with higher rates of complicated grief post-loss (Schulz et al., 2006). Two interventions yielding statistically significant positive results in bereavement focused on skills-building and symptom management of CG burden (Holland, Currier, & Gallagher-Thompson,

2009). Again this study focused solely on quantitative measures and statistical gains. Qualitative research would be helpful to illicit other types of information. Much more needs to be described surrounding the elements of intervention that CGs found beneficial, and the perceived value of programs both short-term and long-term into bereavement.

Literature Review Summary

Despite increasing attention to CG study, methodological challenges (e.g. intervention timing, access to sample, ethical considerations) in psychological intervention and end-of-life studies exist causing a gap in research. Interventions most feasible to evaluation through experimental study designs are often expert facilitated, time-limited, closed programs allowing pre and post outcome measurement (Elvish et al., 2013). In contrast, the real-world widely accessed psychological interventions for CGs of persons with dementia are open, unending, non-structured support groups facilitated by veteran CGs through community Alzheimer's Societies (Hornillos & Crespo, 2011). Caregiver access to intensive programs evaluated in the literature is limited (Ducharme, 2014). Naturalistic inquiry surrounding CG interventions is feasible and necessary to assess program perceived benefits, as opposed to manipulated, experimental groups (Ducharme, 2014; Hornillos & Crespo, 2011). An additional methodological problem with capturing intervention effects is the reliance on short-term follow-up periods and inability to assess long-term benefits (Holland et al., 2009).

Elvish and colleagues (2013) highlight a need for more qualitative studies of CG interventions, which can add valuable process and outcome data contrasting constructs typically measured by quantitative studies. The few qualitative and mixed-method intervention studies have provided rich, significant findings not captured by quantitative data (Harding et al., 2011). Changes in awareness and attitudes, as well as the effects of counseling and psychotherapy can

be examined and described through qualitative interviews accurately providing the premise for this study of the psychoeducation program (Elvish et al., 2013).

Psychoeducation Program of Study

The psychoeducation intervention was a support and education program available to CGs, family members or friends of persons currently or formerly residing in a 70 bed Specialized Care Unit for persons with dementia situated within a chronic care hospital located in Ontario. Specialized Care Units promote family involvement and feature a secure, modified physical environment, trained staff and specialty programming for persons demonstrating acute behaviours and aggression beyond capacity for management in LTC homes (Lai, Yeung, Mok, & Chi, 2009). The program was initiated by the unit social workers and manager in May 2014 based on an evolving professional-led peer support model, in response to the high level of needs of CGs of persons residing in the unit.

Co-facilitated by two unit social workers, approximately ten persons attended the program weekly, and approximately 15 had attended the program since its inception, although it was available to all CGs, family or friends of the 70 persons residing in the Specialized Care Unit. The group was open to new membership (i.e. patient admission into bereavement) and was advertised in the unit through paper flyers and verbal promotion from social workers and staff to families. Members completed an abridged Zarit Burden Index survey at initial program attendance, which quantified their perceived level of burden related to caregiving, providing the social workers facilitating the program with descriptive data (Bedard, Molloy, & Squire, et al., 2001). Three program members whose relatives with dementia passed away in the unit continued attending for over a year post-death, making this a novel program for description.

Program logic model.

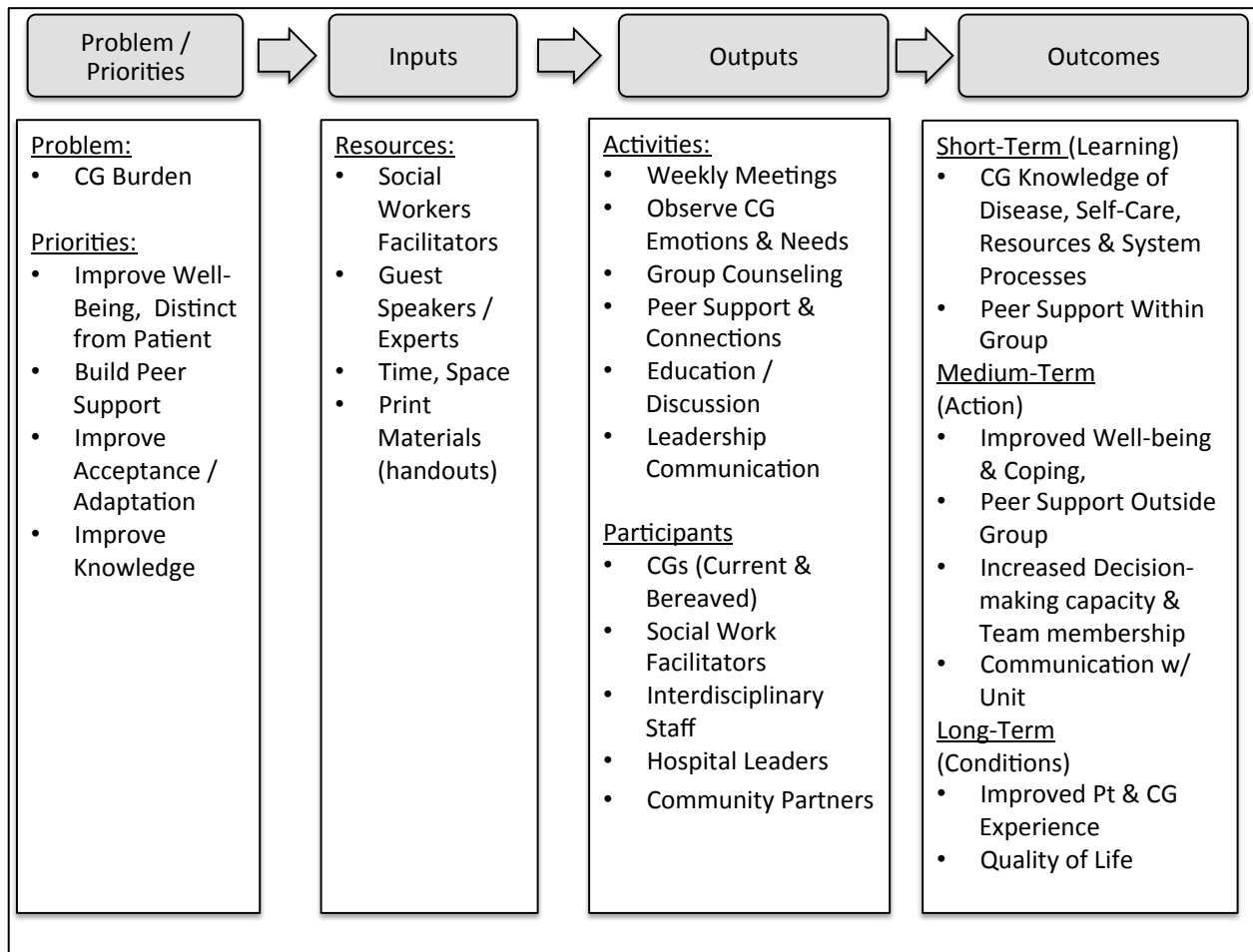
A logic model for the program is presented in Figure 1 to provide “an illustration of the logical sequence of events in the intervention program resulting in a change in response to a behaviour” (Goldman & Schmalz, 2006, p.8.). The model presents linear flow from characterization of the problem (i.e. CG burden) to identification of outcomes allowing firm association between the intervention and outcomes. Inputs or resources required for the program included: staff, time, meeting space, materials, technology and partners. Program outputs (i.e. activities offered and targeted participants) consisted of: weekly share and support or educational sessions on a range of psychoeducational topics provided by the social workers or guest speakers focusing on dementia, community resources and organizational processes.

Program objectives or priorities were developed by Master’s degree prepared social workers and unit nursing manager based on their past experiences as educators for the Alzheimer’s Society, clinical training in dementia care (each approximately 20 years) and professional training in support group facilitation. Program objectives included: 1) improvement in emotional well-being perceived by CGs, 2) CG improved skill in separating personal well-being from mood/status/behaviour of the persons with dementia, 3) increased CG knowledge and support from other group members through sharing of experiences 4) increased CG knowledge through education from social workers and relevant guest speakers, and 5) CG peer support extending informally outside of the group.

The psychoeducational program consisted of weekly meetings (as per CG request) in a multi-purpose room at away from the unit. Meetings were 1.5 to 2 hours in length with refreshments provided. A former content schedule of psychoeducational topics such as decision-making at end-of-life and dietary planning, is summarized in Appendix B. Caregivers also had

the opportunity to provide and receive feedback with the unit manager concerning their experiences regularly at meetings. Group process included an informal ‘check-in’ at the beginning of each meeting to discuss member’s situations and present coping. Group member guidelines including confidentiality and respect were observed.

Figure 1. Study program logic model



Research Problem Statement

The rising number of CGs of persons with dementia worldwide and national dependence on CGs as unpaid, care providers dictated research and investigation into novel, innovative interventions to improve CG well-being. There was a lack of qualitative research describing the experience of interventions provided to CGs of persons with advanced dementia (Schulz, 2013). Few, if any, researchers had described or studied the relationship of pre-bereavement interventions to post-bereavement adjustment with qualitative description. The study program presented a unique opportunity for description of a specialized intervention aimed at CGs during a specific time of high need. The supported, joint membership of current and bereaved CGs was uncharacteristic of traditional support program models utilized by hospices and organizations such as the Alzheimer's Society.

Research Questions

Based on the gap in literature in qualitative description of CG experiences of this novel psychoeducational intervention, I posed the over-arching question: What were caregivers (both current and bereaved) perceptions of a psychoeducation intervention? Secondary questions includes: a) What did CGs perceive as benefits of the study program? b) What were the perceived challenges to participating in the study program? c) What were the perceptions of CGs of the study program whom did not attend? d) What were the perceived benefits of joint attendance with current and bereaved CGs?

Chapter Three

Methodology

Research Design

A qualitative descriptive design was used for this study (Sandelowski, 2000). Qualitative descriptive methodology is outlined including: research design, setting and participants, sampling and recruitment, data collection, analysis, results, discussion and techniques to enhance rigour. A summary of ethical considerations for this study is also provided.

A qualitative descriptive study was essential to capture perceptions of the study program. Sandelowski (2000) and Patton (2015) provided predominant reference for design methods. Sandelowski (2000) defines qualitative description as detailed, comprehensive summary of a phenomenon or event in simple language. Qualitative description is a method of naturalistic inquiry allowing study of phenomenon in its natural state. Utilizing this method can provide clear, concise answers to questions posed by clinicians, policymakers and stakeholders (Sandelowski, 2000). Accurate presentation of phenomenon, and accurate explanation of the meaning people connect to the phenomenon results in descriptive and interpretive validity of the research findings. Minimal theory is applied to the data allowing the presentation of an organized summary of inductive information in a fitting, natural way (Sandelowski, 2000; Sandelowski, 2010).

Qualitative descriptive methods are ideally suited to explaining persons' experience of an intervention (Neergaard, Olesen, Andersen, & Sondergaard, 2009; Sandelowski, 2000; Sullivan-Bolyai, Bova, & Harper, 2005). This design assists in the assessment, development and refinement of clinical interventions (Sullivan-Bolyai et al., 2005). Rich presentation of data

described the value of the study program and will allow tailoring, planning and communication of the intervention by program administrators (Neergaard et al, 2009; Sandelowski, 2000; Schildmann & Higginson, 2010). Qualitative description design proved feasible and allowed the researcher to stay closer to the data than other qualitative methods, which require conceptual interpretation during analysis (Neergaard et al, 2009; Sandelowski, 2000).

Setting

Qualitative description methodology requires a naturalistic setting to study an event without manipulation (Sandelowski, 2000). The psychoeducational study program was situated within the context of a Specialized Care Unit based in a hospital in southern Ontario. The hospital specialized in care of the elderly and persons with chronic illness. Four pillars of care included: dementia care, palliative care, aging and rehabilitation.

The Specialized Care Unit encompassed 70 beds providing person and relationship-centered care to persons with dementia. Person-centered care focused on recognizing each person's individuality and history apart from illness, while relationship-centered care encouraged positive and meaningful interactions between staff, patients, families and within oneself. Clinicians utilized a high-touch and low-technology approach to meet patients' physical, emotional, mental and spiritual needs. The unit provided services to persons with dementia exhibiting challenging behaviours related to exit seeking, activities of daily living, social interaction, aggression and wandering. Within hospital-based Specialized Care Units 68% of persons with dementia demonstrate verbal aggression or violence often directed at CGs, compared to only 20% of persons outside of these units, and is often the reason for admission (Arai et al., 2014; Wharton & Ford, 2014). Therefore families were often in crisis at time of admission having experienced escalating aggression, added burden and distress.

The goals for persons with dementia were: behavioural stability, abilities enhancement; and personhood facilitating discharge home or to alternate levels of care such as LTC. Length of stay varied from as little as 60 days and extended longer than three years. One of the objectives of the unit was to include family and CGs of persons with dementia as partners in care while providing support and education throughout an illness. Case management with interdisciplinary team assessment, treatment and management plan was provided by a geriatric psychiatrist and primary physician, social worker, case manager, speech-language pathologist, dietician, chaplain, recreation therapist, and registered nurse.

Advanced staged dementia and related complications led to significant numbers of deaths of persons and required end-of-life care in the unit. Health care professionals recognized the high level of needs and care required by CGs during end-of-life. The study program was a singular intervention program developed and facilitated by two social workers working in the Specialized Care Unit. The program's content was based on the social workers' clinical expertise regarding CG needs and health, formal education and past experience as educators for the Alzheimer's Society. Developed and implemented in May 2014, content evolved to meet the needs and interests of members.

Sampling and Recruitment

Purposive sampling was the primary method of sampling utilized in this qualitative study in order to obtain information-rich cases (Patton, 2015; Sandelowski, 2000). The researcher sampled six program-attending CGs including six current and three bereaved, two non-attending CGs and five HCPs for a total sample size of 16. Active and passive recruitment procedures conformed to the policies approved by the Hamilton Integrated Research Ethics Board [HiREB]. Recruitment occurred between November 2015 and March 2016. The student researcher

established relationships with program-attending CGs, the unit manager, hospital director and the social workers during a clinical practicum in the unit.

The unit social workers leading the program were ‘within the circle of care’ and provided access to participants acting as ‘gate-keepers’ by presenting a study information sheet to CGs at a program meeting with the option of providing contact information to the student researcher or contacting the researcher themselves in November 2016 (Creswell, 2013). The social workers allowed the contact sheet to be filled out in their absence to reduce intrusion or pressure to participate and to ensure anonymity (Hynson, Aroni, Bauld, & Sawyer, 2006). Snowball sampling was employed to recruit additional CGs not in attendance.

Non-attending CGs were purposively selected to add variety to the sample based on demographics known to the social workers. Time of bereavement for CGs varied between 10 and 11 months, which limited the distress imposed by the researcher. All CGs in the study opted to have the student researcher contact them by phone or by email.

The student researcher emailed registered nursing staff employed in the unit advertising the study, followed by reminders from a nurse leader. As a result, five HCPs agreed to be interviewed, including the two social work facilitators of the study program. The researcher sampled HCPs to create maximum variability in perspective through: participant’s role (case manager versus staff nurse), gender and length of time of employment.

Either by telephone or email, the student researcher explained the study purpose and procedures to interested participants. Participant preference for date, time and location (i.e. hospital or home) for the one-on-one data collection interview was then organized. Incentives to participate in the study included Tim Horton’s gift cards valued at \$10.00. This incentive was

minimal and was approved by HiREB. The student researcher offered to reimburse CGs for their parking at the hospital for interviews.

Data Collection

Data collection was conducted through semi-structured interviews with open-ended questions and researcher field notes (Sandelowski, 2000). These standard methods within qualitative description research are aimed at discovering the ‘who’, ‘what’ and ‘where’ of the experience according to experts (Sandelowski, 2000; Patton, 2015; Neergaard et al., 2009). Data collection continued to occur until informational redundancy was reached within each subgroup, and prior to acquiring such a large extent of data that precluded deep analysis (Sandelowski, 1995b).

Demographic data was collected from each CG participant including a Zarit caregiver burden index score (Appendix C). The 12 question abridged Zarit index is a valid and reliable instrument tested in CGs of persons with dementia for assessment of two main constructs: personal and role strain (Cronbach’s $\alpha=0.88$) (Bedard, Molloy, Squire, Dubois, Lever, & O’Donnell, 2001; Stagg & Lerner, 2015; O’Rourke & Tuokko, 2003). Scores can range from 0 to 48 with higher scores indicative of higher levels of burden. Bedard and colleagues (2003) cite scores greater or equal to 17 as severe and indicative of depressive symptomatology, although others maintain cut-off levels for severe, clinically significant versus moderate levels of burden are unclear (O’Rourke & Tuokko, 2003). As per HiREB policy, CGs consented to have the student researcher obtain their Zarit indexes from the social workers. Alternatively, non-program attending CGs consented to fill out a Zarit index at the time of the interview.

Semi-structured interviews.

Sixteen semi-structured, face-to-face interviews were conducted by the student researcher with CGs and HCPs. The student researcher planned for interviews to last between 30 minutes and one hour to allow collection of data without increasing emotional burden to participants. The researcher maintained a professional, but warm and empathetic presence. Interview guide questions surrounded: caregiving experiences, program activities, perceived benefits, challenges, facilitators and recommendations for the program (DiCicco & Bloom, 2006; Sandelowski, 2000). Open-ended questions were generated based on the study research questions. The original interview guide is provided in Appendix D.

Field notes.

The researcher recorded handwritten field notes during and immediately following each interview in a notebook. Field notes were detailed and concrete, which supported qualitative description methodology through accurate, clear description (Patton, 2015). Used in combination with the interview transcripts, field notes documented participant behaviour during interviews, significant quotations by participants, growing questions and emerging themes perceived by the researcher (Patton, 2015). The student researcher also audio-recorded and transcribed a personal reflection following each interview to promote awareness of her personal perceptions and the impact of these on the data through reflexivity (Patton, 2015).

Data Management and Analysis

Interview data was audio-recorded with permission and transcribed verbatim by the researcher to preserve all spoken words of participants. Identifying markers and names were removed prior to transcription. The transcribed interview was read and compared to the audio recording, ‘proofing’ to ensure accuracy.

An inductive, data-derived coding framework was developed by the student researcher and her supervisor, and approved by the thesis committee through the hand coding and content analysis of three transcripts. This framework continued to involve during analysis. All transcribed interview data were uploaded into Dedoose, a secure online qualitative analysis system for coding (SocioCultural Research Consultants, LLC, 2014). Utilizing the analysis software allowed easy and efficient coding of transcripts. Multiple readings of each transcript ensured the researcher did not become distanced from the data.

Content analysis.

Content analysis was the mainstay method used for this study, which allowed the transformation of data into shareable findings (Patton, 2015; Sandelowski, 1995a). Concurrent analysis began during data collection as the student researcher contemplated themes prior to, during and after each interview capturing thoughts and ideas in reflections and field notes. Content analysis was comprised of pattern and thematic analysis, meaning the identification and understanding of core consistencies within and across participant interviews (Patton, 2015).

The researcher initially contemplated each interview as a whole and then conducted a process of data reduction (coding) using the interview guide as a framework (Sandelowski, 1995a). The process of data reduction is aimed at selecting and emphasizing the essential features of the interview while retaining the context, namely breaking down the data (Sandelowski, 1993). The researcher transcribed each interview and reflection, making field notes of facts inherent to the participant's story and potential themes (Sandelowski, 1995a). Each interview was re-read multiple times immersing the researcher in the data and allowing constant comparison between interviewee perceptions.

Data reduction.

Independently the student researcher and her supervisor analyzed three transcripts. Significant words were underlined in each transcript and notes added in margins delineating both story facts and initial ideas of patterns or themes. These notes allowed the participant's words to be transformed into 'meaning units' or codes (Sandelowski, 1995a). Initial codes were organized into a table with corresponding excerpts as evidence. Codes were then clustered and categorized according to interview guide questions (Sandelowski, 1995a). Data was segmented to produce something new, however too much detail was avoided as this constitutes 'flooding' and can interfere with understanding the essence of the experience. Patterns emerged related to frequently reported emotions such as guilt, peace or well-being and activities such as sharing and learning. Categorical themes emerged through data reduction including: perceived program outcomes, perceived barriers and facilitators (Patton, 2015). In a table the student researcher titled categorical codes as 'root codes' and patterns as 'main or sub-codes'. Patterns were further identified amongst various sub-groups. All transcripts were then analyzed in Dedoose utilizing this framework.

