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Working with Family Caregivers: Case Managers' Perspectives

by

Kelsey Myers, BSW, LSW

MSW Clinical Research Paper

Presented to the Faculty of the
School of Social Work
St. Catherine University and the University of St. Thomas
St. Paul, Minnesota
in Partial Fulfillment of the Requirements for the Degree of
Master of Social Work

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The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with the basic social research methods. Student must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis nor a dissertation.

Abstract

The purpose of this study was to explore from the case managers' perspective how they work with family caregivers. Eighteen social workers from 5 community based case management agencies completed an online survey about their work family caregivers. Case managers indicated involvement with family caregivers in the areas of assessment, creating a care plan, education, making referrals, advocacy and assistance with problem solving. Case managers indicated that they typically complete the assessment with a caregiver present and invite the caregiver to participate in creating the care plan. Respondents indicated they provide updates less than once a month and use email to provide those updates. Case managers provide education materials to caregivers about community resources and assist them with problem solving related to home care services. When offered the opportunity to comment on their work with family caregivers, case managers emphasized the importance of family involvement and the role of the client in making decisions about the nature and level of family involvement as they are able. Implications for practice and research are also addressed.

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Introduction

People 65 and older comprise one of the fastest growing populations in the United States (Vincent & Velkoff, 2010). Between 2000 and 2010 the number of people 65 and older increased at a faster rate than the entire United States population, and by 2050 the population is expected to increase to 88.5 million (Vincent & Velkoff, 2010). Another growing population in the United States is those who are 90 and older. This population reached 1.9 million in 2010 and by 2050 is expected to comprise 10 percent of the 65 and older population (He & Muenchrath, 2011).

Because people are living into their 90's, they are at risk of developing chronic illnesses such as arthritis, diabetes, osteoporosis and dementia. Those who develop chronic illnesses are likely to need increased assistance with Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) (United States Census Bureau, 1995; Center on Aging Society, 2005; Feinberg, Reinhard, Houser and Choula, 2011). ADLs include dressing, grooming, bathing, eating, positioning, transferring, mobility, toileting and behavior management. IADLs include using the telephone, shopping, preparing meals, housekeeping, laundry, transportation and medication and money management and (Minnesota long term care consultation services assessment form, 2012; Feinberg et al. 2011).

Family members are often the primary caregivers for loved ones who are in need of increased assistance (Kelsey & Laditka, 2009). Families often prefer to be the caregiver due to inadequate long term care services, fear of a stranger caring for their loved one, shortage of home care workers or inability to pay for services (Feinberg et al., 2011; Levine & Kuerbis, 2002). When caring for a loved one in their home, family caregivers assist with ADLs/IADLs, provide companionship and support, coordinate community services and communicate with healthcare professionals on their loved ones behalf (Feinberg et al., 2011). Caregiving does not stop when a loved one is placed in a long term care facility (Hertzberg & Ekman, 2000; Chene, 2006;

Gaugler, Margriet & Zarit, 2007). When caring for a loved one in a long term care facility family caregivers provide emotional support, visit their loved one, communicate with care facility staff, provide information for assessments and care planning and may spend a significant amount of time worrying about their loved one (Hertzberg & Ekman, 2000; Chene, 2009). In 2009, an estimated 42.1 million family caregivers reported caring for a loved one at some point in time and an estimated 61.6 million reported they provided care to a loved one in the past year. The total cost of this care provided was an estimated \$450 billion (Feinberg et al. 2011).

Case managers are frequently in a position where they interact with family caregivers (Abramowitz, Obten & Cohen, 1998). Case managers provide services such as assessment, creating care plans, education, making referrals, advocacy and assistance with problem solving (Claiborne, 2006; Koenig, Lee, Fields and Macmillan, 2011; Kelsey & Laditka, 2007; Boyd, Fisher, Davidson and Neilsen, 1996; Bowers & Jacobson, 2006). Case managers may need to include the family when creating a care plan (Pashby, Hann and Sunico, 2009) or provide them with education materials about their loved ones illness (Waldrop 2006; Kelsey & Laditka, 2009). Case managers are also in position to provide counseling and additional supportive services to families due to the high demands of being a caregiver (Abramowitz et al., 1998). The purpose of this study is to explore from the case manager's perspective how they work with family caregivers.

Literature Review

Overview

The focus of this literature review will be family caregivers and case managers and will be separated into two sections. Each section will discuss themes found throughout the literature relating to family caregivers and case managers.

Family Caregivers

Four themes found throughout the literature relating to family caregivers include coping, education, poor physical and mental health of caregivers and benefits of caregiving. The first theme that will be discussed is coping.

Coping

Problem focused coping and *emotion focused coping* are two strategies identified in Lazarus and Folkman's (1984) model of stress and coping. This model is not exclusive to caregivers, but provides a framework for understanding how caregivers cope (Lazarus & Folkman, 1984). *Problem focused coping* strategies are directed at solving a problem by taking action such as seeking information, planned problem solving and self-change (Lazarus & Folkman, 1984). Sun et al. (2010) defined coping styles among caregivers that utilize problem solving as *deliberate coping*. Tasks associated with deliberate coping include personal growth, seeking emotional help, suppressing competing demands, seeking instrumental support, active coping and planning. Based on a study of 138 dementia caregivers, Sun et al. (2010) found that caregivers who were using deliberate coping strategies experienced higher levels of life satisfaction. Similarly, another study found that caregivers who receive assistance with caring for their loved one reported feeling less strained than those who did not receive assistance (Townsend, Ishler, Shapiro, Pitorak, and Matthews, 2010)

Lazarus and Folkman (1984) also identified *emotion focused coping strategies* directed at regulating emotions caused by the stresses of caregiving. Emotion focused coping strategies include denial, wishful thinking, self-blame and avoidance (Lazarus & Folkman, 1984). Caregivers who utilized emotion focused strategies accepted their situation as it was and believed that little could be done to change it (Lazarus & Folkman, 1984). Kramer (1993) utilized Lazarus and Folkman's model of stress and coping to study predictors of individual

differences in caregiver depression and satisfaction among wives caring for their husbands with dementia. Wives caring for husbands who had more memory and behavior problems and who had few physical and social resources were more likely to use emotion focused coping strategies. Use of these strategies was associated with depression and greater use of confronting, criticizing, minimizing contact or ignoring their husbands (Kramer, 1993).

Sun et al. (2010) defined coping styles that use emotion regulation as *avoidance coping*. Tasks associated with avoidance coping strategies included venting of emotions, denial, mental disengagement and behavior disengagement. Caregivers who had higher scores in avoidance coping were more likely to report a higher level of caregiver burden and lower life satisfaction (Sun et al., 2010). Social workers can intervene when avoidance coping strategies are being used by encouraging caregivers to seek out resources to assist with managing the stresses of caregiving (Townsend et al., 2010). In addition to coping skills, education is also a need expressed by family caregivers (Dobrof et al., 2002; Waldrop, 2006; Kelsey & Laditka, 2009; Pashby et al., 2009).

Education

Dobrof et al. (2002) outlined a successful education program at Mount Sinai Medical Center to address the educational needs of caregivers. The education program emerged from a needs assessment completed in 1998 with family caregivers affiliated with Mount Sinai Medical Center. Participants in the needs assessment reported feeling frustrated in meeting their needs for information about programs, services and medical conditions, but were unsure where to go. They wanted one location they could call or visit to obtain education about caregiving or their loved one's medical diagnosis (Dobrof et al., 2002). Waldrop (2006) described this as a need for "anticipatory guidance," or help preparing for the future. Families expressed a desire for

education about symptom recognition and management, caregiver techniques and guidance with end of life decision making (Waldrop, 2006).

Similarly, care managers in a study by Kelsey and Laditka (2009) reported that they frequently educated families about what to expect in the future from their loved ones' illnesses. Another study had similar findings. Pashby et al. (2009) interviewed 15 family caregivers whose loved one resided in a nursing home and had a diagnosis of dementia or another related illness. These family caregivers reported a desire for increased education about dementia and the progression of the illness. Townsend et al. (2010) found that caregivers who did not know what to expect day to day from their loved ones illness reported higher psychological strain and distress. Caregivers also reported a need for resources on legal and financial planning (Rodgers, 2008), community resources, financing options and long term care placement (Kelsey & Laditka, 2009). The next theme that will be discussed is poor physical and mental health of caregivers (Evercare Study of Caregivers in Decline, 2006; Chene, 2006; Schulz & Beach, 1999; Townsend et al., 2011).