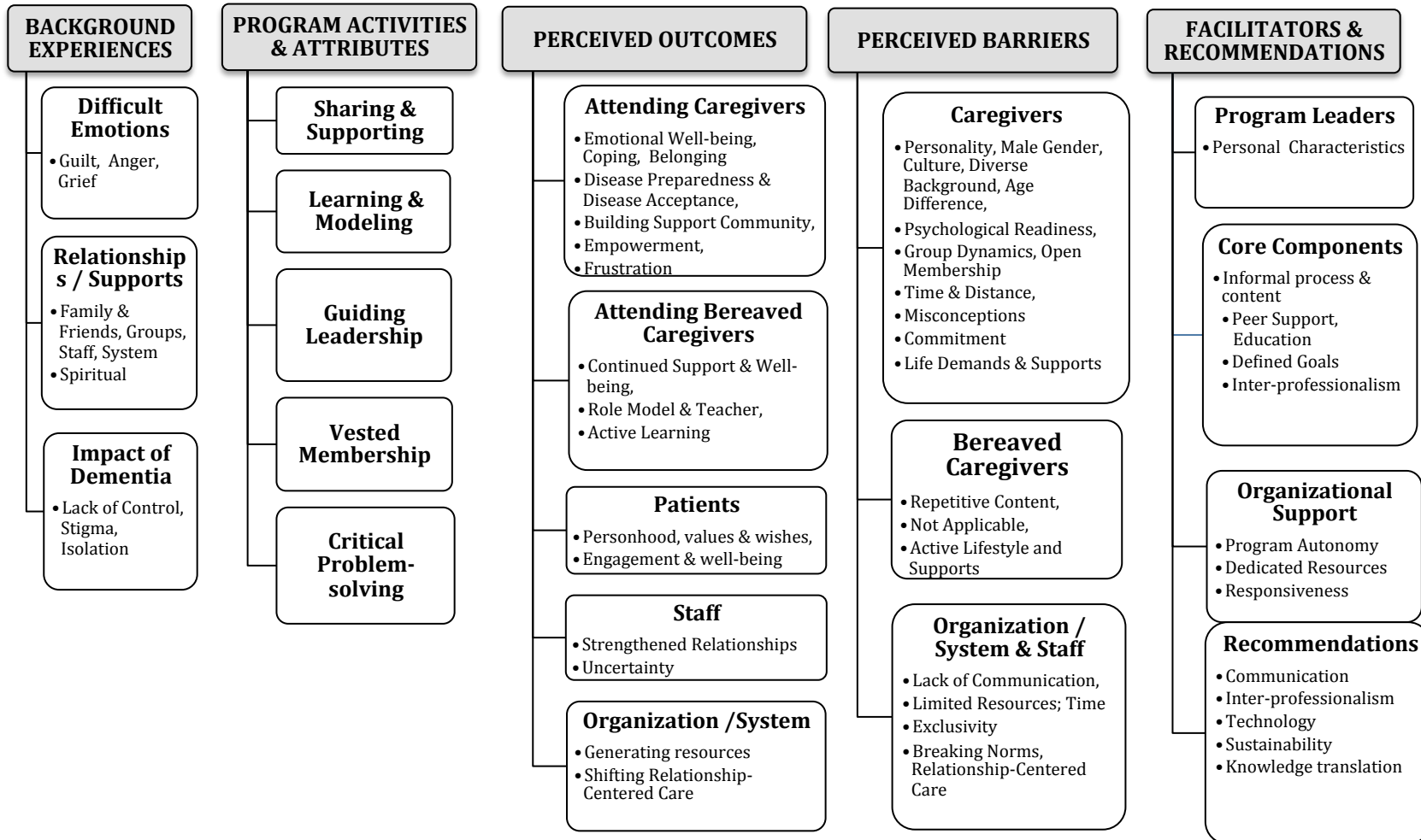
The content analysis was inductive and the initial data reduction framework transitioned through many models to describe emerging patterns and themes. For example, although current, bereaved and non-program attending CGs were the target sample of this study, program outcomes and barriers were perceived as occurring in additional groups including HCPs and the organization.

Within Dedoose, multiple codes were applied to individual excerpts decreasing premature or superficial coding. During final analysis the student researcher had deepened awareness and understanding of all data, reviewing all potential codes for each excerpt and

selecting the most meaningful. Field notes and reflections were particularly helpful in conceptualizing relationships between the emergent themes and patterns. For example, patterns of program activities emerged as linked to perceived outcomes. Excerpts and quotations from participants were selected to represent patterns, illustrating the raw data. Content analysis remained close and faithful to the original data (Sandelowski, 1995a).

Multiple meetings occurred between the student researcher and her supervisor to discuss patterns and themes within the data. Two transcripts were analyzed independently and discussed by the thesis committee to approve an initial coding framework and results, establishing inter-coder agreement (Patton, 2015). The student researcher also conducted two ‘member checking meetings’ to review study findings with participants. (See below for further details on member checking). Consensus was reached with all parties through discussion and clarification. The framework, which most importantly described the perceived outcomes, barriers and facilitators of the program for multiple sub-groups is described in the findings section. The final data reduction framework is illustrated in Figure 2.

Figure 2. Data reduction framework



Ethical Considerations

Approval to conduct this study was granted from the Hamilton Integrated Research Ethics Board. Ethical concern for participants surrounding distress due to research participation was warranted for this vulnerable population of CGs. Addington-Hall (2007) stresses that research related to palliative or end-of-life care must be of high quality to justify any risk to participant mental health. Sensitivity to timing and approach of the researcher is critical (Hynson et al., 2006). The rigorous methods outlined ensured validity of data obtained and created valuable knowledge.

Risks.

Risks for CG participation included emotional stress, anxiety and grief. However, multiple studies including bereaved CGs have indicated there is potential CG benefit including having the opportunity to talk about difficult experiences, and minimal risk of harm (Addington-Hall & McPherson, 2001; Hynson et al., 2006; Roberts & McGilloway, 2011). Confidentiality regarding CG participation was maintained from program leaders. However, many CGs openly discussed their participation, feeling they were benefiting others through sharing of their experiences and providing evidence for the benefits of the program. Many CGs also expressed their contentment at ‘being asked’ their opinion and having someone to listen. Sampled HCPs were at potential risk for harm if they had personal experiences in caregiving, or if the interviews conjured upsetting emotions. Organizational leaders could have responded negatively to views expressed in the study, although confidentiality was maintained, anonymity was limited by small subgroups (i.e. program facilitators, disciplines) in the study. The researcher demonstrated sensitivity by inquiring about HCP’s involvement in family caregiving and informing them of their right to end the interview or leave the study. The researcher informed all participants they

could have breaks or discontinue the interview if needed to minimize distress (Addington-Hall, 2007).

Confidentiality.

Confidentiality was strictly maintained through de-identification of participant data and secure storage of data. Paper data noting participant code and name was stored in a locked cabinet only accessed by the researcher and her supervisor. Electronic data, de-identified transcribed interviews, were stored in the researcher's password protected computer. Participants were informed that the stories they shared may allow others to identify them and to be conscious of this while sharing. These practices protected participants and promoted their sharing of honest perceptions without fear of reaction or consequence from others (Addington-Hall, 2007).

A valid consent accompanied by an understandable and complete information sheet regarding the study in plain English was provided to all participants and was obtained by the researcher (see Appendix E, F and G) (Addington-Hall, 2007). Three variations of information sheets and consents were used for subgroups: attending CGs, non-attending CGs and HCPs to explain the essential purpose of including that group in the study.

Rigour

Lincoln and Guba (1985) provided a framework followed to ensure rigorous qualitative methodology. Accordingly, the study maintained rigour through multiple credibility, confirmability and transferability strategies. Validation and trustworthiness of the qualitative description were demonstrated through these methods.

Credibility.

Credibility is similar to internal validity meaning data truly reflects the phenomena or process, as the population perceives it (Lincoln & Guba, 1985). The processes of member checking and triangulation were performed to enhance credibility.

Member-checking.

Member-checking and validation demonstrated credibility by ensuring participant perceptions of the findings were accurate and adequate (Patton, 2015, Sandelowski, 1993). Both formal and informal member checking occurred. Informally the researcher reviewed and clarified question responses asking participants to elaborate, and completed interviews with an overall summary of themes perceived.

Formally the student researcher met individually with two study participants, one CG and one HCP and presented a lay, abbreviated rendition of the findings. The member-checking process and lay findings summary were approved by the student's supervisor. Each member-checking meeting lasted approximately one hour allowing the researcher to explain the findings, understand participant perceptions and document field notes. Participants felt the findings were accurate and adequate, though sometimes surprising. The CG identified with the perceived outcomes of current and bereaved CGs, and with the perceived barriers. Both the CG and the HCP required clarification over the word 'community' that the researcher had employed in describing a perceived outcome. The CG felt the word 'extended family' conveyed more appropriate meaning. The HCP felt the theme of 'relationship-centered care' could alternately be described as 'family-centered care'. The member-checking process served to clarify and adjust these concepts in the final report. Perceived outcomes and barriers within the HCPs were novel perceptions to the participants selected for member-checking. However, they each perceived

these findings to be true, supporting the assumption that there are multiple realities within naturalistic inquiry.

Triangulation.

Triangulation is a process of verifying evidence through use of multiple sources and methods for data collection and analysis. These methods contribute to credibility and confirmability of the completeness of findings (Sandelowski, 1995c). The use of contrasting data sources and collection techniques obtains different knowledge from which new knowledge can be derived (Lincoln & Guba, 1985; Sandelowski, 1995c). Data acquired from attending CGs, non-attending CGs and HCPs (both front-line staff and social workers) constituted triangulation, which allowed different parts of the program experience or phenomenon to be ‘tapped’ and completely understood. Data was not assimilated but rather varying perceptions between subgroups were incorporated and presented in the findings to provide a wider ‘holistic’ view of the phenomenon (Sandelowski, 1995c).

The use of multiple methods of data collection demonstrated variability. The researcher maintained an audit trail composed of field notes and a personal journal summarizing decisions to provide transparency to readers (Patton, 2015). Triangulation also occurred as the student researcher regularly met with her supervisor and thesis committee to compare content analysis techniques. While contrasts in labelling and strategies occurred, the committee inherently agreed on the findings.

All of the triangulation strategies also served to diminish bias by presenting varying perceptions between subgroups within the sample and by incorporating committee members perceptions of findings (Sandelowski, 1995c). Analyzing field note data offset the limitations of transcript or interview data, which did not capture the mood and personality of the participant

(Sandelowski, 1995c). These elements were essential to accurately understanding and describing persons perceptions of the phenomenon as positive or negative.

Confirmability.

Confirmability denotes that the researcher remains objective and similarly to credibility, verifies the findings (Lincoln & Guba, 1985). Reflexivity and theoretical sensitivity were employed to ensure the researcher did not force data to fit with preconceived ideas and objectively explained data patterns (Lincoln & Guba, 1985). As described, three transcripts were analyzed with the researcher's supervisor to ensure mutual, agreed understanding (i.e. inter-coder agreement) of data themes and patterns while additional committee members reviewed and coded two transcripts. The student's supervisor read all interview transcripts to come to a full understanding and appreciation for the data apart from the student's description and interpretation.

Reflexivity.

Reflexivity refers to systematic, in-depth personal reflection to critique and acknowledge assumptions and past experiences, which can affect the researcher's conduct, description and interpretation of the study (Patton, 2015; Sword, 1999). Because the researcher acted as a qualitative instrument for study, she completed a personal reflection on her background, beliefs and assumptions prior to beginning the study.

Although observations of the program were not incorporated as a data collection method or source, the researcher's observations during the interviews were referred to in written reflections deepening the meaning of the data (Thoresen & Ohlen, 2015). The student researcher recorded a personal reflection following each interview, transcribed and added to a personal journal. She also compared emerging data to personal presumptions, recognizing and

acknowledging new contrasting perceptions of the program from subgroups. The researcher questioned her interpretation of the data to detect if she was imposing her own biases on the data or was accurately describing the participant's meaning. The journal and field notes also maintained an audit trail of decisions made regarding analysis (Patton, 2015).

This practice of reflexivity strengthened the confirmability and trustworthiness of the study findings. Meeting with the researcher's supervisor and thesis committee, and personal reflection assisted the student in maintaining a more objective view of the data. Committee members challenged and contributed perceptions.

Transferability.

Transferability is the relatedness of the findings to the outside population, similar to external validity sought in quantitative research (Lincoln & Guba, 1985). Transferability was not the goal of this qualitative descriptive study, however accurate understanding of the perception of the study program intervention generated hypotheses for similar interventions in the broader CG population (Patton, 2015). Multiple study participants spoke to the feasibility of the program elsewhere, and generalizability of the intervention to other CG groups besides persons with dementia. Knowledge translation strategies including inter-professional conference seminars, and organization presentations will increase awareness amongst HCPs and researchers. New tailored interventions in similar populations or settings, and research questions can be generated.

Chapter Four

Findings

Overall Findings Summary

Overall, participants described their experiences (before, during and after attending the program) related to caring for their family member who had dementia, as well as their perceptions of the psychoeducational program. Background experiences were similar amongst all CGs; highlighting difficult emotions, changing relationships in the context and impact of progressive dementia. Program activities and attributes included: sharing and supporting, learning and modeling, guiding leadership, vested membership and problem-solving.

Outcomes were perceived across participant groups. Perceived outcomes within CGs included: improved emotional well-being, extended community support, empowerment and preparedness. Bereaved CGs felt attending the program maintained their emotional support, assisted them to become role models for peers and provided active learning. Patient outcomes were perceived as enhanced personhood, engagement and well-being. Joint attendance of the program by current and bereaved CGs was perceived as mutually beneficial. Outcomes perceived for HCPs included: strengthened relationships between team members, patients and families with some uncertainty related to program processes. Within the organization, a shift to relationship-centered care and generation of resources was perceived.

Perceived barriers to CGs' program attendance were described such as: time, distance and life demands. Organizational barriers including a perceived lack of involvement of front-line staff in the program and gaps in communication were discussed with potential solutions.

Perceived program facilitators included: characteristics of the program leaders, program core

components and organizational support. Lastly, all persons provided thoughtful recommendations regarding opportunities for program improvement such as strategies to increase communication and interdisciplinary inclusion.

Below follows an in-depth description of these summarized results including a description of sample demographics and the data collection process, participant background experiences shared, program activities and attributes. Perceived outcomes in multiple groups are then described followed by program barriers and facilitators. Abbreviations utilized for quotation reference include PHCP, participant HCP; Program CG, program attending CG participant; and Bereaved CG, bereaved program attending CG participant; Non-attending program CG, non-attending program caregiver.

Participants and collected data

Participants of this study consisted primarily of CGs of persons with dementia admitted to the Specialized Care Unit who currently attended the intervention program. Primarily CGs' family members with dementia were admitted to the Specialized Care Unit for management of responsive behaviours, namely aggression and resistance to care. Caregivers had been providing increasing levels of care from time of dementia diagnosis, which ranged from three months to over 15 years. In total 16 participants comprised the sample allowing in-depth description of data (Sandelowski, 1995b). The sample was comprised of nine program-attending CGs, two non-attending CGs and five HCPs. Descriptive demographics are summarized in Table 2 and 3.

Predominantly program attending CGs were spousal females between 60 and 80 years of age (72.7%) who were attending the program weekly. In contrast, non-program attending CGs included a spouse and adult child ranging in age between 40 and 70 years who had attended the program one time or less. All attending CGs were notably retired living independently, compared

to non-attending CGs who were both employed full-time and had additional dependents living at home (1 adult parent with health needs and 1 adult child). Three attending CGs were bereaved for less than one year, diminishing probability of memory (recall) loss related to the end-of-life experience and six attending CGs were currently providing care (Addington-Hall & McPherson, 2001).

All attending CGs except for two persons had previously completed an abridged version of the Zarit caregiver burden index as they began attending the program (Bédard et al., 2001). Two missing responses for the Zarit score were excluded from mean average calculation. The purpose for use of the instrument in this study was to provide a baseline level of burden within the sample.

Table 2

Demographics of caregivers (program attending and non-attending)

		Attending (n=9)		Non-Attending (n=2)		Total (N=11)	
		n	%	n	%	N	%
Sex	Male	2	22.2	1	50.0	3	27.3
	Female	7	77.8	1	50.0	8	72.7
Age (years)	40-50	0	0.0	1	50.0	1	9.0
	51-60	0	0.0	0	0.0	0	0.0
	61-70	3	33.3	1	50.0	4	36.4
	71-80	4	44.4	0	0.0	4	36.4
	81+	2	22.2	0	0.0	2	18.2
Caregiving Status	Current	6	66.7	2	100.0	8	72.7
	Bereaved	3	33.3	0	0.0	3	27.7
Highest Education Level Completed	Less than High School	1	11.1	0	0.0	1	9.0
	High School	4	44.4	0	0.0	4	36.4
	College/University	3	33.3	2	100.0	5	45.5
	Graduate School	1	11.1	0	0.0	1	9.0
Employment Status	Employed	0	0.0	2	100.0	2	18.2
	Retired	9	100.0	0	0.0	9	81.8

		Attending (n=9)		Non-attending (n=2)		Total (N=11)	
		n	%	n	%	N	%
Living Situation	Dependents at Home	0	0.0	2	100.0	2	18.2
	No Dependents	9	100.0	0	0.0	9	81.8
Relationship to person with dementia	Spouse	9	100.0	1	50.0	10	91.0
	Adult Child	0	0.0	1	50.0	1	9.0
Residence Location of persons with dementia	Specialized Care Unit	5	55.6	2	100.0	7	77.8
	Long-term Care	1	11.1	0	0.0	1	9.0
	Deceased	3	33.3	0	0.0	3	27.3
Length of Time of Residence in Specialized Care Unit	3-6 months	1	11.1	1	50.0	2	18.2
	6-12 months	1	11.1	1	50.0	2	18.2
Length of Time of Program Attendance^a	1.5-2 years	4	44.4	0	0.0	4	36.4
	2-3 years	1	11.1	0	0.0	1	9.0
	Greater than 3 years	2	22.2	0	0.0	2	18.2
Length of Time of Program Attendance^a	3-6 months	0	0.0	NA	NA	0	0.0
	6-12 months	2	22.2	NA	NA	2	22.2
	1.5-2 years	7	77.8	NA	NA	7	77.8
		Attending (n=9)		Non-Attending (n=2)		Total (N=11)	
Caregiver Burden^b	Mean ^c	17.9		28		20.1	
	SD	8.7		22.6		11.9	

Note. PWD = Person with dementia; NA = non-applicable. ^aNon-attending caregiver participants were not included in sample for calculation of length of time of program attendance. ^bShort version of the Zarit Burden Interview (0-48) measures personal and role strain (Cronbach's alpha=.88) with scores greater or equal to 17 as severe with significant indication of depression (Bedard et al., 2001). ^cTwo participants were missing caregiver burden index scores and were removed from the sample for calculation.

Table 3

Health care professional demographics

		Health Care Professionals (N=5)	
		n	%
Sex	Male	1	20.0
	Female	4	80.0
Age (years)	31-40	1	20.0
	41-50	0	0.0
	51-60	4	80.0
Professional Role	Registered Nurse	2	40.0
	Registered Practical Nurse	1	20.0
	Social Work	2	40.0
Time Employed in Specialized Care Unit	1-5 years	1	20.0
	5-10 years	1	20.0
	10-20 years	2	40.0
	Greater than 20 years	1	20.0
Personal Experience as a Family Caregiver	Yes	4	80.0
	No	1	20.0

Almost all (87.5%) CGs' family members living with dementia were residing in the unit except for one person who had been relocated to a LTC home. The average level of CG burden, according to the Abridged Zarit Caregiver Burden Index, was higher in the non-attending group than in attending CGs (17.9, 28). Analysis to detect statistical significance was outside the range of methods for this study and scores were used for descriptive purposes only in light of the small sample sizes. However scores above 17 are considered indicative of depression (Bedard et al., 2001).