Poor physical and mental health of caregivers

Caregivers experience an increased rate of physical symptoms such as headaches, bodily aches and pains, acid reflux, weight gain/loss and are at higher risk of having heart disease than non-caregivers (Evercare Study of Caregivers in Decline, 2006). Chene (2009) reported that the health of the caregiver is an important part of the ability to care for a loved one. The average age of a participant in Chene's (2009) study was 71. Many of the caregivers reported that they could no longer care for their loved one due to their own poor health. Elderly spousal caregivers between the ages of 66 and 96 have a 63% higher mortality rate than those who are not caregivers due to caregiving related stresses (Schulz & Beach, 1999). Chene (2009) also found

that adult children who had multiple caregiving roles, such as caring for their mother and father, also suffered from poor physical health. Dal Santo et al. (2007) surveyed 1,643 caregivers who were providing care for someone age 50 and over and found that those who used respite services were mentally stressed to the point of experiencing physical symptoms. To improve caregiver health, Dal Santo, Scharlach, Nielsen and Fox (2007) suggested that caregivers use respite services to assist with the physical demands of caregiving.

The Center on Aging Society (2005) reported that 26% percent of caregivers reported that stress is one of the most common emotions they experience (Evercare Study of Caregivers in Decline, 2006; Family Caregiver Alliance). Factors that are associated with stress may include younger age, being unsure of what to expect day to day, difficulty with seeing changes in a loved one and lack of caregiving assistance from others (Townsend et al., 2010). Chene (2009) found that caregivers whose loved had dementia and had behavior problems experienced high levels stress. The most troubling behaviors that caregivers reported included resisting cares, verbal or physical aggression, sleep disruption and absconding behavior (Chene, 2009). Similarly, Townsend et al. (2011) found that those caring for a loved one with behavior problems reported higher levels of caregiver burden than those caring for a loved one without behavior problems. In addition to stress, caregivers may also experience depression (Kramer, 1993; Zarit, 2006; Chene, 2009).

Kramer (1993) found that wives caring for their husbands who had diagnosis of dementia had higher depression scores when they used emotion focused coping strategies such as confronting, criticizing, ignoring or minimizing contact with their husbands. Between 40 and 70 percent of caregivers have symptoms of depression, and one quarter of these may meet diagnostic criteria for major depression (Zarit, 2006). Ten out of 20 caregivers in a study by

Chene (2009) were found to be at risk of developing depression. Caregivers stated that depression was the result of sadness from seeing their love one in poor health, stress in their own life, feeling overwhelmed and lack of sleep (Evercare Study of Caregivers in Decline, 2006; Chene, 2009). Although caregivers may experience decreased physical and mental health (Family Caregiver Alliance; Chene, 2009; Center on Aging Society, 2005; Kramer, 1993; Zarit, 2006; Evercare Study of Caregivers in Decline, 2006), there are benefits to caregiving.

Benefits of Caregiving

According to the Center on Aging Society (2005), 47% of caregivers strongly agreed that they appreciated life more as a result of being a caregiver, and 48% reported that caregiving made them feel good about themselves. In a study by Chene (2006), caregivers of loved ones with dementia reported that benefits of caregiving included having their loved one recognize them or joining in on a conversation. Rodgers listed 5 benefits of being a caregiver including: “a new sense of purpose and meaning in life, fulfillment of a lifelong commitment to spouse, an opportunity to give back to a parent some of what has been given to them, renewal of religious faith and closer ties with people through new relationships or stronger existing relationships” (2008, p. 64). Many family members find that caregiving is a source of satisfaction and meaning (Feinberg et al., 2011). The next section of the literature review will outline services case managers provide to clients and their caregivers.

Services provided by case managers

Case managers provide services to clients and their family caregivers that include assessment, creating care plans, education, making referrals, advocacy and assistance with problem solving (Claiborne, 2006; Koenig et al., 2011; Kelsey & Laditka, 2007; Boyd et al., 1996; Bowers & Jacobson, 2006). As each of these services areas area addressed, particular

relevance to family caregivers will be noted. The first service that will be discussed is assessment.