Staff participating in the study were predominantly female (80%) average age 51-60 years old (80%) and possessed varying roles within the unit. Front-line staff including registered and registered practical nurses contributed 60% of the HCP sample with the perspective of social work comprising 20%. Nearly all, (80%) of the HCP sample had previously acted as family CGs

themselves. All staff had pre-requisite training in ‘Gentle Persuasive Approaches’, which enhances knowledge and provides skills related dementia management, personhood, confusion and delirium making their perception of the intervention program valuable. Experience and number of years of employment in the unit were reported.

The original interview guide (Appendix D) was iterative and modified during analysis as themes emerged (Sullivan-Bolyai et al., 2005). For example, two initial CGs interviewed perceived the informal process of the program as a facilitator. Therefore subsequent CGs were questioned as to their feelings about informality. This iterative nature of the interview guide was particularly useful for comparing barriers perceived by CGs and HCPs. Perceived barriers identified in one interview often formed the probes used for later interviews.

Interviews lasted between 30 minutes and one hour in length, conducted in locations selected by participants. Conversation followed the interviewees’ interest to minimize their distress (DiCocco & Bloom, 2006; Hynson et al., 2006). The student researcher was aware that interviews could conjure negative, distressing emotions amongst participants and informed all participants of their ability to leave at any time, or request a break. The researcher observed participants for emotional distress and offered information regarding professional support services (DiCocco & Bloom, 2006). The interview format allowed participants to maintain some control over content and pace of the meeting, which can lead to expressed feelings of empowerment and emotional gain in bereaved persons (Hynson et al., 2006).

Field notes were also collected to capture additional supporting data, observations and record the researcher’s perceptions to assist with data analysis. Field notes in combination with interview transcripts and demographic data assisted the researcher in making connections and identifying emerging themes and concepts.

Potential emotional risks to the researcher related to the emotional subjects of end-of-life, death, dying and CG needs were managed through calming time spent outdoors, support and discussion with family and friends and personal reflection. Occasional debriefing sessions between the researcher and supervisor occurred. Multiple study participants showed emotion during interviews through quiet crying, fidgeting, long contemplative pauses and occasionally guarded, short responses to questions. The student researcher often provided support and reassurance by recognizing emotional experiences and hardships, validating and encouraging the normalcy of these feelings. When persons appeared guarded in response to a particular question the researcher utilized minimal probes and then moved to a different subject area. All persons chose to complete their interviews despite their ability to withdraw; emotion was intermittent and controlled.

Participant Background Experiences

Attending caregivers.

Study participants shared background caregiving experiences providing context and rationale for the program need and their attendance. Caregivers had faced difficult emotions, experienced positive and negative relationships with family, friends, HCPs and endured the impact of dementia on their daily lives.

Difficult emotions related to caring for persons with dementia included: guilt, anger and grief. Transitioning a spouse into hospital care after decades of marriage, "...was the toughest decision I've ever made. We've been married for over 62 years and [we were] always together..." (Program CG). Another CG shared her feelings, "I get a little angry at the guy upstairs [God], sometimes really angry...I just say 'stop giving me hope. Stop giving me little bits of him.' That's what I get every day. Little bits of him" (Program CG).

Caregivers described relationships with family and friends explaining, "...they are one step back from the problem...So that isn't to say that your family doesn't care, they care, but it's not the same. It's not their life partner" (Program CG). Spiritual relationships were described as comforting by some CGs stating, "...it's amazing the things we can do when we have to. And to know that we have this spiritual entity that you can trust. That was a great strength to me" (Program CG). Caregivers also spoke of their relationships with HCPs, healthcare organizations and navigation of the system as influencing their journey. Staff participants in the study described their own personal caregiving experiences and perceived that these contributed to forming positive relationships and feeling 'in tune' with current CGs (PHCP)

The impact of dementia was linked to CG lack of control, stigma and isolation. One CG described feeling helpless, "I didn't want to face [anyone]...He's trapped in a world, non-verbal...He's lost so much in life, there has to be more I can do" (Program CG). Caregivers also felt stigmatized due to their family member's specific illness as an HCP described, "...the D word is what they fear more than the C word. Because...the cancer is public...you actually look sick so people can sympathize...with dementia...it's hidden" (PHCP). The HCP went on to describe CG isolation stating, "...average society shies away from people who quote 'behave inappropriately'...so the family members start to protect them, their circle of support gets narrower and narrower...to the point where you become very isolated" (PHCP).

Non-attending caregivers.

For CGs not attending the program, persistent, ongoing feelings of isolation, lack of control, support and information were described. A CG described, "And I don't see an end in sight and that's what's disturbing for me, having a life...if I could look ahead into the future...and know this is where I was going to be I would be horrified" (Non-Attending CG).

The CG went on to share, "...the anger in me is so deep...I've got to get rid of it" (Non-Attending CG).

Non-attending study participants did not verbalize feelings of community support or relationships with other CGs on the unit, and were largely unfamiliar with other patients, families or organization activities. One CG described reluctance to approach the social workers for personal support not wanting to impose. However, both persons did feel that they were able to communicate with HCPs regarding care for their family member when needed. Both CGs felt that attending the program could offer positive benefits.

Program Activities and Attributes

Study participants described multiple activities as occurring within and related to the program. Such activities included: sharing and supporting, learning and modeling, vested participation, guiding leadership, and critical problem-solving. Attributes and activities were perceived as contributing to outcomes.

Sharing and supporting, 'you're not alone'.

Caregivers felt they provided and received emotional support, understanding and encouragement from fellow group members. One CG described, "No one outside this group would listen to what we had to say, or to our tears and to our happiness" (Program CG). Another CG expressed that, "It's the basic knowledge that you're not alone. There is help out there, you just have to look for it" (Program CG). Meeting other CGs was also perceived as beneficial, "...getting to know other spouses for the first time...was really encouraging" (Program CG). An HCP described sharing within the group:

...allows the acknowledgement that you need the help... over time...they start to share more and more...surrendering a bit of their privacy when they can see the benefit they

can get from sharing. The level of disclosure that happens in our share and support sessions is...very vulnerable and very deep (PHCP).

Despite the high level of disclosure occurring, sharing was also described as ‘selective’ meaning that group members elected to discuss personal family matters and concerns over care privately with staff as opposed to within the group setting, ensuring confidentiality of unit staff involved. One CG explained, “...that’s not the kind of thing I would share with the group” (Program CG).

Learning and modeling, ‘listening to experiences’.

Education and modeling, both formal and informal, were described as regularly occurring within the program. A CG recalled a memorable presentation stating “I liked it when they had the minister come...speaking about the issues around death and dying” (Program CG). Group members also listened to one another describing, “...listening to some of the spouses’ experiences...recognizing that nothing happens overnight. That with medication, it takes time for the changes” (Program CG).

Guiding leadership, ‘social work skills’.

Caregivers described social work leadership and facilitation within the program. Study participants explained disciplinary skills of the social workers in the program stating, “...they directed us to find out what we needed” (Program CG). An HCP described social work as “...the discipline that works at bringing the feelings out” (PHCP). Group members also recognized that, “...the social workers have to be very well aware of the person they are talking to, their level of intellect” (Program CG). An HCP elaborated on their program objectives, “...our goal was to provide peer support. To have people sit and use social work skills to facilitate the conversation, but the primary means of therapy would be people helping each other” (PHCP).

The leaders adopted an informal style of facilitation and program structure consistent with a professionally-led peer-support model, which group members described and perceived as a facilitating factor of the group:

It's informal, everybody can say what they want...there's a certain structure, what we're going to talk about...not somebody sitting at the head of the table...so you don't have your freedom to express your cares and concerns (Program CG).

Program leaders explained that the group content, process and weekly frequency were member driven, "...the group ruled" (PHCP).

Vested membership, 'the stakes are higher'.

Group members demonstrated high levels of dedication, maturity and respect towards one another. Members took on various roles as champions, came from diverse backgrounds and demonstrated longevity with returning attendance even after the person with dementia was deceased or relocated. One HCP described champion members explaining, "...some members of the group are always kind of natural leaders" (PHCP). Another participant went on to describe, "The group members are very vested. They make it work. And they are actively recruiting people" (PHCP).

One CG perceived that the high level of investment in the program was related to the heightened seriousness of life and death situations they were facing, in comparison to other group experiences explaining, "The stakes are higher" (Program CG). Health care professionals also perceived that unique vested membership was linked to a positive relationship between the CG and patient, and desire to help them. The HCP explained, "...their commitment to their spouses comes from a history of a relatively good marriage...and it comes from good opposed to coming purely from duty" (PHCP).

The dedicated attendance of CGs, both current and bereaved, also contributed to the level of cohesion in the group. One CG described what she termed ‘generosity of spirit’ as evident in a returning bereaved member, “Her husband is no longer living, she still comes to the group...she brings all those wonderful treats to us week after week. She's like a mother to us” (Program CG). An HCP perceived continued attendance as related to CGs’ altruistic wish to help others in the community, “I think it's on a bigger level...hopefully through process they can get wider into the circle [affecting change], into the community. And I'm thinking that's why a couple of them still continue to engage” (PHCP).

The diverse backgrounds of group members were also described as factors within program characteristics, which aided in presenting varied, respected perspectives. One CG expressed, “We're from all different walks of life. We're from a professor to a welder to a housewife...we touch all of society, within the group” (Program CG). An HCP commented on the group’s diversity stating:

Dementia is a great leveler...it doesn't matter what you did before...Everyone with dementia is experiencing the same type of cognitive impairment. And I guess...that's also true of the families. Because they have the dementia in common...the rest of it is not important (PHCP).

Engaging in critical problem-solving, ‘dwell on the negative’.

Sharing experiences between CGs’ was also described as allowing members to “...put your concern in a context...whether anybody else has experienced that problem, you hear how it’s been dealt with...” (Program CG). However, repetitive critical problem-solving and discussion of broad concerns with patient care was sometimes perceived as a negative group activity. While CGs frequently expressed gratitude and appreciation for their family members’ care, they also described that occasionally they “...dwelt on the negative...” (Program CG). Program leaders described redirecting conversation to focus on CG well-being, “...we keep

bringing it back to 'how does this effect how you feel?' And trying to get people to express that. And they do, with a little bit of support and encouragement they do” (PHCP).

Summary

The similar and distressing background experiences described by CGs across all groups (i.e. current program members, bereaved and non-attending) provided rationale and illustrated the need for the intervention program. Concrete examples of difficult emotions, a frequent lack of supportive relationships, and impact of dementia created context for the CG experience.

Program activities and attributes were defined by CGs and HCPs and were linked to perceived outcomes in multiple groups.

Perceived Outcomes

Participants’ perceived outcomes related to the program were the most valuable results of this qualitative descriptive study in response to the study questions. These perceived program outcomes were both positive and negative and are described for current and bereaved CGs attending the program, patients or persons with dementia, HCPs and the hospital organization.

Perceived outcomes for program attending current caregivers.

Maintaining emotional well-being, ‘I can be me’.

Family CGs who attended the program described feeling emotionally balanced, accepted, and less stressed with increased ability to cope. One participant expressed, “...prior to coming I might be stressed out, but after I leave the forum...let's say I'm on an even keel...again” (Program CG). Sharing and celebrating positive caregiving moments with group members was perceived as promoting balance. One participant described, “So it’s not all negative...the Forum in itself was a powerful tool to...make people realize that it was not the end of the world”

(Program CG). This participant went on to share, “It kind of balances our life. You know not just misery...if we have good moments we share those too because...If it’s that important to me then I know that it’s important to them too” (Program CG).

Feelings of acceptance within the group also contributed to well-being. In contrast to relationships with family members and friends outside of the program, CGs described members’ ability to relate to the difficulties associated with caring for a person with dementia. Members’ shared-experience was perceived as providing relief and comfort. One participant described:

There is a feeling of solidarity at times that we are all going through this. That we are all on the same journey...And sometimes I'm really exhausted, and yet I struggle with not being [at the hospital]. So just knowing that other people have the same experience, and it's ok not to [visit]...it's just that little bit of encouragement (Program CG).

Another participant expressed the ability to be herself in the group, “And you don't have to put on a happy face for everybody...Another friend of mine said... 'all you have to do is smile and they'll love you'...I can't smile sometimes, [Here] I can be me” (Program CG).

Difficulty coping with their family member’s illness and emotions such as guilt were commonly expressed problems by CGs. However, support and modeling from program members was perceived as assisting with coping. One participant described:

...all of us come here every day, all of us feel guilty. Ah the guilt is tremendous. Tremendous. That's one of the things we learn. Oh my God together we learn to deal with the guilt. You know and alone it’s a lot harder to do it (Program CG).

Health care professionals perceived similar program benefits to the emotional well-being of CGs. One HCP shared, “I think for those who come to the group, it's very uplifting. We’ve heard many people say that they wouldn’t know what to do if the group wasn’t there... You know just to have the synergy with everybody else who has walked that journey” (PHCP). An HCP did

acknowledge that low mood persisted amongst group members because of their situation but program attendance, "...changes the support that they have as they go through that" (PHCP).

Overall, the program was perceived as improving CGs' emotional well-being. Attending supported stress management, coping, balance, and feelings of acceptance or solidarity.

Emotional well-being was linked to program activities.

Building a supportive community, 'It's not just here for that hour'.

Caregivers attending the program felt they had built a supportive community, which extended beyond meeting times. Study participants described the group as an 'intimate family' or 'village'. Caregivers described: care and concern for each other, co-dependency, socialization in and outside of hospital, inclusion of persons with dementia in activities and shared vigilance for persons with dementia. One CG shared, "...I really don't want [the group] to suffer more than they have to. So when they do have a bad situation I really, really feel for them...I feel protective of them" (Program CG).

The shared experience of being in the program led to varying degrees of friendship. One CG described, "[We] go out to lunch...or out to dinner together... So...it's not just here for that hour, or for the time that you're on the ward...you can rely on these people. I could call anyone...and they would help me" (Program CG). Similarly a bereaved CG recalled the group's support of one another during bereavement, "...we went to her husband's funeral to support her..." (Bereaved CG).

The relationships developed within the program were perceived as diminishing CGs' feelings of isolation when visiting patients. A bereaved CG recalled:

[There] is a feeling of isolation if you don't develop friendships with other people...you're going there on a regular basis [and]...you looked forward to going

because there were other people to talk to, than your spouse who was getting less able to communicate (Bereaved CG).

Similarly, an HCP recognized that "...if they didn't have the group, the burden of visiting would be that much greater" (PHCP).

Caregivers also appreciated the inclusion and vigilance for persons with dementia as part of the community. One CG described, "Everybody asks how your loved one is. It's not like, you know, they are just there for themselves. No they are there for everybody" (Program CG).

Another CG noted, "...as soon as we know one of our member's [patient]...you just pay more attention to them..." (Program CG). Another participant described communication occurring between group members as a 'pipe line' stating, "...they will tell me how my wife is doing when I'm not there...[which] takes a lot of pressure off of me...even though we have excellent staff here, it's still nice to know there's an outside individual looking in" (Program CG).

Staff also perceived the program's supportive community as beneficial explaining:

It decreases the sense of loneliness...they go around and look out for each other's patients, so that is a huge part of the benefit. Because they get to know other patients too... Expanding their field...When they come here it's not so dreary. They are coming and [making] connection, you know, it's not just a task they do (PHCP).

Another HCP noted that group members have, "another set of eyes when they can't come. It makes them less anxious...[which] improves their overall health" (PHCP).

A lack of privacy could be associated with being a part of a community although this was not expressed by CG participants. Health care professionals did acknowledge that CGs could become enmeshed in one another's situations making it difficult to maintain confidentiality. They described, "...there is no privacy anymore...but certainly there is privacy in this setting...the families are quite careful of that" (PHCP).

Overall study participants perceived the supportive community of members outside the program as extremely beneficial. Caregivers expressed concern for fellow CGs and persons with dementia, socialized in multiple settings and described feelings of co-dependency and vigilance for persons with dementia. In general these experiences were perceived as decreasing CG burden and isolation.

Growing preparedness and disease acceptance, ‘Insight into where they’re at’.

Persons perceived the program as assisting them with emotional acceptance, peace and coping through increased understanding and knowledge regarding dementia, behaviours, treatments and prognosis. Formal and informal educational activities were linked to preparedness. One participant recalled, “I think the presentations...gave us some insight in what to expect down the road...like when I got a phone call that my wife was choking...It was another stage, but I was prepared for it...” (Program CG). This participant went on to say that the educational presentations, “...give better understanding, this is happening and why...[And] it allows us to cope with it” (Program CG). A bereaved CG also recognized that education regarding the disease allowed her to accept her spouse’s behavior changes as part of the dementia and not of personal choice. She stated, “I had all the books and everything. And they laid out the progression of the illness...like you knew it wasn't him, like he was totally, totally different” (Bereaved CG).

Being present in the group heightened a bereaved CG’s awareness of her spouse’s disease progression stating the program, “...made [me] more aware...and I would say [that] my husband is not leaving here. Ever...it would be in relation to some other kind of question but...it was just a matter of time” (Bereaved CG). Group members felt their emotional acceptance of their family member’s disease contributed to feelings of peace stating, “I think I’m a little bit more at peace

now that I've accepted where he is at. And that I accept the fact...that I am doing as much as I can" (Program CG).

Program attendance of bereaved CGs assisted current CGs' future preparedness. A current CG described, "They want to report how they feel...and we want to hear because it's going to happen to us...it's good for the live group to listen to the practical aspect of the loss, the financial aspect of the loss" (Program CG).

Despite education in the group, some CGs still demonstrated negative symptoms of denial. An HCP explained, "Most understand after they've been to the [program]...but there is the odd one where it is really challenging...to let them know what their loved ones are really doing, or do these medication changes...we go over it...again" (PHCP). One group participant shared that disease education and sharing of experiences aimed at assisting in preparedness also led to negative feelings. This CG described her mood after meetings stating, "I usually feel better...but...sometimes I feel worse because I know what's coming. I don't want to accept that. I'm one of those in denial people and that I don't want to think of my husband at another stage" (Program CG).

Overall participants perceived disease acceptance and preparedness as positive outcomes associated with program activities including: formal educational presentations as well as experiences shared by group members, particularly those bereaved. Disease acceptance and preparedness contributed to new feelings of peace, ability to cope and plan for the future.

Empowering their role, "To say you can".

Caregivers perceived new feelings of empowerment and confidence characterized by: perception of personal value, decision-making capacity, advocacy and inclusion on the healthcare team and comfort in navigating the organization. Empowerment was linked to

program activities of peer support and education, and connection to interdisciplinary team members. One member described the new value she felt supporting recreation initiatives for persons with dementia, “[It] gave me...new meaning to my life...all of a sudden I found myself a goal...you could say this helped me blossom...that made my life, it really helped me”

(Program CG). An HCP further elaborated on one group member’s personal accomplishment:

The group empowers them to do that. To say you can...we had one individual who did a [community] presentation...about something that she cares very deeply about, a dementia program that was initiated here...the group empowered her to do that...and her intelligence...and what she wrote and how heartfelt she was...just blew us away (PHCP).

Solidarity amongst group members was also perceived as contributing to CG empowerment. A CG suggested, “...you have a group of individuals...you bring things together to the management or to the proper areas and you can follow it up” (Program CG). An HCP described, “...[CGs] see themselves as advocates not just for their family members but also for every patient on the floor” (PHCP). Caregivers demonstrated a collective voice by supporting safety initiatives on the unit. An HCP described the response of CGs to news concerning the initiative, “They felt ‘Yes. Our concerns are heard’. And that’s all family wanted, was that their concerns were heard and attended to...they feel they are actually doing something for their loved one” (PHCP). Caregivers also perceived that they gained valuable skills and information within the program, which aided them in navigating the hospital system. One CG explained, “I mean it’s a big institution...without a group like that...I don’t know how people maneuver through it and how they manage” (Program CG).

Another CG participant described new confidence in communicating with HCPs:

Well...these gentlemen are professionals [doctors] and in my day and age you always took a step back...but one of the things I feel I’ve learned, that it’s ok to talk with these

people. That's what they're there for...the people...say at the [program], 'go ahead' and that's how sometimes problems are solved (Program CG).

Health care professionals linked empowerment to education within the program explaining, “I firmly believe the more we can educate them, the more they are empowered and then through empowering them...[they] participate in the care component” (PHCP).

Overall empowerment was perceived to be a positive outcome, however some HCPs perceived that a shift of power to families is not traditional or comfortable. One HCP described, “For some staff...they see the power imbalance...and some staff, not all, are feeling threatened by it...they feel they are being dictated to” (PHCP). Apprehension or perception of CG empowerment as a negative outcome associated with the program may be linked to misconceptions or barriers to the program.

Facing frustration, ‘Let’s make it constructive’.

Some CGs felt frustrated during or after attending the program. While all CGs expressed their perceived positive benefits as outweighing negative feelings, persons did acknowledge that group process, dynamics, content or lack of change could sometimes be aggravating. Frustration was perceived by CGs as related to the voicing of repetitive complaints, monopolization of speaking time and nonrelative education. However, group members demonstrated tolerance and appreciation for one another. One group member noted, “...complaining...to me sometimes is a waste. Let's make it constructive” (Program CG). An HCP also recognized that CGs feel frustrated if they do not feel acknowledged. This HCP explained, “The challenge for them would be that they bring concerns and it's not acknowledged” (PHCP).

Educational topics perceived as unrelated to person’s level of need or stage of disease were also linked to CG frustration. A CG described her response to various educational speakers

stating, "...if I learn something new I feel it's been a benefit. If it's information that isn't new to me, or isn't helping me problem-solve my husband's needs, than it isn't useful" (Program CG). Another group member similarly expressed that occasionally community service education was not relevant to her situation, "...we're not in touch at all with [homecare providers]...I feel like we could have put the time to better use" (Program CG).

Informal group process and dynamics were also perceived as frustrating by some CGs. One participant described, "...I was expecting a more task-oriented process. So it took me a while to get used to it..." (Program CG). Caregivers commonly described frustration related to 'talkers' in the group as one participant stated, "...if I've had a bad day...and...maybe somebody is doing a lot more talking than I feel, maybe they should be I get a little wrangled. But you know, you have to just take it as it comes" (Program CG).

Overall, frustration was not an uncommon perceived outcome associated with the program. However, participants were quick to diminish negative comments by adding that they valued all group members' responses to concerns were understandably slow in organizations. Members also expressed that they continued to attend the program despite occasional feelings of frustration as the perceived benefits vastly outweighed any negative experiences.

Perceived outcomes for program attending bereaved caregivers.

Maintaining support through bereavement 'they have empty hours'.

Bereaved CGs perceived continued emotional support from group members during the dying process and after the person with dementia had died. While persons were actively dying, CGs described keeping vigil at the bedside and having other group members 'check-in' on them frequently. Persons felt they could express their grief openly to members and were able to maintain valuable connections afterwards despite loss of their CG role. Health care professionals

perceived continued attendance as therapeutic and social, and provided a unique opportunity for the social workers to monitor bereaved persons' adjustment.

One bereaved CG explained why she continued to attend the program, "Because we can talk and we can cry if we want to. Everybody's in the same boat. It's been really beneficial. I mean I can stop...because there is no reason for me to be here" (Bereaved CG). In contrast to other persons outside of the program who were uncomfortable discussing loss, bereaved CGs perceived that group members wanted to hear how they were doing. A bereaved participant explained,

Others [outside the group] don't want to know that I'm not fine. Because the minute that you're not fine that drives them away. So...as far as they are concerned I'm fine...you don't lose your friendships that way...[Group members] want to know because they are living it...the end of the road is the same for them as it is for me (Bereaved CG).

Another participant encouraged bereaved people to attend saying, "...other people don't want to listen. Our group knows how to listen. Regardless of whether your husband is alive, or not alive...it doesn't matter. It's loss...And if you can talk about it with somebody that understands, come" (Program CG).

The transition of active CG into bereavement represented a huge challenge. Continued program attendance and connection to group members was perceived as beneficial as one bereaved CG recalled, "I felt at a loss...[after the death] because I had gone on a regular basis to the hospital...my world's kind of turned upside down. And I was...nervous about going to the meeting after...but everybody was very warm...and you really do miss them" (Bereaved CG). A current CG explained the need for continued support throughout the journey stating, "They need the support more now...because now they have empty hours...first comings, first

Christmas, first anniversary...traditions, all change...For example one member...said she wouldn't have made it had it not been for the group” (Program CG).

An HCP recognized that attending the program provided some bereaved persons with a social activity describing, “They need an activity...a reason to get up on a Thursday...they still identify so much with...family members on the unit...over time it becomes the social as opposed to therapeutic. And that's what I would hope for them” (PHCP). The program social workers were also able to monitor and support bereaved persons’ adjustment and explained, “[As] clinicians if we...picked up that people were really stuck...struggling in their grief...we'd...refer them on...what we have picked up is they're making appropriate progress...And that's what it's like with grief...It's going to take as long as it takes” (PHCP).

Overall bereaved CGs perceived continued emotional support, which assisted them in their grieving process. Bereaved CGs were encouraged to continue actively attending the program by group members. They were invited to express their grief openly, socialize and have access to social work help if needed.

Becoming the teacher ‘and the group learns from it’.

Persons attending the program perceived that bereaved CGs emerged as teachers. Current CGs and HCPs recognized the valuable information and modeling that bereaved CGs provided. Bereaved persons’ modeling was linked to preparedness, emotional well-being and hope in current CGs. One HCP described role modeling:

...shows the rest of the group that they will be fine...when their loved one dies, because there's the model...people who talk openly about their grief... how they cope...carrying their grief but still moving forward. And the group learns from it...Here you are a very active caregiver and then once that caregiving role stops, life still goes on. And there's still a lot of hope (PHCP).

Similarly another HCP explained that initially she was uncertain about the joint attendance of bereaved and non-bereaved CGs because it was untraditional and could be difficult for current CGs to witness others' bereavement. However she was impressed with the mutual, therapeutic support saying, "I actually think it helps them...because they know they're going there...the amount of support they've provided the people that are bereaved is...incredible...to let people tell their story as often as they need to with a positive response and support" (PHCP). A group member confirmed her appreciation for returning bereaved CGs, "I think it let's you know that life goes on, life goes on" (Program CG).

Informal, practical teaching by bereaved CGs was also perceived as beneficial as a current CG explained, "...they have information on what's coming in the future for us. Dealing with the incessant paperwork. Your dining room table so covered in papers you don't know where to start...health claims and pensions" (Program CG). A bereaved CG was also open in discussing her Christian faith and practical preparations as her husband declined with group members, "I would always encourage people to be prepared" (Bereaved CG). She recalled her own preparations saying:

...there was a point when I realized that things...were getting far worse for my husband. So I had to put a step out and get myself prepared for the final days...[So] I had a close friend go with me to the funeral home (Bereaved CG).

Interestingly bereaved CGs were not cognizant of their teaching role within the group and were surprised to hear that they provided inspiration, modelling and insight. Bereaved CGs did describe a desire to reciprocate support they had received. One person stated, "I hope I'm here to help them" (Bereaved CG). An HCP further acknowledged, "They want to contribute" (PHCP). The desire to 'give-back' was mirrored by another participant whose spouse was moved to an

LTC home and continued to attend the program whom stated, “I’m still giving back, and will continue to do so as long as allowed, permitted, as you said a lifer” (Program CG).

Active learning, ‘this is how they learn’.

Bereaved CGs continuing to attend the program perceived that acquiring further valuable knowledge about dementia was satisfying, and allowed them to better understand and reflect on the person with dementia’s disease process and journey. Their knowledge could also assist others in the future. One bereaved CG explained, “[When] we have speakers I learn a lot from that...what I could have done. So that if somebody else is in the same boat than I can kind of pass on what I know (Bereaved CG)”. Similarly another bereaved CG shared, “...I like the group and I learn...Every time I come I learn something different...with new people coming in, it's probably going to be repetitious but...we'll cross that bridge when we come to it” (Program CG).

An HCP further explained that:

...thirst for knowledge is just human and it's life long. And we certainly have seen that in this group...they'll share resources between them, they'll pass books around... and I think they enjoy learning and this is how they're learning (PHCP).

The group was also perceived as a practical resource for information. A CG explained, “...when they have problems, there is a group of people here, everybody has maybe just a smidgen of information or help that they can utilize to help solve their problem” (Program CG).

Overall, perceived outcomes for bereaved CGs included: continuing support for well-being, becoming the teacher and on-going active learning. These outcomes were linked to program activities including: formal and informal education, expressed genuine concern from group members, and socialization, which continued through the transition into bereavement.

Perceived outcomes for persons with dementia.*Promoting personhood ‘What is best for the person with dementia’.*

Caregivers and HCPs perceived that attending the program promoted the personhood of the person with dementia, through the empowerment, preparedness, education and emotional well-being of CGs. Study participants perceived that the program facilitated CGs ability to express and articulate the person with dementia’s wishes and values, maintaining their personhood. One CG described that the education and insight they gained from a particular speaker assisted with them in identifying their spouse’s wishes. The CG described:

Well in the case of the minister it really helped me to start thinking through...some of the decisions I might have to make, at the end of my husband's life...if he stopped eating, how I would handle that... How I need to be thinking about what it is that my husband wants...So that was very helpful (Program CG).

An HCP also perceived the program as promoting personhood through empowering the CGs’ role or voice, and confidence in decision-making consistent with patient wishes. The HCP explained, “...bringing forward the family voice...is also very critical...persons with dementia...need somebody who can bring forward who they were...prior to the illness. Because all we see is the person with the illness, and not who they were” (PHCP). Another HCP confirmed:

We did a lot of work when the group first started about end-of-life decisions and I think that helps the patient too...[We] speak at length with family members about...patients wishes' because they can't express them...to help the family members identify that for the clinical team without being overwhelmed by the emotion of the decision...And by having the education...I think it helps (PHCP).

Overall personhood can be perceived as being promoted by CG education and empowerment within the program as well as personal reflection on the values of the patient.

Supporting engagement and well-being ‘it even brought them out’.

Caregivers and HCPs perceived that persons with dementia were more likely to be included and engaged in social activities if their CG attended the program, which extended to a supportive community. Attending CGs provided assistance and care to persons with dementia when their CG was absent. One CG described, “I visit her husband or I’ll go into the ward and speak to all the people...because it does extend beyond that hour that we are in our meetings together” (Program CG). Another participant recalled, “When one member wasn’t there I would walk her husband all over the place...” (Bereaved CG). Socialization amongst program members also fostered engagement of persons with dementia as a CG described:

[We] would go down to the cafeteria, or...to the birthday parties...you didn’t feel so isolated with just your patient...we would be in a group and we would be talking. So they [patients] are listening more. Maybe they don’t participate as far as speaking, but they are aware...it even brought them out (Bereaved CG).

Caregivers who attended the program expressed comfort in visiting and engaging with group family members, and felt it supported well-being of persons with dementia as one participant explained, “...one participant’s husband we seem to have a...rapport...all’s you have to do is just speak to them or just sit with them and talk to them or hold their hand...and they’re just as happy as anything” (Program CG).

Group members organized and funded monthly entertainment together with the Specialized Care Unit Recreational Therapist. These activities were perceived as positively engaging persons with dementia. One HCP described patients enjoying a birthday party, “...it’s

entertaining, like if someone's singing...they feel the party...All day long they yell, yell, yell. But at that moment they're very happy and they start talking to each other” (PHCP).

The well-being of persons with dementia was also perceived as being related to the emotional balance and well-being of CGs attending the program. One HCP explained that, “[We] know how attuned dementia patients are to...emotion in the people that they know the best...The benefits to the patient are a family member who is more educated, more supported...who's emotional state is a little more settled (PHCP)”.

Overall the program was perceived as encouraging engagement and well-being in persons with dementia. These outcomes were characterized by socialization of persons with dementia with program members, attendance and enjoyment of entertainment, and sensitivity to emotional balance within program attending CGs.

Perceived outcomes for health care professionals.

Raising relationships, ‘bringing the program together’.

Perceived program outcomes in staff included an openness and desire for CG feedback on care provision and vested participation in social events with persons with dementia and families. Health care professionals perceived that care provision was being discussed in the program and expressed motivation and willingness to tailor care. One HCP shared, “[Staff] are very flexible, they can adjust and change their intervention if they are given some feedback...you know your loved one...be a little bit descriptive and cooperative...tell us the best way to help them” (PHCP).

Staff also perceived that the program had fostered collaboration and inter-professionalism between healthcare team members. One HCP described, “[We] pull in a lot of the education from the team. So the team also is asking about the group...Before that was strictly social work”

(PHCP). Staff also perceived that education provided to CGs in the program promoted positive relationship-centered care and cooperation. One HCP described that program CGs are, "...more realistic and accepting and they seem to participate more in the treatment program...When they are not as educated or as aware or understand... makes it more challenging for the patient" (PHCP).

Caregivers also attributed the perceived engagement and rapport with staff to the program, "[Without the program] I don't think we [would] have had, the closeness...and the rapport with the nursing staff and with the social workers and the coordinators on the floors and the doctors..." (Program CG). An HCP poignantly expressed, "To me it's changed the culture on the unit in terms of how families are part of what's going on" (PHCP).

Health care professionals further perceived that the entertainment funded by group members through the hospital foundation supported patient engagement and relationships between staff, families and persons with dementia. One HCP explained parties were, "Really well attended by patients and...staff are invested" (PHCP). Another HCP further explained that increasing the frequency of the birthday parties to every month through group funding, "...brings the whole... [unit] together..." (PHCP). This participant recalled a birthday party stating, "...patients were up dancing...it's really helped them a lot to have more activity" (PHCP).

Revealing uncertainty, 'I don't know a lot about it'.

Although HCPs were perceived as supportive and engaged in program related activities, HCPs expressed a lack of knowledge and uncertainty about the actual meeting proceedings, goals and content. The front-line staff study participants were unaware that the entertainment was funded through the foundation by the CGs and were also unaware of program topics or presenters. When questioned about their familiarity with the program, an HCP responded:

...to tell you the truth...I don't know a lot about it...I don't have a valid paper that I can read off that I can say these are the times, these are the families...All I heard was that the families can come together and provide support and make some suggestions...on how they perceive the care for their loved one (PHCP).

An HCP raised concerns over program presenters and consistency to care practices on the unit explaining, "...you might be speaking of an educator that has never been on the level that I have...on the front-line" (PHCP). Health care professionals also expressed concern and uncertainty over the sharing of concerns in a group forum stating, "Maybe they should do it privately with the social worker or case manager...that shouldn't be broadcasted...they might identify names of nurses or...create increased anxiety" (PHCP).

Conversely the social work program leaders and CGs within the program felt the program was fully 'transparent' and described speaking openly of it with staff to let them know CGs would be away from their family member during meeting times. Inter-professionalism and education from multiple disciplines such as speech language pathology, recreation therapy, geriatric psychiatry and pharmacy was encouraged, however the mainstay of the program remained support above education, which provided rationale for social work leadership.

Perceived outcomes for organization / system.

Generating resources 'reaching out'.

Caregivers and HCPs perceived an increase in financial resources and physical or accessible services associated with the program for the resource-limited, publicly funded hospital. Financially, in addition to personal donations, CGs also devoted personal time and effort in support of large organizational fundraisers such as a bake sale and walk-a-thon. One HCP recalled, "The family took the whole thing...they took it upon themselves...they baked and

they manned the booth! And they raised the most money! Oh, I was like...incredible...it's a tribute to the people that make the group” (PHCP). Group members also supported initiatives to increase the frequency of recreation activities, such as birthday parties, for persons with dementia through fundraising. Caregivers also “...brought in enough money through personal donations from the group...to have a Christmas party, a tree trimming party...and are trying to get a music system in the two dining rooms” (Program CG).

The psychoeducation program itself was perceived by CGs and HCPs as an enhanced organizational resource. The program’s large group format was perceived as providing increased access and intervention to a larger number of CGs than could have been reached individually by social work. One HCP explained:

Our time is just crazy, so being able to treat, an intervention, of a big group of people in that stretch of time, I think that's a huge thing for us. I don't think we could have reached out to that number of people in that time frame...And there is things [shared] that we didn't know and then we can also follow-up on that which is wonderful for us (PHCP).

Some CGs were hesitant to approach or access the social workers for support prior to the program initiation as one CG described, “...although the social workers were available, I never interacted in that way before, so I felt very isolated and I was getting burnt out” (Program CG). Staff also perceived the program as creating a new service available to bereaved CGs explaining, “...it’s not well recognized how [dementia] effects people who are bereaved either. And we've never, through resources been able to offer a bereavement group for family members... So this way we can help those people too” (PHCP).

Shifting to relationship-centered care, ‘incorporating them into the care’.

Health care professionals perceived an ongoing shift in the organization from a traditional model of care delivery, which did not confer power to families or patients, towards relationship-

centered care. Perceived program outcomes of CG empowerment and staff engagement were linked to enhanced relationships. One HCP described efforts to improve relationship-centered care:

Our goals for 2016 are to sit down with the families and talk to them about...the certain goals that we set...in completing care. So I think we're getting better at sharing that...We say their husband, or their wife was a little bit challenging...and we re-approached...letting them know what's going on...incorporating them into the care (PHCP).

Another HCP described multidisciplinary care planning meetings held to understand both the team and family's views regarding issues stating, "...we'll have a multidisciplinary...meeting about it...come up with a new care plan, a new strategy...as a trial first...and if the family are satisfied with it then we will carry on that care plan...the best care for that patient" (PHCP).

Health care professionals still perceived an ongoing struggle between traditional and relationship-centered care describing, "Be compliant...[families] are basically told...if we would only give family...all families...a chance, they can come up with very creative, innovative ideas to improve care, and I think the healthcare system needs to allow that to happen" (PHCP).

Participants also perceived the organization's inability to meet all CG ideals, possibly due to difficulty in changing organization processes, standards or models of care delivery. One HCP expressed, "...some of the [family requests]...you just can't meet...But...you have to talk about the difficult things and silence doesn't help...Like if we don't talk about it...how are we ever going to deal with it?" (PHCP).

Caregivers also perceived new communication channels linked to the program. Monthly attendance at the program by the unit manager, interdisciplinary team members and other hospital leaders allowed CGs to communicate concerns and gain information. An HCP explained, "Family find it very helpful and...felt that, yes, they have a direct-line to the

managers...they felt that the group is known...their concerns are heard and attended to” (PHCP). Overall perceived outcomes in the organization related to the program included the generation of new resources and services, and a trend towards relationship-centered care.

Summary of perceived outcomes.

Outcomes related to the program were perceived in multiple sub-groups within the study sample including attending CGs, bereaved CGs, persons with dementia, HCPs and the organization. The majority of outcomes were perceived as beneficial, particularly for CGs the target of this intervention program, and included: support for emotional well-being, extended supportive community, and empowerment. The ripple effect of positive support for CGs was linked to perceived benefits to persons with dementia including the promotion of personhood and engagement. A significant perceived organizational outcome was the generation of resources. All perceived outcomes across sub-groups speak to an ongoing shift towards relationship-centered care for the betterment of patients and families. Perceived barriers or challenges to the program did persist and discussion of these factors will follow.

Perceived Program Barriers

Perceived program barriers were defined as factors or characteristics, which challenged or diminished program attendance, participation and provision. Barriers were also described as factors perceived as challenging group members’ support for organizational initiatives. All attending CGs and HCPs speculated informatively on the barriers to program attendance. The most significant explanations came from the non-attending CGs themselves. A summary of all perceived barriers and their relative sub-groups is depicted in Table 4. A specific description of program barriers perceived by non-attending CGs is provided.