Assessment

Completing a thorough assessment is essential to social work (Kelsey & Laditka, 2007). Social workers complete many types of assessment including initial assessments, ongoing assessments, psychosocial assessments, mental health assessments and crisis assessments (Dubus, 2010; Koenig et al. 2011; Boyd et al. 1996; Claiborne, 2006). One third of social worker participants in a study by Kelsey and Laditka (2007) reported that assessments are critical to good care and that family support is also important. Family involvement in assessment can help remind the client of questions that need answers or help clarify aspects of existing services (Purk & Richardson, 1994).

Bowers and Jacobson (2006) conducted a study to explore how “excellent” case managers do their jobs. To gather this information, they interviewed informant staff from a Wisconsin management group that completes quality reviews of case managers. One result of the study was that “excellent” case managers not only formally assess their clients as needed, but are constantly completing informal needs assessments to determine what is important to the client in the present and what they may need in the future. One case manager in a study by Kelsey and Laditka (2007) reported that assessments are the “cornerstone” of care management, and without them, nothing can be done. Another serviced provided by case managers is creating care plans (Boyd et al., 1996; Pasbhy et al., 2009; Koenig et al., 2011; Bowers & Jacobson, 2007).

Creating care plans

Boyd et al. (1996) identified creating care plans as one task of a case manager. Care plans are based on the client’s assessment and addresses physical and mental health, strengths,

limitations, goals, safety needs and accepted services. (Medica collaborative care plan for Minnesota senior health options, 2011; Pashby et al., 2009). One model for creating a care plan is the CARE approach. Pashby et al. (2009) discussed using the CARE approach as a way to effectively create a care plan that involves the patient, family and care staff. Family involvement in care planning is important as families often possess knowledge of their loved ones' psychosocial history (Port, Gruber-Baldini, Burton, Baumgarten, Hebel & Zimmerman, 2001). The CARE approach identifies communication, collaboration, assessment, resources and referrals for caregivers and education for caregivers and care providers as elements of a care plan (Pashby et al. 2009). Similar to the CARE approach, the assisted living administrators in a study by Koenig et al. (2011) reported that they viewed communicating with families and communicating client changes to other staff as aspects of care planning. Another aspect of creating a care plan is monitoring the client's overall progress (Koenig et al., 2011).

Claiborne (2006) sought to find out if monitoring overall progress through care coordination improved well-being for clients who had suffered from a stroke. It was found that clients using the services of a case manager, referred to as a care coordinator in this study, had improved quality of life, reduced depressive symptoms and improved adherence to self-care practices. Care coordination can also reduce the number of hospital stays, emergency department visits and clinic visits (Boyd et al. 1996). Bowers and Jacobson (2006) found that "excellent" case managers monitored the quality of their clients' services by regular communication and paying close attention to changes in their circumstances rather than relying only on standard indicators, such as agency surveys. Another service provided by case managers is education (Kelsey & Laditka, 2007; Abramowitz et al. 1998; Claiborne, 2006; Waldrop, 2006).

Education

The care managers in Kelsey and Laditka's (2007) study reported that education was one of the most important services they provided. Kelsey and Laditka (2007) reported that approximately 60% of the social workers they interviewed in the geriatric care management field spoke about the importance of education. Care managers reported that families frequently requested education about community resources and options to finance the care of their loved one. Care managers stated that they often educated caregivers about what they could expect from their loved one's illness in the future. This can ease distress in families who are caring for a terminally ill loved one by preparing them for future challenges (Waldrop, 2006).

In a study of stroke survivors and how they benefitted from care coordination, education was used as an intervention to improve their quality of life. Care coordinators educated patients about the importance of healthy lifestyle changes such as diet and exercise and assisted patients with creating simple reminder techniques to help them remember to take the correct medications at the correct time (Claiborne, 2006). In addition to providing education, case managers also make referrals (Boyd et al., 1996; Kelsey & Laditka, 2007; Claiborne, 2006).