Non-attending caregivers, ‘more things I have to fit into my schedule’.

The primary reasons CGs perceived they were not attending the program related to a lack of time, scheduling conflicts or general life demands. Non-attending CGs also demonstrated a lack of knowledge of the program specifics regarding content, timing and process. One CG was already occasionally attending another support group provided by the Alzheimer’s Society prior to their family member’s admission to the Specialized Care Unit, and perceived positive support from that group. The non-attending CG explained, “I was already going to another support group so I didn’t really need to go” (Non-attending CG). Unfortunately, barriers such as time, distance and life demands also inhibited the CG’s attendance of that alternate support group.

Similarly both CGs were employed and living with dependents at home. For one CG the dependent was an adult child who required little care, whereas for the other CG the dependent was an aging parent with dementia themselves whom required significant care. The CG explained that they normally visited the hospital with their dependent mother, which could have been perceived as an additional barrier to attending. They explained, “My mother, she's not very social and...she's very proud. And she doesn't want to express. I'm the total opposite, I've got an avenue, people are going to listen to me, oh I'm talking” (Non-Attending CG). However this CG did hypothesize that they could attend the group independently while their mother visited the patient in the unit. This non-attending CG represented the only adult child in the study sample and described a high level of burden and stress within themselves related to caring for two parents with dementia. This CG also felt that re-arranging their exhaustive employment schedule to attend or commit to the psychoeducation program or other programs would create added stress:

I did talk to one therapist at the Alzheimer Society, and that was more or less just sending a bunch of information of workshops...resources...But to me it just seems like an overburden, just more things that I have to fit into my schedule (Non-Attending CG).

However, this non-attending CG did feel that the program would provide valuable support and disease education explaining, “I need to know about the disease...but things have accelerated...so quickly...I don't even know how to cope with it...how to catch up with it...I've learned a bit from [the previous hospital]...and bits from the family doctor...” (Non-Attending CG). Overall the characteristics of employment and dependents contrasted demographics of persons in the group whom were all retired and lived alone. Furthermore neither non-attending CG lived locally close to the program setting, creating a barrier of distance.

Additionally one non-attending CG also perceived that age of group members was a barrier and felt that they would be younger than the other persons in the program, making it difficult to relate. The participant described, “...if I'm in a group with some 80 year old spouses, I'm in a different place in life than they are” (Non-Attending CG). Sample demographics confirmed an age difference between some attending and non-attending CGs. Alternatively this CG perceived that persons in their Alzheimer's Society support group were “...all about the same age” (Non-Attending CG). The roles of CGs were similar between both the Alzheimer's support group and the psychoeducation program, with all persons representing spouses of persons with dementia. This CG speculated that it would be beneficial if leaders could, “...gather together the early onset [for a program] specifically focused on families of younger persons with early onset dementia” (Non-Attending CG).

This non-attending CG expressed satisfaction with care and with levels of communication they received from HCPs. They expressed much gratitude towards the staff and may have had an aversion to hearing critical evaluation of the care by group members, which is

an additional perceived barrier. The CG shared, “I am quite confident, I think [the staff] are doing a marvelous job with her. She seems really happy for the most part which is most important for me and comfortable” (Non-Attending CG). This CG did not perceive high personal need for attendance at the study program.

In contrast, the other non-attending CG expressed mistrust and difficulty navigating the system. They perceived that attending the study program could meet many personal needs and felt frustrated from being unable to attend. This CG was anxious to find ways to overcome perceived barriers to the program using technology suggesting, “...the whole idea of [electronic] handouts...a monthly newsletter or blog, so you could get the information and you could communicate with each other if you chose to. And build something, or have a private, secret group on Facebook” (Non-Attending CG).

The two study participants representing the sub-group of non-program attending CGs shared important characteristics perceived as a barriers to attending including: lack of time and life demands. However, different life circumstances, perceived outside support and additional burdens from dependents may have influenced CGs contrasting perceptions and interest in attending the program.

Table 4

Perceived program barriers

Perceived Caregiver Barriers	
Physical and emotional factors perceived as impeding attendance or participation in the program.	
Factors	Supporting quotes
Personal Characteristics: <ul style="list-style-type: none"> • Diverse factors affecting group relationships, i.e. <ul style="list-style-type: none"> ○ Personality ○ Culture / Background ○ Education Level ○ Male Gender or Age ○ Disagree with critiques 	"...just aren't able to open up...willingness to expose yourself to some extent...an aversion to being in groups" (Program CG) "...their education is different...intimidated by these...highly knowledgeable people" (PHCP) "...don't like to hear the critique of...authority...overwhelmed with gratitude" (PHCP)
Psychological Readiness: <ul style="list-style-type: none"> • Willingness and ability to receive and share information 	"...not ready to hear...grappling, coming to terms with the whole idea of their loved one having dementia" (PHCP) "My family member isn't like this" (PHCP)
Group Dynamics & Open Membership: <ul style="list-style-type: none"> • Interactions between group members • Original versus new members 	"...liked doing things on my own...with a group you are going to have friction, some kind or another" (Program CG) "...quieter maybe not bringing forward...concerns...'newbies' because it's such a tight group" (PHCP) "...newbies may be unintentionally left out by pioneer members" (PHCP)
Time and Distance: <ul style="list-style-type: none"> • Physical factors surrounding scheduling or location 	"...working, they can't come to the group...pitfall of having it in the afternoon. But...[others] don't drive after dark" (Program CG) "Every semester the schedules a little different..." (Non-Attending CG)
Misconceptions: <ul style="list-style-type: none"> • Assumptions about the program, <ul style="list-style-type: none"> ○ Undervalue ○ Required sharing 	"...don't...realize the value of it...don't realize what you need until you are there...think it's a 'bitch session' (Program CG) "People think you have to lay bare everything" (PHCP)
Commitment: <ul style="list-style-type: none"> • Responsibility to attendance 	"...there because you want to be there...committed to something at this stage of the game...don't think I could" (Bereaved CG)
Life Demands and Alternate Supports <ul style="list-style-type: none"> • Duties to other roles and existence of other supports • Added burden 	"...already going to another support group" (Non-Attending CG) "...taking care of aging parents...young families...commitments...lives" (Program CG) "...seems an overburden" (Non-Attending CG).

Perceived Bereaved Caregiver Barriers	
Factors perceived as impeding bereaved caregivers from continuing to attend the program	
Factors	Supporting Quotes
Repetitive Content: <ul style="list-style-type: none"> • Recurrent formal / informal information 	“If it starts getting repetitious it’ll be time for me to go” (Bereaved CG)
Not Relevant: <ul style="list-style-type: none"> • Non-applicable to present situation 	“...discussing...things...related to the hospital...it’s not that relevant...I don’t feel I should...comment” (Bereaved CG)
Active Lifestyle and Supports: <ul style="list-style-type: none"> • Alternate existing supports 	“...a lot of support through most of my life...group would [not] be helpful to me at that stage...my life can be very busy without that group” (Program CG)
Perceived Health Care Professionals & Organization / System Barriers	
Factors perceived as impeding HCPs from providing, supporting or attending the program; factors restricting organization services and care requested by program members.	
Factors	Supporting Quotes
Lack of Involvement <ul style="list-style-type: none"> • Feelings of not being a part of meetings 	“They might not see...the benefits...Because they’ve...never actually sat in the [group]...(PHCP) “And the Forum is the best place to bring [issues] up, but if nursing is not a part of it? Not good” (PHCP)
Limited Resources <ul style="list-style-type: none"> • Lack of finances or time to provide programs or services 	“...real challenge...to live up to [family’s] expectations too...haven’t got the people...haven’t got the money” (Program CG) “...sometimes plan [meetings] on the fly...didn’t have any...time” (PHCP)
Lack of Communication <ul style="list-style-type: none"> • Lack of concrete, accessible, information regarding the program 	“...don’t have a valid paper that I can read off that i can say these are the times, these are the families and all of this...it shouldn’t be just email (PHCP)
Resistance to Breaking Norms <ul style="list-style-type: none"> • Discomfort with transferring power to families 	“...healthcare...inclusive of the views of families...they come with a wealth knowledge...and a lot of times that is discounted...form a relationship is what’s best for the patient” (PHCP)

Perceived Program Facilitators

Perceived facilitators of the program were described as factors assisting in the provision, attendance or success of the program. Factors are summarized in Table 5. In addition to supporting the program, the perceived program facilitators are also linked to the necessary movement towards relationship-centered care of persons with dementia. Social work leadership, core components, and organizational support were perceived as promoting program success.

Caregivers and HCPs described characteristics, factors and activities they perceived as contributing to personal, patient and organizational wellness through relationship-centered care.

Table 5

Perceived program facilitators

Perceived Program Facilitators Characteristics or factors perceived as supporting the provision and success of the program.	
Factor	Supporting Quotes
Program Leaders <ul style="list-style-type: none"> • Personal characteristics and professional skills of current leaders i.e. <ul style="list-style-type: none"> ○ Social work role ○ Communication ○ Passion ○ Warmth ○ Flexibility 	<p>“I’m really not a major joiner...But I did it because of who they were” (Bereaved CG).</p> <p>“Communication skills...flexibility, willingness to let the group run itself too. Not be controlling the group...letting the group unfold...with some boundaries” (PHCP)</p> <p>“...passion, and willing to be the champion, that’s definitely the criteria” (PHCP)</p>
Core Components <ul style="list-style-type: none"> • Informal process and content of program i.e. <ul style="list-style-type: none"> ○ Defined goals ○ Education and support ○ Inter-professionalism 	<p>“...dual purpose of education and support...connect the families with individuals in the community and in the hospital setting who had expertise...to work more effectively with the team of staff as well” (PHCP)</p> <p>“no pecking order” (Program CG)</p> <p>“...social work skills to facilitate the conversation, but the primary means of therapy would be people helping each other” (PHCP).</p>
Organizational Support <ul style="list-style-type: none"> ○ Program autonomy ○ Dedicated resources ○ Responsiveness 	<p>“Requires...the buying in...of the administration. We have incredible support to do the group...a lot of autonomy” (PHCP)</p> <p>“...their concerns were heard and attended to” (PHCP)</p>

Chapter Five

Discussion

This objective of this study was to contribute a valuable description of CG (current and bereaved) and HCP perceptions of a psychoeducation program offered during end-of-life. New data and understanding will allow HCPs to understand if CGs feel this program model meets their needs at end-of-life. New data can be used to tailor the current program and inform future program development, and also provides insight into CG intervention receptivity and need for continuity of care into bereavement. Key study findings are discussed in this chapter including: a) perceived similar therapeutic benefits for current and bereaved CGs influenced by joint attendance; b) perceived growing preparedness for end-of-life in CGs; c) perceived benefit of the study program as an organizational resource for bereavement support; d) perceived program barriers experienced by adult children CGs; e) perceived CG experiences' of group work process and skilled facilitation, and f) perceived importance and fostering of relationship-centered care for CGs and persons with dementia. Study limitations and strengths are also described.

Positive Outcomes

A key finding of this study was the perceived similar outcomes of emotional well-being and mutual support in current and bereaved CGs, which was influenced by joint attendance. This data suggests that both current and bereaved CGs can benefit from reciprocal relationships developed from jointly attending psychoeducation programs occurring during late-stage illness and end-of-life for persons with dementia. The novel attendance of current and bereaved CGs in a singular intervention program transcends other program models described in the literature, which separate persons at a time of critical transition (i.e. death).

A large number of studies of education/support groups for current CGs confirm the positive perceived benefits in this study including emotional well-being and social support (Chien et al., 2011; Elvish et al., 2013). A systematic review of studies evaluating bereavement interventions show mixed results in the literature with some group interventions decreasing depression, improving adjustment over time and reducing avoidant coping with grief (Waller et al., 2016). However, no studies were found of psychoeducation programs jointly attended by current and bereaved CGs.

This study therefore contributes a valuable description of a unique program model with positive benefits for both current and bereaved CGs related to joint attendance. Current CGs supported bereaved persons by normalizing and validating their emotions, encouraging storytelling and reminiscing, activities associated with tasks/strategies of approach-oriented coping in grief therapy (Knight & Gitterman, 2013). For example, a study participant explained that bereaved group members were encouraged to share their stories as many times as needed with attentive support, which normalized their situation and grief. Knight and Gitterman (2013) confirm that psychoeducation groups provide necessary socialization and social support critical in aiding bereaved persons to process their grief. Current CG participants were also curious, and felt it was beneficial to learn how bereaved persons were coping and how they had ‘downsized’ because they were going to face the same situation. Observing bereaved CGs provided reassurance to current CGs that life continued after caregiving ended.

All CGs in the study also described a desire to ‘give back’ to fellow participants by providing emotional support, assistance and information. This altruistic benefit of mutual aid programs promotes empowerment and self-efficacy (Knight and Gitterman, 2013). This reciprocal relationship is supported by mutual aid or peer support models which focus on

strengths and recovery, indicating that persons with shared experiences provide validation and authentic empathy as they are all ‘in the same boat’ (Knight & Gitterman; Repper & Carter, 2011). In mutual aid support models group members further along in their recovery (i.e. bereaved CGs) are perceived as role models, providing inspiration, hope and guidance to others, as was the case in the study program (Repper & Carter, 2011). The unique joint attendance of current and bereaved CGs in the study program created a therapeutic, reciprocal relationship, which contributed to the beneficial, perceived outcomes of emotional well-being and support.

Psychological Preparedness for End-of-Life

Another key finding of the study was CGs’ perception of growing psychological preparedness for end-of-life fostered by joint attendance, education and sharing. Preparedness is defined as a person’s perception of their own readiness for the death of a loved one in multiple domains including: medical, psychosocial, spiritual and practical (Hebert, Prigerson, Schulz & Arnold, 2006). In the theoretical framework of preparedness, Hebert and colleagues describe end-of-life conversations regarding topics such as: prognosis, advance care planning, grief and loss as fulfilling domains of preparedness and precipitating outcomes including: satisfaction with care, mental health and adjustment during bereavement, and surrogate decision-making (Hebert et al., 2006). A literature review by Hebert and colleagues in 2006 found that 23% of bereaved CGs felt unprepared for the death of their loved one even if they had endured a long chronic illness, and 25% felt that HCPs should have prepared them more (Hebert et al., 2006). Caregivers who perceived themselves as unprepared were more likely to experience depression, low satisfaction with end-of-life care and complicated grief (Hebert et al., 2006).

For example, in the study program CGs described learning about the financial paperwork required when the person with dementia died, medical indicators of progressing dementia like

impaired swallowing and discussed practical tasks such as planning a funeral, which constitute end-of-life and advance care planning conversations. Multiple domains in the preparedness framework were addressed. Bereaved CGs also described the importance of being prepared and wanted to impart this to current CGs. The education, sharing and discussion within the study program assisted CGs in feeling prepared for end-of-life.

Preparedness is a predicting variable of CGs' adjustment to death as demonstrated in an RCT including 89 bereaved CGs in LTC (Schulz, Boerner, Klinger & Rosen, 2015). Attendance of a multi-component intervention focused on: increasing knowledge of processes in the LTC, advance care planning and emotional well-being resulted in CGs feeling more prepared and experiencing less complicated grief than the control group (Schulz et al., 2015). Similarly, preparedness was facilitated in the study program through interdisciplinary group discussions of organizational processes and end-of-life decision-making. Interdisciplinary education and peer support from jointly attending current and bereaved CGs within the study program was perceived as facilitating preparedness for end-of-life with lasting effects into bereavement. Study findings are in-line with published research surrounding preparedness.

Organizational Support for Bereaved Caregivers

Another valuable finding was the perception of the study program as a new, beneficial, organizational support service for bereaved CGs. At the program's initiation, leaders assumed that bereaved persons would stop attending the study program upon the death of the person with dementia. However, bereaved CGs continued attending, providing and receiving emotional support through their grief. Utilization of the program as a bereavement service evolved because: CGs had pre-established routines of visiting the hospital setting, existing supportive relationships within the group, and maintained a feeling of solidarity and empathy for current

CGs. Bereaved CGs were not required to seek out new providers in alternative settings for bereavement support.

Alternately, few bereavement support programs exist within the hospital or LTC due to scarce resources, although in Canada half of adult deaths occur in hospital and 30% in LTC (Canadian Institute for Health Information (CIHI), 2007). A survey of 161 bereaved CGs conducted by Cherlin and colleagues in 2007 found that services were most often (49.7) accessed through hospices and 26% received support from other community services. Seeking out a new support provider and forging new relationships during a difficult time of transition may represent an overburden for CGs, diminishing use of bereavement services. In a study of bereaved family members by Walsh, Foreman, Curry, O'Driscoll and McCormack (2008) 18% wished bereavement services had been offered prior to the death. Walsh and colleagues (2008) recommended that bereavement services be offered by hospitals as part of a palliative approach to care.

On average family CGs underutilize bereavement services with only 30% accessing supportive interventions (Bergman, Haley & Small, 2011; Cherlin et al., 2007). A follow-up study of the REACH trial revealed that only 13% of CGs of person with dementia attended bereavement support groups (Bergman et al., 2011). For CGs who did not utilize services in Cherlin's survey (2007), 2.7% cited lack of awareness of service and 6.3% cited difficulty in attending location (i.e. time, distance, transportation) as rationale, while 66.7% felt they were adjusting well to the loss and 44.6% had developed informal support elsewhere (Cherlin et al., 2007). Alternatively, for bereaved CGs in the study program, location, awareness and presence of existing support within the group were facilitators to attendance of the program and led to positively perceived outcomes, which can inform future program development.

Bereaved CGs also continued to closely identify and empathize with current CGs of persons with dementia, which encouraged their continued attendance of the study program for bereavement support. Apart from the study program, there is a lack of availability of bereavement services specifically for CGs of persons with dementia (Team AlzLive, 2016). Programs and services provided by the Alzheimer's Society vary between provinces and locales with no national database of services available per region. The researcher contacted the national office, ten provincial head offices for the Alzheimer's Society and three local offices in Ontario regarding bereavement services and four (two in Ontario, one in British Columbia and one in Quebec) currently offer closed-ended group support/education programs specifically for CGs after the person with dementia has died (Private Communication, ASC, June 2016).

Society administrators reported referring bereaved CGs to other community resources for bereavement support, providing a one-on-one counselling session after death, or allowing CGs to continue attending support groups with current CGs, although administrators acknowledged a need for increased services from their organization barred by lack of resources (Team AlzLive, 2016). The Alzheimer's Society has recently expanded online and print resources related to grief and loss to address this need. In the Peel region of Ontario, Canada, a unique 10 week, closed, psychoeducation bereavement program is offered a few times a year (AlzLive, 2016). Overall, the evolving development of the psychoeducation program of study as a bereavement support service was perceived as beneficial to CGs, with ongoing access and utilization facilitated by existing supportive relationships and routine attendance at the study site. This new information supports the development of bereavement support services both in hospital, or LTC and specific to CGs of persons with dementia.

Perceived Program Barriers

Barriers to attendance of this CG program were highlighted through this study offering important information. For example, non-attending program CGs were employed, cared for other dependents at home and were of a younger age than retired, single-dwelling, program attending CGs. Non-attending CGs described time, distance, location and perceived dissimilarity to other CGs within the program as barriers to their attendance.

Service non-use by CGs of persons with dementia in the community has been attributed to: managing at the moment, reluctance (i.e. denial of need, invasion of privacy), impeding service characteristics (i.e. hours of operation, unsure of eligibility) and lack of awareness (Brodarty, Thomson, Thompson & Fine, 2005). In particular, barriers to attendance due to service characteristics (i.e. hours/timing) may be experienced more by younger, employed, adult child CGs with dependents at home, than by older, retired, spousal CGs. The perception of similarity to other group members, based on age, gender, culture and relationship to persons with dementia, was also found to be a predictor of support group attendance in a six month longitudinal study (Steffan & Mangum, 2012). Therefore programs devoted to a specific demographic (i.e. adult child, males, or minority CGs) may be more appealing than the study program which attracted spousal CGs only. Typically psychoeducation and support programs are accessed by educated (i.e. completion of at least high-school), non-minority, women spouse CGs (Bergman et al., 2011; Pinquart & Sorensen, 2011; Steffen & Mangum, 2012). These demographics were characteristic of our study sample of program attending CGs.

The alternate population of adult children CGs are often caring for older (i.e. >5 years) persons with dementia than spouses, and report more responsive behaviours than spousal CGs (Pinquart & Sorensen, 2011). Adult children also report performing the same number of

caregiving tasks as spousal CGs, but in a lessened number of hours, validating their need for quality, accessible support. Younger, adult child CGs may be interested in accessing support and education in different formats than older spousal CGs.

Adult child CGs may be more technologically savvy preferring an online program format, which can overcome barriers to access, infringe less on privacy and appear to have positive effects. A study of 47 participants' use of an internet-based Savvy Caregiver program from the Alzheimer's Association in the United States found CGs perceived the program to be convenient and easy to access, particularly by minority CGs (Lewis, Hobday & Hepburn, 2010). The majority of participants (62%) were less than 55 years of age and 76% reported they enjoyed learning more through the internet format than in a live class, suggesting that online access to programming may be desirable to younger CGs such as adult children (Lewis et al., 2010). Study participants reported feeling more confident in caring for persons with dementia (Lewis et al., 2010). Overall, perceived barriers to attendance of the study program included life demands such as: employment and dependents and perceived differences in experience and age from attending CGs. These findings are consistent with barriers described in the literature and may potentially be overcome by introduction of technology to facilitate access, or creation of additional programs aimed at specific CG subgroups such as adult CGs.

Effective Groupwork Process

Activities and perceived experiences in the study program contribute evidence for effective groupwork process and skilled facilitation. Groupwork process is defined as a method to help persons meet individual and group needs, influencing personal, organizational, group and community problems, through purposeful group experiences (Lindsay & Orton, 2011). Tuckman describes a linear model of 5 'Stages of Group Development': forming, storming, norming,

performing and adjourning (Bonebright, 2009; Lindsay & Orton, 2011). For example, study program-attending CGs' described members' described cohesion, role establishment and mature acceptance of one another's idiosyncrasies as maintaining harmony, which deftly describes the 'norming' stage of group development (Bonebright, 2009). Harmony of the group was further described as a factor intrinsic to group dynamics in a phenomenological study of a nurse-facilitated psychosocial group intervention, along with hard effort and collaboration between facilitators (Chujo & Okamura, 2015a).

High level group 'performance' was also evident as CGs emerged as a problem-solving instrument or entity, focused on education and mutual aid inclusive of persons with dementia. For example, CGs described sharing their 'problems' and concerns with group members to learn about others' experiences. Group members also became involved in Specialized Care Unit initiatives in order to improve the lives of persons with dementia. The open-ended nature of the study program resisted a strictly linear model with addition of new members and evidence of iterative stages.

The professionally-led program model integrated guidance from leaders trained in groupwork with peer support. For example, group members described facilitators' ability to assist CGs in identifying and expressing personal needs, handle conflict within the group, provide information suitable for multiple levels of education and create a warm, welcoming atmosphere without imposing or acting as a 'dictator'. Literature confirms facilitators of groupwork require skills in: assessing the functioning of group members, assessing the functioning and process of the group as a whole, assessing the environment group members face and developing goals with effective problem-solving and informal, casual leadership (Toseland & Rivas, 1998). Facilitators of groups associated with loss and grief, such as the psychoeducation

program of study, also require skills in approach-oriented coping in order to assist group members with developing resolution and adjustment to the loss.

Nurses are ideally situated in many environments to facilitate psychoeducation programs for families and persons of varied illnesses, however organizations must ensure that training in groupwork and psychosocial facilitation is available to any discipline pursuing the role, as this affects the perception and performance of the group (Kruske, Schmied, Sutton, & O'Hare, 2004). It is an expectation and within nurses' scope of practice to provide both formal and informal education and support to families in their clinical areas. A study assessing nurses' facilitation skills in a psychosocial group intervention for cancer patients assessed intervention skills (i.e. assisting group dynamics, decreasing burden and improving quality of life). Results showed that nurses both experienced and new to leading the program were able to: encourage participants to reflect on themselves, provide presence, grasp the context, return the topic to the theme, while experienced facilitators weaved multiple skills together (Chujo & Okamura, 2015b). Both new and experienced facilitators encountered problems in delivering the intervention, and benefitted from role-playing and simulation (Chujo & Okamura, 2015b). The impact of the intervention group and facilitation on group participants was not evaluated.

Overall, CGs' perceived experiences in the psychoeducation program in our study provided evidence of high performance and effective groupwork performance. Skilled facilitation was provided by social workers, which promoted harmony, cohesiveness and problem-solving. There are further opportunities for nurses to participate in the study program as educators or facilitators, provided they have training in this area.

Relationship-Centered Care

Lastly, the importance and significance of relationship-centered care emerged as an overarching theme throughout the study findings. For example, CGs perceived having a closer, intimate relationship with staff as a result of the study program. Caregivers also expressed that when they perceived a positive, connection and trusting relationship with the HCP providing care to the person with dementia, they felt more at peace and were able to eat and sleep better. Both CGs and staff perceived interdisciplinary education provided in the study program as fostering relationships and empowering CGs with confidence to collaborate with the healthcare team, improving care for persons with dementia. Caregivers' involvement in hospital initiatives such as entertainment and fundraising also created opportunities for interactions and relationships between staff, CGs and persons with dementia. Multiple disciplines (i.e. nursing, social work, medicine, physiotherapy, recreation, occupational therapy, etc.) developed a vested interest in the study program and well-being of members, which also strengthened relationships.

Perceived as an extension to person-centered care, which seeks to enhance the values of patients, relationship-centered care is a philosophy stressing both the personhood of patients, families and HCPs, and the partnerships/interactions between them (Ryan, Nolan, Reid & Enderby, 2008; Suchman, 2006). Although relationship-centered care was perceived as strengthened as a result of the study program by CGs and some HCPs, other staff perceived uncertainty and gaps in communication, which inhibited the overall shift from provider-focused care to relationship-centered care. For example, some HCPs felt that they had little knowledge of the study program and did not have opportunities to participate or attend, although their personal care was being discussed in the program. This uncertainty may have led to negative feelings in HCPs and perception of a 'power imbalance' imparted to CGs in the program.

The shifting, or sharing of power relationships between HCPs and CGs may also be uncomfortable as it represents a change from traditional services which are provided separately for persons with dementia and CGs, and remain provider-focused (Ryan et al., 2008). However, persons with dementia in particular should be considered in the context of their crucial family relationship because of their neurological decline, as the relationship-centered care model suggests (Ryan et al., 2008). A framework of six senses integral to achieving positive interactions between patients, HCPs and CGs includes: security, continuity, belonging, purpose, achievement and significance (Ryan et al., 2008). These senses are mirrored by perceived outcomes in program-attending CGs and persons with dementia. Fulfillment of the ‘Senses’ relationship-centered care framework was used to explain the success of a Community Dementia Support Service offering respite to CGs of persons with dementia, which demonstrated low staff turnover and high family satisfaction (Ryan et al., 2008). The uncertainty expressed by front-line HCPs in our study may be attributed to perceived ‘lack of belonging’ or ‘lack of significance’ related to lack of direct involvement and knowledge of the study program. Overall, relationship-centered care was perceived as strengthened by CGs and some HCPs in relation to the study program. However, other HCPs felt uncertain and uncomfortable which diminished relationships between CGs and HCPs.

In summary, the study program was perceived as: mutually beneficial to both bereaved and current CGs, partly because of joint attendance; assistive in increasing preparedness for end-of-life; a valuable organizational bereavement support resource; and largely supportive of relationship-centered care. Perceived barriers specific to adult child CGs were highlighted in this study as well as illustration of effective groupwork process and facilitation. This study provides

valuable insight into perceived benefits and challenges of the study program that can allow tailoring of the intervention and inform the development of new programs for CGs.

Strengths and Limitations

Strengths of the study include the depth and breadth of data shared by willing participants. Both program-attending and non-attending CGs expressed a deep, altruistic desire to share their stories in order to help others. This desire led to open expression and eager participation in the study. The variety in the sample including current, bereaved, and non-attending CGs, as well as HCPs of varied disciplines also provided a broader, more reliable description of the study program and illuminated unexpected, perceptions valuable to tailoring the program, particularly within HCPs.

A limitation of this study was the recruitment of only one adult child CG. Although this participant shared demographics and characteristics with the other non-program attending participant, which highlighted program barriers, additional adult children may have further confirmed/refuted results. Similarly, all HCPs in the study sample were either front-line nurses or social workers, and insight could have been gained from interviewing hospital leaders such as the unit manager, regarding organizational outcomes. Member-checking was performed with two diverse participants, and potentially further checks could have been conducted to increase confirmability and reliability. Persons choosing to attend the study program may also represent a unique sample of CGs, different from other CGs of persons in the Specialized Care Unit (approximately 50-60) who choose not to attend, therefore perceived program benefits may not be universal to all CGs. Lastly, although the student researcher exercised reflexivity, and confirmed thematic/content analysis with her supervisory committee, her own personal history and experience likely flavoured the overall interpretation of the study findings.

Chapter Six

Implications and Recommendations

Research

Much new research has been conducted during the past two decades regarding the effects of caregiving with recent attempts to systematically review the plethora of interventions and programs occurring, isolated, within healthcare settings. Future study of the psychoeducation program should include statistical analysis of participants' pre and post intervention Zarit CG burden indexes, to gain quantitative evidence of the program's effectiveness on perceived burden.

Further quantitative and qualitative research is needed to study the impact of pre and post bereavement interventions, including the study program, on outcomes of bereaved CGs of persons with dementia. Consistent, specified outcomes including complicated grief, anxiety, burden and depression scores using validated instruments, will allow valuable comparison of interventions. An observational mixed-methods study of benefits of the study program for participating bereaved CGs, in comparison to bereaved CGs attending outside, exclusive programs is also warranted to understand if the continued, joint membership is more valuable or effective than traditional content and programming.

Additional research questions remain surrounding effective measures to overcome barriers to program attendance, particularly for adult child CGs. For example would the introduction of teleconferencing during meetings prove a useful avenue for CG participation and would perceived benefits of the program be equal to persons attending in person? The introduction of a technology option for current persons unable to attend the study program is

feasible and recommended. Development and evaluation of the study program within an alternative setting such as LTC would also provide valuable information regarding the program's applicability and feasibility.

Practice

Multiple implications for HCP practice stem from the research findings. The many perceived benefits of this study suggest the program model should be implemented elsewhere, in varied settings including: LTC, acute care and community, however champion, trained clinicians are required for program facilitation. Staff caring for persons with dementia or providing primary care to current or bereaved CGs should encourage and assist them to seek out accessible psychoeducation and support services.

Research findings also illustrated a shift towards relationship-centered care, which requires the conceptualization of CGs and families as integral components of the healthcare team, particularly in the care of persons with dementia who often cannot advocate or speak for themselves (Ryan et al., 2008). Health care professionals must increasingly find ways to collaborate and utilize the expertise of CGs, without over burdening them (Ryan et al., 2008).

There is opportunity to tailor practice within the study program and support relationship-centered care through increased participation of front-line staff in the educational component. While members of varied disciplines such as dietitians, physiotherapists, and physicians had provided formal education to the CG group, front-line staff including Registered Nurses and Registered Practical Nurses had minimally participated in program content. Recommended collaboration on educational presentations would increase staff knowledge and participation in the program, as well as facilitate further positive relationships with CGs.

Policy

Implications of this study include the development of social policies, which define care needs and resources entitled to CGs of families across settings (i.e. acute care, LTC, community), including access to open support groups inclusive of current and bereaved persons (Walsh et al., 2008). Within acute care costs are allocated ‘per patient’ although increasingly relationship-centered care is encouraged, recognizing the family as part of the patient. Caregivers continue to encounter barriers in accessing social services (such as bereavement support). Policies linking community support service providers such as Bereaved Families of Ontario or the Alzheimer Society, together with hospital and LTC sites where persons with dementia and CG are experiencing end-of-life may improve access and service utilization.

Organizational policies facilitating person-centered care (the underpinning of relationship-centered care) are needed. Policies should outline strategies for: engagement of families and patients throughout the hospital, measurement and feedback regarding patient experiences, HCP satisfaction, communication, HCP capacity building and foster a supportive culture for learning and change (Lexford, Safran & Delbanco, 2011). Social and organizational policies are recommended to support collaboration with, and health of CGs.

Education

Knowledge gaps were identified in a survey of nurses and aids caring for persons with dementia in multiple LTCs in Australia, with 50% of participants failing to recognize dementia as a life-limiting disease, thus limiting HCPs’ ability to educate and prepare CGs for end-of-life (Robinson et al. 2014). Unfortunately the Dementia Knowledge Assessment tool utilized in the study by Robinson and colleagues (2014) does not assess knowledge of care for CGs. Similarly, residents surveyed expressed they felt more competent caring for patients with cancer than for

persons with dementia and their CGs, owing to a lack of education and training (Manu et al., 2012).

The recognized gap in education regarding dementia within healthcare school curricula and within workplaces leads to HCP discomfort in provision of palliative or end-of-life care and discussion of dying (Chang et al., 2005; Chenoweth, Jeon, Merlyn, & Brodarty, 2010; Mitchell et al., 2009). In a systematic review of factors improving nurse retention in caring for persons with dementia, education and skills training were cited (Chenoweth et al., 2010). Therefore, staff within the study setting may appreciate and benefit from education surrounding family experiences of end-of-life in dementia, effective interventions such as the psychoeducation program, mutual aid, and long-term affects into bereavement.

Staff uncertainty surrounding the study program content and specifications cited by participants could also be resolved through communication/education strategies. Printed materials, in-services (educational meetings) and reminders (verbal or computerized) are evidence-based knowledge translation strategies which can increase staff knowledge of the study program and CG needs (Grimshaw, Eccles, Lavis, Hill, & Squires, 2012). Study participants recommended development of printed information (i.e. pamphlet) about the study program that they could refer to and use as a resource. A pamphlet could describe program goals, activities, location, time, confidentiality rules, and brief key points of evidence for intervention effectiveness. Study participants also recommended a weekly reminder at healthcare team ‘huddles’ regarding the program topic for the week to facilitate communication and education regarding the program. Additional knowledge translation strategies to widely disseminate a formalized program model, positive study findings and promote implementation elsewhere are recommended.

Summary

Key findings of this study hold significant implications for practice, education, policy and research in the field of end-of-life care for persons with dementia and CGs. Recommendations for both program facilitators, HCPs, organizational leaders and policy makers stemmed directly from study participants' thoughtful reflections expressed during data collection and member checking. A summary of recommendations is provided in Table 6.

Table 6

Recommendations

Program Recommendations
<ol style="list-style-type: none"> 1. Provide increased communication through multiple strategies to improve staff knowledge of program, communication and decrease uncertainty. Strategies may include: <ul style="list-style-type: none"> • Regular verbal communication at daily huddles regarding the program's weekly topic • Printed resource material i.e. pamphlet, available to staff and families regarding program goals, structure and activities, including participant guidelines and 'selective sharing' 2. Provide opportunities for inter-professionalism with participation of front-line staff in program. Strategies may include: <ul style="list-style-type: none"> • Inviting front-line staff to provide educational presentations to the group • Inviting a designated staff representative and case manager in addition to the nurse manager to attend occasional meetings to receive and provide feedback on group member's concerns, consider development of devoted separate resident council apart 3. Consider availability and use of technology to provide long-distance access to the program. Strategies may include: <ul style="list-style-type: none"> • Use of teleconference or video conference to facilitate long-distance participation in meetings • Dissemination of meeting educational handouts electronically through email • Audio recording of meetings to be shared with non-attending CG • Voluntary linking of CGs through email if desired 4. Consider program sustainability. Strategies may include: <ul style="list-style-type: none"> • Formalized program logic model 5. Consider knowledge translation. Strategies may include: <ul style="list-style-type: none"> • Dissemination and description of program model to other settings/stakeholders to assist in uptake • Presentation to stakeholders including the Alzheimer's Society

Conclusions

Caregivers of persons with dementia have unique, progressive needs associated with end-of-life that carry into bereavement. The study program and perceived benefits align with optimal palliative care practices for persons with dementia as defined by the White paper, developed by the European Association for Palliative Care (van der Steen et al., 2014). Health care professionals have an ethical responsibility and obligation to be knowledgeable, assess these needs, provide support and assist CGs in accessing appropriate resources. Perceived program benefits to CGs' overall well-being during an arduous, isolating journey are difficult to categorize and convey in words. Few negative impacts were perceived in relation to the study program and tailoring of the program with recommendations aimed at negative outcomes and barriers will lead to overall improvement for all participants. With continued organizational support, the innovative study program and its social work facilitators have potential to provide guidance and foundation for care of CGs internationally.

References

- Addington-Hall, J. M. (2007). *Research Methods in Palliative Care*. Oxford University Press.
- Addington-Hall, J., & McPherson, C. (2001). After-death interviews with surrogates/bereaved family members: Some issues of validity. *Journal of Pain and Symptom Management*, 22(3), 784-790.
- Adelman, R. D, Tmanova, L. L., Delgado, D., Dion, S., & Lachs, M. (2014). Caregiver burden: A clinical review, *JAMA*, 311(10), 1052-1059.
- Alzheimer's Society of Canada (2012). *A new way of looking at the impact of dementia*. Retrieved from: http://www.alzheimer.ca/~media/Files/national/Media-releases/asc_factsheet_new_data_09272012_en.pdf
- Alzheimer's Society of Canada (2014). *Caregiver support groups: Making a meaningful impact*. Vancouver, BC: Alzheimer's Society. <http://www.alzheimer.ca/bc/~media/Files/bc/Programs-and-services/2014-08-29-CSG-Program-Evaluation-Summary-Report.pdf>
- AlzLive Team (2016). *A case for bereavement support groups*. Retrieved from: <http://alzlive.com/your-health/good-grieving/case-bereavement-support-groups/>
- American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders* (5th ed). Arlington, VA: American Psychiatric Publishing.
- Arai, T., Abe, S., Kurita, H., Ikeda, M., Eboshida, A., Kitamura, T., ... & Asada, T. (2014). Clinical characteristics of demented patients with prolonged stays in a psychiatric hospital in Japan. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 10(4), P533-P534.

- Bass, D. M., Judge, K. S., Snow, A. L., Wilson, N. L., Looman, W. J., McCarthy, C., . . . Kunik, M. E. (2012). Negative caregiving effects among caregivers of veterans with dementia. *American Journal of Geriatric Psychiatry, 20*(3), 239-247.
- Bédard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J. A., & O'Donnell, M. (2001). The Zarit Burden interview a new short version and screening version. *The Gerontologist, 41*(5), 652-657.
- Beinart, N., Weinman, J., Wade, D., & Brady, R. (2012). Caregiver burden and psychoeducational interventions in Alzheimer's disease: a review. *Dementia and Geriatric Cognitive Disorders extra, 2*(1), 638.
- Bergman, E. J., Haley, W. E., & Small, B. J. (2011). Who uses bereavement services? An examination of service use by bereaved dementia caregivers. *Aging & Mental health, 15*(4), 531-540.
- Boerner, K., & Schulz, R. (2009). Caregiving, bereavement and complicated grief. *Bereavement Care: For All Those Who Help the Bereaved, 28*(3), 10–13.
- Bonebright, D. A. (2010). 40 years of storming: a historical review of Tuckman's model of small group development. *Human Resource Development International, 13*(1), 111-120.
- Brown, M. A., Sampson, E. L., Jones, L., & Barron, A. M. (2012). Prognostic indicators of 6-month mortality in elderly people with advanced dementia: a systematic review. *Palliative Medicine, 0*(0),1-12.
- Canadian Institute for Health Information (2007). *Health care use at the end of life in western Canada*. Ottawa, ON: CIHI.

- Chan, D., Livingston, G., Jones, L., & Sampson, E. L. (2013). Grief reactions in dementia carers: a systematic review. *International Journal of Geriatric Psychiatry*, 28(1), 1-17.
- Chang, E., Hancock, K., Harrison, K., Daly, J., Johnson, A., Easterbrook, S., ... & Davidson, P. M. (2005). Palliative care for end-stage dementia: A discussion of the implications for education of health care professionals. *Nurse Education Today*, 25(4), 326-332.
- Chenoweth, L., Jeon, Y. H., Merlyn, T., & Brodaty, H. (2010). A systematic review of what factors attract and retain nurses in aged and dementia care. *Journal of Clinical Nursing*, 19(1-2), 156-167.
- Chien, L. Y., Chu, H., Guo, J. L., Liao, Y. M., Chang, L. I., Chen, C. H., & Chou, K. R. (2011). caregiver support groups in patients with dementia: A meta-analysis. *International Journal of Geriatric Psychiatry*, 26(10), 1089-1098.
- Cherlin, E. J., Barry, C. L., Prigerson, H. G., Green, D. S., Johnson-Hurzeler, R., Kasl, S. V., & Bradley, E. H. (2007). Bereavement services for family caregivers: how often used, why, and why not. *Journal of Palliative Medicine*, 10(1), 148-158.
- Chujo, M., & Okamura, H. (2015a). Partnership in psycho-social group intervention for cancer patients: factors to creating group dynamics. *Yonago Acta Medica*, 58(1), 45-50.
- Chujo, M., & Okamura, H. (2015b). The skills of facilitator nurses in psycho-social group intervention for cancer patients. *Yonago Acta Medica*, 58(2), 69.
- Creswell, J. W. (2013). *Research design: Qualitative, quantitative, and mixed methods approaches*. Thousand Oaks, CA: Sage publications.
- Critical Appraisal Skills Programme, Oxford (CASP) (2014). *CASP checklists*. Retrieved from: <http://www.casp-uk.net>
- Davies, N., Maio, L., Rait, G., & Iliffe, S. (2014). Quality end-of-life care for dementia: What

have family carers told us so far? A narrative synthesis. *Palliative Medicine*, 28(7), 919-930.

DiCicco-Bloom, B., & Crabtree, B. F. (2006). The qualitative research interview. *Medical Education*, 40(4), 314-321.

Ducharme, F. (2014). Psychoeducational interventions for family caregivers of seniors across their life trajectory: an evidence-based research program to inform clinical practice. *Advances in Geriatrics*, 2014.

Durepos, P., Wickson-Griffiths, A., Hazzan, A. A., Kaasalainen, S., Vastis, V., Battistella, L., Papaioannou, A. (2016). Assessing the palliative content in dementia care guidelines: A systematic review. *In Preparation July 2016*.

Elvish, R., Lever, S. J., Johnstone, J., Cawley, R., & Keady, J. (2013). Psychological interventions for carers of people with dementia: A systematic review of quantitative and qualitative evidence. *Counselling and Psychotherapy Research*, 13(2), 106-125.

Gallagher-Thompson, D., & Coon, D. W. (2007). Evidence-based psychological treatments for distress in family caregivers of older adults. *Psychology and Aging*, 22(1), 37.

Garrido, M. M., & Prigerson, H. G. (2014). The end-of-life experience: Modifiable predictors of caregivers' bereavement adjustment. *Cancer*, 120(6), 918-925.

Gauthier, S., Patterson, C., Chertkow, H., Gordon, M., Herrmann, N., Rockwood, K., ... & Soucy, J. P. (2012). Recommendations of the 4th Canadian consensus conference on the diagnosis and treatment of dementia (CCCDTD4). *Canadian Geriatrics Journal*, 15(4), 120-126.

Givens, J. L., Lopez, R. P., Mazor, K. M., & Mitchell, S. L. (2012). Sources of stress for family members of nursing home residents with advanced dementia. *Alzheimer Disease and*

- Associated Disorders*, 26(3), 254-259.
- Goldman, K. D., & Schmalz, K. J. (2006). Logic models: the picture worth ten thousand words. *Health Promotion Practice*, 7(1), 8-12.
- Grimshaw, J. M., Eccles, M. P., Lavis, J. N., Hill, S. J., & Squires, J. E. (2012). Knowledge translation of research findings. *Implementation Science*, 7(1), 50-65.
- Haley, W. E., Bergman, E. J., Roth, D. L., McVie, T., Gaugler, J. E., & Mittelman, M. S. (2008). Long-term effects of bereavement and caregiver intervention on dementia caregiver depressive symptoms. *The Gerontologist*, 48(6), 732-740.
- Harding, R., List, S., Epiphaniou, E., & Jones, H. (2011). How can informal caregivers in cancer and palliative care be supported? An updated systematic literature review of interventions and their effectiveness. *Palliative Medicine*, 26(1), 7-22.
- Hebert, R. S., Dang, Q., & Schulz, R. (2006). Preparedness for the death of a loved one and mental health in bereaved caregivers of patients with dementia: findings from the REACH study. *Journal of Palliative Medicine*, 9(3), 683-693.
- Hebert, R. S., Prigerson, H. G., Schulz, R., & Arnold, R. M. (2006). Preparing caregivers for the death of a loved one: a theoretical framework and suggestions for future research. *Journal of Palliative Medicine*, 9(5), 1164-1171.
- Herrmann, N., & Gauthier, S. (2008). Diagnosis and treatment of dementia: 6. Management of severe Alzheimer disease. *Canadian Medical Association Journal*, 179(12), 1279-1287.
- Holland, J. M., Currier, J. M., & Gallagher-Thompson, D. (2009). Outcomes from the Resources for Enhancing Alzheimer's Caregiver Health (REACH) program for bereaved caregivers. *Psychology and Aging*, 24(1), 190-202.
- Hennings, J., Froggatt, K., & Keady, J. (2010). Approaching the end of life and dying with

- dementia in care homes: the accounts of family carers. *Reviews in Clinical Gerontology*, 20(02), 114-127.
- Hornillos, C., & Crespo, M. (2011). Support groups for CGs of Alzheimer patients: A historical review. *Dementia*, 11(2), 155-169.
- Hudson, P., Remedios, C., Zordan, R., Thomas, K., Clifton, D., Crewdson, M., ... & Bauld, C. (2012). Guidelines for the psychosocial and bereavement support of family CGs of palliative care patients. *Journal of Palliative Medicine*, 15(6), 696-702.
- Hudson, P. L., Remedios, C., & Thomas, K. (2010). A systematic review of psychosocial interventions for family carers of palliative care patients. *BMC Palliative Care*, 9(1), 17.
- Hynson, J. L., Aroni, R., Bauld, C., Sawyer, S. M. (2006). Research with bereaved parents: A question of how not why. *Palliative Medicine*, 20, 805-811.
- Kim, Y., & Schulz, R. (2008). Family caregivers' strains: comparative analysis of cancer caregiving with dementia, diabetes, and frail elderly caregiving. *Journal of Aging and Health*.
- Knight, C., & Gitterman, A. (2013). Group work with bereaved individuals: The power of mutual aid. *Social Work*, 59(1), 5-12.
- Kruske, S., Schmied, V., Sutton, I., & O'hare, J. (2004). Mothers' experiences of facilitated peer support groups and individual child health nursing support: a comparative evaluation. *The Journal of Perinatal Education*, 13(3), 31-38.
- Lai, C. K., Yeung, J. H., Mok, V., & Chi, I. (2009). Special care units for dementia individuals with behavioural problems. *Cochrane Database of Systematic Reviews*, 4(CD006470).
- Lewis, M. L., Hobday, J. V., & Hepburn, K. W. (2010). Internet-based program for dementia caregivers. *American Journal of Alzheimer's Disease and Other Dementias*, 25(8), 674-

679.

- Lincoln, Y. S. & Guba, E. G. (1985). *Naturalistic inquiry*. Newbury Park, CA: SAGE Publications, Inc.
- Lindsay, T. & Orton, S. (2011). *Groupwork practice in social work*. Exeter, UK: Learning Matters Ltd.
- Luxford, K., Safran, D. G., & Delbanco, T. (2011). Promoting patient-centered care: a qualitative study of facilitators and barriers in healthcare organizations with a reputation for improving the patient experience. *International Journal for Quality in Health Care*, 23(5), 510-515.
- Manu, E., Marks, A., Berkman, C. S., Mullan, P., Montagnini, M., & Vitale, C. A. (2012). Self-perceived competence among medical residents in skills needed to care for patients with advanced dementia versus metastatic cancer. *Journal of Cancer Education*, 27(3), 515-520.
- McAiney, C., Hillier, L., Stolee, P., Harvey, D., & Michael, J. (2012). ‘Throwing a lifeline’: The role of First Link in enhancing support for individuals with dementia and their caregivers. *Neurodegenerative Disease Management*, 2(6), 623-638.
- Mitchell, S. L. Black, B. S. Ersek, M, Hanson, L. C., Miller, S. C., Sachs, G. A. Teno, J. M. MD, MS; & Morrison, R. S. (2012). Advance dementia: State of the art and priorities for the next decade. *Annals of Internal Medicine*, 156(Part 1), 46-51.
- Mitchell, S. L., Teno, J. M., Kiely, D. K., Shaffer, M. L., Jones, R. N., Prigerson, H. G., . . . Hamel, M. B. (2009). The clinical course of advanced dementia. *The New England Journal of Medicine*, 361(16), 1529-1538.
- Meuser, T. M., & Marwit, S. J. (2001). A comprehensive, stage-sensitive model of grief in

- dementia caregiving. *The Gerontologist*, 41(5), 658-670.
- Moher D, Hopewell S, Schulz KF, Montori V, Gøtzsche PC, Devereaux PJ, Elbourne D, Egger M, Altman DG. (201). CONSORT 2010 explanation and elaboration: Updated guidelines for reporting parallel group randomised trials. *British Medical Journal*, 340 c869.
- National Collaborating Centre for Methods and Tools (2011). *Critical appraisal tools to make sense of evidence*. Hamilton, ON: McMaster University. (Updated 16 December, 2011) Retrieved from <http://www.nccmt.ca/resources/search/87>.
- Neergaard, M. A., Olesen, F., Andersen, R. S., & Sondergaard, J. (2009). Qualitative description—the poor cousin of health research?. *BMC Medical Research Methodology*, 9(1), 52.
- O'Rourke, N., & Tuokko, H. A. (2003). Psychometric properties of an abridged version of the Zarit Burden Interview within a representative Canadian caregiver sample. *The Gerontologist*, 43(1), 121-127.
- Patton, M. (2015). *Qualitative research and evaluation methods* (4th ed.). Washington, DC: Sage.
- Papastavrou, E., Kalokerinou, A., Papacostas, S. S., Tsangari, H., & Sourtzi, P. (2007). Caring for a relative with dementia: family caregiver burden. *Journal of Advanced Nursing*, 58(5), 446-457.
- Peacock, S., Duggleby, W., & Koop, P. (2014). The lived experience of family caregivers who provided end-of-life care to persons with advanced dementia. *Palliative and Supportive Care*, 12(2), 117-126.
- Peacock, S. (2013). The experience of providing end-of-life care to a relative with advanced dementia: An integrative literature review. *Palliative and Supportive Care*, 11(2), 155-168.

- Pinquart, M., & Sörensen, S. (2006). Helping caregivers of persons with dementia: which interventions work and how large are their effects?. *International Psychogeriatrics*, *18*(04), 577-595.
- Pinquart, M., & Sörensen, S. (2011). Spouses, adult children, and children-in-law as caregivers of older adults: a meta-analytic comparison. *Psychology and Aging*, *26*(1), 1-14.
- Prince, M., & Jackson, J. (eds.) Alzheimer's Disease International, (2009). *World Alzheimer Report*. Retrieved from: <https://www.alz.co.uk/research/files/WorldAlzheimerReport.pdf>
- Prorok, J. C., Horgan, S., & Seitz, D. P. (2013). Health care experiences of people with dementia and their CGs: A meta-ethnographic analysis of qualitative studies. *CMAJ: Canadian Medical Association Journal*, *185*(14), E669-80.
- Raymond, M., Warner, A., Davies, N., & Iliffe (2014). Palliative care services for people with dementia: A synthesis of the literature reporting the views and experiences of professionals and family carers. *Dementia*, *13*(1), 96-110.
- Repper, J., & Carter, T. (2011). A review of the literature on peer support in mental health services. *Journal of Mental Health*, *20*(4), 392-411.
- Roberts, A., & McGilloway, S. (2011). Methodological and ethical aspects in evaluation research in bereavement. *Bereavement Care*, *30*(1), 21-28.
- Robinson, A., Eccleston, C., Annear, M., Elliott, K., Andrews, S., Stirling, C., ... McInerney, F. (2014). Who knows, who cares? dementia knowledge among nurses, care workers, and family members of people living with dementia. *Journal of Palliative Care*, *30*(3), 158-65.
- Romero, M. M., Ott, C. H., & Kelber, S. T. (2014). Predictors of grief in bereaved family

- caregivers of person's with Alzheimer's disease: A Prospective Study. *Death Studies*, 38(6), 395-403.
- Ryan, T., Nolan, M., Reid, D., & Enderby, P. (2008). Using the Senses Framework to achieve relationship-centred dementia care services A case example. *Dementia*, 7(1), 71-93.
- Sampson, E. L. (2010). Palliative care for people with dementia. *British Medical Bulletin*, 96(1), 159-174.
- Sanderse, N. M., & Cochran, C. D. (2014). Prognostication in chronic disease. *Hospital Medicine Clinics*, 3(1), e15-e31.
- Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in Nursing & Health*, 33(1), 77-84.
- Sandelowski, M. (2000). Focus on research methods-whatever happened to qualitative description? *Research in Nursing and Health*, 23(4), 334-340.
- Sandelowski, M. (1995a). Qualitative analysis: What it is and how to begin. *Research in Nursing & Health*, 18(4), 371-375.
- Sandelowski, M. (1995b). Sample size in qualitative research. *Research in Nursing & Health*, 18(2), 179-183.
- Sandelowski, M. (1995c). Triangles and crystals: on the geometry of qualitative research. *Research in Nursing & Health*, 18(6), 569-574.
- Sandelowski, M. (1993). Rigor or rigor mortis: the problem of rigor in qualitative research revisited. *Advances in Nursing Science*, 16(2), 1-8.
- Schildmann, E. K., & Higginson, I. J. (2011). Evaluating psycho-educational interventions for informal carers of patients receiving cancer care or palliative care: Strengths and limitations of different study designs. *Palliative Medicine*, 25(4), 345-356.

- Schulz, R. (2013). Research priorities in geriatric palliative care: Informal caregiving. *Journal of Palliative Medicine, 16*(9), 1008-1012.
- Schulz, R., Boerner, K., Klinger, J., & Rosen, J. (2015). Preparedness for death and adjustment to bereavement among caregivers of recently placed nursing home residents. *Journal of Palliative Medicine, 18*(2), 127-133.
- Schulz, R., Boerner, K., Shear, K., Zhang, S., & Gitlin, L. N. (2006). Predictors of complicated grief among dementia caregivers: a prospective study of bereavement. *The American Journal of Geriatric Psychiatry, 14*(8), 650-658.
- Schulz, R., Mendelsohn, A. B., Haley, W. E., Mahoney, D., Allen, R. S., Zhang, S., ... & Belle, S. H. (2003). End-of-life care and the effects of bereavement on family caregivers of persons with dementia. *New England Journal of Medicine, 349*(20), 1936-1942.
- Schulz, R., Rosen, J., Klinger, J., Musa, D., Castle, N. G., Kane, A. L., & Lustig, A. (2014). Effects of a psychosocial intervention on caregivers of recently placed nursing home residents: A randomized controlled trial. *Clinical Gerontologist, 37*(4), 347-367.
- Shanley, C., Russell, C., Middleton, H., & Simpson-Young, V. (2011). Living through end-stage dementia: The experiences and expressed needs of family carers. *Dementia, 10*(3), 325-340.
- SocioCultural Research Consultants, LLC. (2014). *Dedoose Version 5.0.11* (web application management, analysis, presentation of qualitative and mixed method research data). Los Angeles, CA.
- Sörensen, S., & Conwell, Y. (2011). Issues in dementia caregiving: effects on mental and physical health, intervention strategies, and research needs. *The American Journal of Geriatric Psychiatry, 19*(6), 491-496.

- Stagg, B., & Lerner, A. J. (2015). Zarit Burden Interview: pragmatic study in a dedicated cognitive function clinic. *Progress in Neurology and Psychiatry, 19*(4), 23-27.
- Steffen, A. M., & Mangum, K. R. (2012). Predicting attendance at dementia family support groups. *American Journal of Alzheimer's Disease and Other Dementias, 27*(8), 633-639.
- Stroebe, M., & Boerner, K. (2015). Caregiving and bereavement research: Bridges over the gap. *Palliative Medicine, 29*(7), 574-576.
- Suchman, A. L. (2006). A new theoretical foundation for relationship-centered care. *Journal of General Internal Medicine, 21*(S1), S40-S44.
- Sullivan-Bolyai, S., Bova, C., & Harper, D. (2005). Developing and refining interventions in persons with health disparities: The use of qualitative description. *Nursing Outlook, 53*(3), 127-133.
- Sword, W. (1999). Accounting for presence of self: Reflections on doing qualitative research. *Qualitative Health Research, 9*(2), 270-278.
- Thoresen, L., & Öhlén, J. (2015). Lived observations linking the researcher's personal experiences to knowledge development. *Qualitative Health Research, 25*(11), 1589-1598.
- Toseland, R. W., & Rivas, R. (1998). *Group work practice*. Boston, MA: Allyn & Bacon.
- Van der Steen, J. T., Radbruch, L., Hertogh, C. M., de Boer, M. E., Hughes, J. C., Larkin, P., ... & Koopmans, R. T. (2013). White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care. *Palliative Medicine, 28*(3), 197-209.

Waller, A., Turon, H., Mansfield, E., Clark, K., Hobden, B., & Sanson-Fisher, R. (2016).

Assisting the bereaved: A systematic review of the evidence for grief counseling.

Palliative Medicine, 30(2), 132-148.

Walsh, T., Foreman, M., Curry, P., O'Driscoll, S., & McCormack, M. (2008). Bereavement

support in an acute hospital: An Irish model. *Death Studies*, 32(8), 768-786.

Wharton, T. C., & Ford, B. K. (2014). What is known about dementia care recipient violence and

aggression against caregivers?. *Journal of Gerontological Social Work*, 57(5), 460-477.

World Health Organization (2015). *Dementia*. Retrieved from

<http://www.who.int/mediacentre/factsheets/fs362/en/>

World Health Organization [WHO] (2012). *Dementia: A public health priority*. United

Kingdom: WHO.

http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf

Appendix A

Key Studies Informing literature Review

Paper & Country	Title & Design	Sample & Residence	Results	Comments
Beinart, et al., (2012), UK	CG burden & interventions; Literature review	8 studies, CGs of patients with Alzheimer's; Home	Burden defined, tailored interventions combine emotion & problem-based coping; improves burden & depression	Description of CG burden & key studies. Limitations: Technology interventions may be obsolete, difficult comparing studies
Chan et al, (2013), UK	CG grief reactions; Systematic review	31 papers, current or bereaved CGs; LTC / home	Anticipatory grief increase in advanced PWD, LTC placement, spouse CGs, also increases risk of complicated grief	Quality of studies assessed using tools & independent reviewers. Limitations: Difficulty scoring studies, only English studies
Chien et al, (2011), Taiwan	CG support groups for PWD ¹ ; Meta-analysis	30 studies, current CGs of PWD; not reported	Support group moderate effects on well-being, depression, Longer sessions, model, professionally-led improve effect	Search protocol followed, statistical analysis, 95% CIs. Limitations: Small subgroups, effect sizes may not be fully generalizable
Davies et al, (2014), UK	EOL ² in dementia; Literature review	8 studies, Current & bereaved CGs, PWD, staff, home, LTC, hospital	Perceptions of care quality based on: CG & staff relationships decision-making, ability to think about death	PRIMSA tool reporting, quality evaluation, Limitations: Poor method reporting in some papers, staff and CGs' views mingled
Ducharme (2014), CA	Psychological Interventions CGs of seniors; Literature review	3 programs evaluated, CGs of senior patients; home / LTC	'Taking Care of Myself Program' improved CG relationships with staff, and problem-solving, lasting effects	Significant outcome differences in experimental group. Limitations: No system perspective, program eval. methods not described
Durepos et al., (2016). CA	Palliative content dementia; Systematic review	9 guidelines PWD; any setting	Content / recommendations for EOL, grief, loss and spiritual care lacking	Systematic search & quality assessment, organizational template analysis Limitations: English guidelines only
Elvish, et al., (2013), UK	Psychological Interventions for CGs; Systematic review	20 studies of CGs of PWD, not reported	5 CG program models, positive outcomes, i.e. improved emotional well-being, depression & quality of life	CONSORT tool used, Updated 2 previous systematic reviews, 2 assessors, quality grading Limitations: Qualitative studies difficult assess methodology, many excluded
Haley et al., (2008), USA	Long-term effects of Bereavement; RCT	254 bereaved CGs of PWD; home/LTC	Intervention pre & post bereavement decreased chronic depression in CGs compared to usual	NYU ² study, large sample randomization, long follow-up Limitations: Blinding method not described, usual care

			care	group had access to intervention
Holland et al., (2009), USA	Outcomes from REACH ³ ; RCT	224 bereaved CGs of persons with dementia; home/LTC	Larger dose intervention lowered depression scores	REACH study, large sample, randomization, long follow-up Limitations: Fidelity of intervention may vary amongst practitioners
Hennings et al., (2010), UK	Dementia EOL ⁴ & dying in care homes; Literature review	10 studies of current & bereaved CGs of PWD; LTC	CG experience themes: Lack of knowledge of dying process, difficult decision-making inhibited by grief, desired relationships with staff	Systematic search, meta-ethnographic summary of each paper, comparison of themes Limitations: Small sample size
Hudson et al, (2012), AUS	Pre/post bereavement guideline; Clinical practice guideline	CGs of palliative patients; any setting	Recommendations: 20 principles aimed at improving preparation for death	Informed by literature review, stakeholders, consensus, delphi, Limitations: Response rate not optimal for Delphi
Mitchell, et al., (2009), USA	Course of advanced dementia; Observational	323 PWD; LTC	Pneumonia, febrile episode, eating problems, dyspnea & burdensome interventions at EOL, difficult prognostication	Large sample size, prospective study, demonstrated trajectory of dementia. Limitations: Use of chart data
Peacock et al., (2014), CA	Lived experience dementia CGs; Phenomenology	11 bereaved CGs of PWD; LTC	2 essences: being-with & being-there, affected by spatiality, temporality, corporeality, relationality	Hermeneutical analysis, trustworthiness, member checking done Limitations: Small sample, may not generalize
Schulz et al., (2006), USA	Predictors of complicated grief in REACH; RCT	217 Bereaved CGs of PWD; home / LTC	Symptoms of depression and burden pre-bereavement increase risk for complicated grief	Regression analysis using REACH study data Limitations: Questionable fidelity of intervention

Note. Abbreviations: ¹PWD refers to person with dementia, ²NYU refers to New York University trail, ³REACH refers to Resources for Enhancing Alzheimer's Caregiver Health trial, ⁴EOL refers to end-of-life.

Appendix B

Study Program Schedule of Content

Date	Topic	Speaker/Host
January 14 th	Share and Support	Social Worker
January 22 nd	Part 2: Brain and Behaviour	Occupational Therapist
January 29 th	“Hard Choices for Loving People” Part 1	Chaplain
February 5 th	“Hard Choices for Loving People” Part 2	Chaplain
February 12 th	Grief and Loss Unit Management Communication & Feedback	Social Worker Unit Manager
February 19 th	Chaplaincy Services	Chaplain
February 26 th	Gentle Persuasive Approaches	Unit Manager & Nurse
March 5 th	Share and Support	Social Worker
March 12 th	Alzheimer’s Society: Research and Advocacy	Alzheimer Society Representative
March 19 th	Alzheimer’s Society: Services	Alzheimer Society Representative
March 26 th	Share and Support	Social Worker
April 2 nd	Behavioural Supports Ontario	Representative
April 9 th	Share and Support	Social Worker
April 16 th	Music & Dementia	Social Worker
April 23 rd	Share and Support	Social Worker
April 29 th	Role of the Most Responsible Physician (MRP)	Unit Physician
April 30 th	Unit Memorial Service	Chaplain, Social Worker
May 7	Unit Birthday Party	Music Entertainment Recreation Therapist
May 14	Mindful Moments: Art & Dementia Unit Management Communication & Feedback	Unit Manager
May 21	Share and support	Social Worker
May 28	CCAC services	TBD
June 4	Share and Support	Social Worker
June 11	Unit Birthday Party	Music Entertainment Recreation Therapist
June 18	Food Services Update	Speech-Language & Dietician
June 25	Summer Celebration	Family Member Host
July 2	Birthday Party	Music Entertainment Recreation Therapist
July 9	Pharmacy presentation	Unit Pharmacist
July 16	Share and Support	Social Worker
July 23	To Be Announced	Social Worker
July 30	Birthday Party	Music Entertainment Recreation Therapist
August 6	Behavioural Services Ontario	BSO Representative

Appendix D

Interview Guides

Guide for Caregivers (CG) Attending the Study Program

- 1) Please tell me about yourself.
- 2) How did you start attending the Study Program?
- 3) What has been your experience of attending the Study Program?
- 4) What do you think the benefits are of attending the Study Program?
- 5) What are the challenges?
- 6) If you have attended other programs, how do you feel the program is similar or different?
- 7) What are the supports like in your life?
- 8) What help do you think family caregivers of people with dementia need?
- 9) A. If the CG is bereaved; how did the study program influence your end-life-experience and grieving afterward?
B. If the CG is not bereaved; how do you feel about people continuing to attend the study program after they are bereaved?

Guide for Caregivers (CG) Not Attending the Study Program

- 1) Please tell me about yourself and your experience on the Specialized Care Unit.
- 2) What have you heard about the Study Program?
- 3) What do you think about education / support programs? Benefits / challenges?
- 4) Is there a reason why you have not attended?
- 5) What are the supports like in your life?

Guide for Health Care Professionals

- 1) What is your experience working on the Specialized Care Unit?
- 2) What needs do you believe family caregivers have, especially at end-of-life?
- 3) What do you think of the Study Program (content, structure, support)?
- 4) How do you think your experiences as a personal caregiver affect your care?

Appendix E

Program Attending Caregiver Participant Letter of Information and Consent

LETTER OF INFORMATION / CONSENT

Participants: Family Caregiver Attending Study Program

Caregiver Perceptions of an Psychoeducation Program

Investigators:

Local Principal Investigator:

Dr. Sharon Kaasalainen, RN, PhD
Department of Nursing
McMaster University
Hamilton, ON, Canada
(905) 525-9140 ext. 22404
kaasal@mcmaster.ca

Student Investigator:

Pamela Durepos, RN, MSc (candidate)
Department of Graduate Studies
McMaster University
Hamilton, ON, Canada
xxx-xxx-xxxx
lapospm@mcmaster.ca

Introduction:

When family members are caring for someone with dementia the demands are great. Health care professionals are not sure how to help family caregivers of people with dementia, especially during end-of-life. The study program is a special, new education and support program for families of people with dementia who live or have lived in the Specialized Care Unit of the hospital.

You are invited to participate in a study about the support/education program. This research is part of a student investigator's nursing graduate thesis.

What are we trying to discover?

- We would like to learn how current and bereaved family caregivers, and health care professionals perceive the Study Program.
- This will help us understand the benefits challenges of the program.

What will happen during the study?

- With your permission, we will speak to you in person or by phone to describe the study.
- If you are interested we will make an appointment with you for a one-on-one interview.
- The interview can be at the hospital, or at a location of your choosing such as your home if that is more comfortable for you.
- We will ask you to fill out a form with information like your age, gender and time caregiving.

- We will ask your permission to include a form you filled out about caregiver burden in the past to show the average level of burden in the group. You can choose to decline access to your form and still participate in the study.
- The interview will last approximately 1 hour and will be audio-recorded. We will also take written notes. The recording will later be written down.
- After all the interviews are completed, we will write a report of our findings.
- We hope to complete a total of 15 interviews including family caregivers who attend the program, caregivers who do not, and some health care staff.

Are there any risks to doing this study?

- The risks to this study are very low.
- Talking about your experiences might make you emotional or upset.
- You may worry that we are going to share your feelings with the people who run the program or others who attend the program.
- You are able to take breaks from the interview at any time.
- You do not have to answer any questions that make you feel uncomfortable.
- You can also stop the study at any time by letting the student or supervising researcher know.

Are there any benefits to doing this study?

- The research may not benefit you directly.
- Some people feel it helps them to share their experiences and feelings..
- What we learn from this study may help us to improve the study program or help others develop new programs in other places.

Will I be paid to be in the study?

- A \$10 coffee shop gift certificate will be provided to thank you for participating.
- If you choose to attend an interview at the hospital outside of your normal visiting time and do not have a monthly parking pass, the researcher can reimburse your parking costs.

What will happen to my personal information?

- You are participating in this study confidentially.
- We will not use your name or any information, which allows you to be identified. A code will be used instead.
- However, you may be identified by the stories you choose to tell.
- No-one but me will know whether you participated unless you choose you to tell them.
- The information you provide will be kept in a locked cabinet, which only the supervisor and student researcher have access to.
- Information kept on my computer will be protected by a password.
- Once the study is complete, information without your name will be kept for 5 years and then destroyed.

What if I change my mind about being in the study?

- Your participation in the study is voluntary.
- You can leave the study at any time even after signing the consent.
- There will be no consequences to you if you decide to stop the study. You can continue to attend the program or work.
- You can let the student researcher or supervisor know in person, by phone, by email or letter.
- If you choose to leave the study you can have all of your information destroyed immediately or kept for use in the study.

How do I find out what was learned in this study?

We expect to have this study completed by August 2016. If you would like a brief summary of the results please include your address or email, on the consent form and we will mail it to you. We will also offer a presentation about the study findings at the hospital.

If I have questions about the study who should I call?

If you have questions or need more information about the study itself, please contact the student investigator:

Pamela Durepos xxx-xxx-xxxx (h)
lapospm@mcmaster.ca

or:

Sharon Kaasalainen 905-521-2100 x22404
kaasal@mcmaster.ca

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HIREB). The HIREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the REB Chair, HIREB at 905.521.2100 x 42013

CONSENT

Participant:

I have read the information in the information letter about a study being conducted by Pamela Durepos of McMaster University.

I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.

I understand that if I agree to participate in this study, I may withdraw from the study at any time.

I have been given a signed copy of this form. I agree to participate in the study.

I would like to receive a summary of the study's results.

Yes No

If yes, where would you like the results sent?

Email: _____

Mailing Address: _____

I give permission for Pamela Durepos to access my Zarit Caregiver Burden survey for this study.

Yes No

Name of Participant (Printed) Signature Date

Consent form explained in person by:

Name and Role (Printed) Signature Date

Appendix F

Non-Program Attending Caregiver Participant Letter of Information and Consent

LETTER OF INFORMATION / CONSENT Participant Family Caregivers Not Attending the Program Caregiver Perceptions' of a Psychoeducation Program

Investigators:

Local Principal Investigator:

Dr. Sharon Kaasalainen, RN, PhD
Department of Nursing
McMaster University
Hamilton, ON, Canada
(905) 525-9140 ext. 22404
kaasal@mcmaster.ca

Student Investigator:

Pamela Durepos, RN, MSc (candidate)
Department of Graduate Studies
McMaster University
Hamilton, ON, Canada
xxx-xxx-xxxx
lapospm@mcmaster.ca

Introduction:

When family members are caring for someone with dementia the demands are great. Health care professionals are not sure how to help family caregivers of people with dementia, especially during end-of-life. The study program is a special, new education and support program for families of people with dementia who live or have lived on the Specialized Care Unit at the Hospital.

You are invited to participate in a study about a program at the Hospital. This research is part of a student investigator's nursing graduate thesis.

What are we trying to discover?

- We would like to learn how current and bereaved family caregivers, and health care professionals feel about the program and support programs in general.
- This will help us understand the challenges and benefits of the program as well as reasons people attend or do not attend.

What will happen during the study?

- With your permission, we will speak to you in person or by phone to describe the study.
- If you are interested we will make an appointment with you for a one-on-one interview.
- The interview will be at the hospital, or at a location of your choosing such as your home if that is more comfortable for you.

- We will ask you to fill out a form with information like your age, gender and time caregiving.
- We will ask you to fill out a form about caregiving burden to show the average burden level of persons in the study. You can choose not to fill out the form and still participate in the study.
- The interview will last approximately 1 hour and will be audio-recorded. We will also take written notes. The recording will later be written down.
- After all the interviews are completed, we will write a report of the findings.
- We hope to complete a total of 15 interviews including family caregivers who attend the program, caregivers who do not, and some health care staff

Are there any risks to doing this study?

- The risks to this study are very low.
- Talking about your experiences might make you emotional or upset.
- You may worry that we are going to share your feelings with the people who run the program or others who attend the program.
- You are able to take breaks from the interview at any time.
- You do not have to answer any questions that make you feel uncomfortable.
- You can also stop the study at any time by letting myself, or my supervisor know.

Are there any benefits to doing this study?

- The research may not benefit you directly.
- Some people feel it helps them to share their experiences and feelings..
- What we learn from this study may help us to improve the program or help others make new programs in other places

Will I be paid to be in the study?

- A \$10 coffee shop gift certificate will be provided to thank you for participating.
- If you choose to attend an interview at the hospital outside of your normal visiting time and do not have a monthly parking pass, the researcher can reimburse your parking costs.

What will happen to my personal information?

- You are participating in this study confidentially.
- We will not use your name or any information, which allows you to be identified. A code will be used instead.
- However, you may be identified by the stories you choose to tell.
- No-one but the researchers will know whether you participated unless you choose you to tell them.
- The information you provide will be kept in a locked cabinet, which only the two investigators have access to.
- Information kept on the student researcher's computer will be protected by a password.

- Once the study is complete, information without your name will be kept for 5 years and then destroyed.

What if I change my mind about being in the study?

- Your participation in the study is voluntary.
- You can leave the study at any time even after signing the consent.
- There will be no consequences to you if you decide to stop the study. You can continue to attend the program.
- You can let the student or supervisor researchers know in person, by phone, by email or letter.
- If you choose to leave the study you can have all of your information destroyed immediately or kept for use in the study.

How do I find out what was learned in this study?

We expect to have this study completed by August 2016. If you would like a brief summary of the results please include your address or email, on the consent form and we will mail it to you.

If I have questions about the study who should I call?

If you have questions or need more information about the study itself, please contact the student investigator:

Pamela Durepos
xxx-xxx-xxxx (h) xxx-xxx-xxxx (c)
lapospm@mcmaster.ca or:

Sharon Kaasalainen 905-521-2100 x22404 kaasal@mcmaster.ca

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HIREB). The HIREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the REB Chair, HIREB at 905.521.2100 x 42013

CONSENT

Participant:

I have read the information in the information letter about a study being conducted by Pamela Durepos and Sharon Kaasalainen of McMaster University.

I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.

I understand that if I agree to participate in this study, I may withdraw from the study at any time.

I have been given a signed copy of this form. I agree to participate in the study.
I would like to receive a summary of the study’s results.

Yes No

If yes, where would you like the results sent?

Email: _____

Mailing Address: _____

I choose to fill out the Zarit Caregiver Burden survey for the study.

Yes No

Name of Participant (Printed)

Signature Date

Consent form explained in person by:

Name and Role (Printed)

Signature Date

Appendix G

Health Care Professional Participant Letter of Information and Consent

LETTER OF INFORMATION Participants: Health Care Professionals

Caregiver Perceptions of a Psychoeducation Program

Investigators:

Local Principal Investigator:

Dr. Sharon Kaasalainen, RN, PhD
Department of Nursing
McMaster University
Hamilton, ON, Canada
(905) 525-9140 ext. 22404
kaasal@mcmaster.ca

Student Investigator:

Pamela Durepos, RN, MSc (candidate)
Department of Graduate Studies
McMaster University
Hamilton, ON, Canada
(289) 895-8945
lapospm@mcmaster.ca

Introduction:

When family members are caring for someone with dementia the demands are great. Health care professionals are not sure how to help family caregivers of people with dementia, especially during end-of-life. The Family Forum is a special, new education and support program for families of people with dementia who live or have lived on the Specialized Care Unit at the Hospital.

You are invited to participate in a study about a program at the Hospital. This research is part of a student investigator's nursing graduate thesis.

What are we trying to discover?

- We would like to learn how current and bereaved family caregivers, and health care professionals perceive the Program.
- This will help us understand the challenges and benefits of the program.

What will happen during the study?

- With your permission, we will speak to you in person or by phone to describe the study.
- If you are interested we will make an appointment with you for a one-on-one interview.
- The interview can be at the Hospital around your working hours.
- We will ask you to fill out a form with information like your age, gender and time working in the Specialized Care Unit.

- The interview will last approximately 1 hour and will be audio-recorded. We will also take written notes. The recording will later be written down.
- After all the interviews are completed, we will write a report of our findings.
- We hope to complete a total of 15 interviews including family caregivers who attend the Program, caregivers who do not, and some health care staff

Are there any risks to doing this study?

- The risks to this study are very low.
- Talking about your experiences might make you emotional or upset.
- You may worry that we are going to share your feelings with the people who run the program or others who attend the program.
- You are able to take breaks from the interview at any time.
- You do not have to answer any questions that make you feel uncomfortable.
- You can also stop the study at any time by letting the student or supervising researcher know.

Are there any benefits to doing this study?

- The research may not benefit you directly.
- Some people feel it helps them to share their experiences and feelings..
- What we learn from this study may help us to improve the program or help others develop new programs in other places

Will I be paid to be in the study?

- A \$10 coffee shop gift certificate will be provided to thank you for participating.

What will happen to my personal information?

- You are participating in this study confidentially.
- We will not use your name or any information, which allows you to be identified. A code will be used instead.
- However, you may be identified by the stories you choose to tell.
- No-one but the researchers will know whether you participated unless you choose you to tell them.
- The information you provide will be kept in a locked cabinet, which only the supervisor and student researcher have access to.
- Information kept on the researcher's computer will be protected by a password.
- Once the study is complete, information without your name will be kept for 5 years and then destroyed.

What if I change my mind about being in the study?

- Your participation in the study is voluntary.

- You can leave the study at any time even after signing the consent.
- There will be no consequences to you if you decide to stop the study. You can continue to attend the program or work.
- You can let the student researcher or supervisor know in person, by phone, by email or letter.
- If you choose to leave the study you can have all of your information destroyed immediately or kept for use in the study.

How do I find out what was learned in this study?

We expect to have this study completed by August 2016. If you would like a brief summary of the results please include your address or email, on the consent form and we will mail it to you.

If I have questions about the study who should I call?

If you have questions or need more information about the study itself, please contact the student investigator:

Pamela Durepos
xxx-xxx-xxxx (h) xxx-xxx-xxxx (c)
lapospm@mcmaster.ca

or:

Sharon Kaasalainen 905-521-2100 x22404 kaasal@mcmaster.ca

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HIREB). The HIREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the REB Chair, HIREB at 905.521.2100 x 42013

CONSENT

Participant:

I have read the information in the information letter about a study being conducted by Pamela Durepos of McMaster University.

I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.

I understand that if I agree to participate in this study, I may withdraw from the study at any time.

I have been given a signed copy of this form. I agree to participate in the study.

I would like to receive a summary of the study's results.

Yes No

If yes, where would you like the results sent?

Email: _____

Mailing Address: _____

Name of Participant (Printed) Signature Date

Consent form explained in person by:

Name and Role (Printed) Signature Date