Making referrals

Another task of case managers is making referrals (Boyd et al., 1996). Case managers have knowledge of the health care system (Boyd et al., 1996) and the ability to assist caregivers with making referrals to agencies that can provide instrumental support such as assistance with caregiving tasks or household chores (Pearlin, Mullan, Semple and Skaff, 1990). Referrals connect clients with community resources and provide them with services to keep them safe in their home (Kelsey & Laditka, 2007). Referrals are often made after an assessment is completed and it is determined there is an unmet need (Claiborne, 2006). Another service provided by case

managers is advocacy (Koenig et al., 2011; Kelsey & Laditka, 2009; Levine & Kuerbis, 2002; Bowers & Jacobson, 2007).

Advocacy

Social workers advocate for their clients by protecting confidentiality, addressing conflict and ensuring that rights and choices are being upheld (Koenig et al., 2011; Kelsey & Laditka, 2009). Assisted living administrators in Koenig et al.'s (2011) study reported that is it the job of the social worker to ensure confidentiality within the facility so that if the resident has a complaint, they have a safe place to go. Administrators also reported that it is the job of the social worker to address conflict between other staff and the resident to ensure that the resident's choices are upheld. Another administrator reported that when a new resident moves in, they are told immediately that the facility has a social worker, and it is the social worker's job to advocate on their behalf (Koenig et al., 2011).

Social workers can also advocate for families in a community setting by finding other care options when a family member is unable or unwilling to provide care for their loved due to their own limitations (Levine & Kuerbis, 2002). Family caregivers often become caregivers with little preparation, support or understanding of how to provide long term care (Center on Aging Society, 2005). In addition, Kelsey and Laditka (2009) found that care managers working with the elderly population frequently emphasized the importance of treating clients as individuals and recognizing that each client is unique. Care managers also reported that self-determination and independence are important to older clients. Even when families are involved in the care process, if able, the client should always be the first decision maker (Kelsey & Laditka, 2009). Bowers and Jacobson (2006) reported that "excellent" case managers understand how and when to call in favors and know when it's important to bend the rules in order to advocate for their

clients. Another service provided by case managers is assistance with problem solving (Claiborne, 2006; Bowers & Jacobs, 2007; Koenig et al., 2011).

Assistance with problem solving

A study to explore the effectiveness of case management with stroke survivors identified problem solving as one intervention provided by case managers (Claiborne, 2006). Claiborne (2006) reported that case managers frequently assisted the client with problem solving related to basic needs such as transportation issues, financial issues, housing needs, equipment modification and employment issues. Similarly, Bowers and Jacobs (2007) reported that “excellent” case managers possessed the ability to problem solve and match clients to services that help them meet their basic needs.

Caregiver assistance with problem solving can establish a stronger relationship between client and caregiver, and most clients desire more family involvement than they experience (Botelho, Lue & Fiscella, 1996). Case managers working with families are more likely to be involved in hard to resolve problems related to the needs of the family or related to the complex medical needs of the client (Abramowitz et al., 1998). Similarly, in a study with administrators at an assisted living facility about the role of the social worker, Koenig et al. (2011) reported that family members caring for a loved one would not pursue resolving a problem upon finding out there was no social worker at the facility.

Connection to Social Work

Case managers working in long term care are often social workers (Bowers & Jacobson, 2002). As the United States population ages, community based care is a growing trend and social workers will often be in a case management role (Hughes, Sutcliffe & Challis, 2005). Case managers have the knowledge and skills to navigate a fragmented and complicated service

delivery system and create an integrative care plan that is able to meet the needs of their clients (Seltzer, Litchfield, Lowy & Levin, 1989; Abramowitz, 1998; Claiborne 2006). Case managers can help to improve the quality of life and quality of care for clients by assisting them with problem solving, encouraging self-care, providing education, counseling and advocacy and monitoring their overall progress (Claiborne, 2006).

Families are often an integral part of this process as they can remind patient of questions they needs answers to, provide emotional support, provide information for assessments and assist with decision making (Hertzberg & Ekman, 1999; Claiborne, 2006; Pashby et al., 2009).

Although families are an important part of the case management process, there were few studies that directly explored how case managers involve families in the case management process. The purpose of this study is to explore from the perspective of case managers how they work with family caregivers. This information will be shared with other social workers to improve their understanding of how case managers work with families.

Conceptual Framework

The conceptual framework used for this study was grounded in the services provided by case managers and guided the focus of the survey questions and data collection for this study. Services provided by case managers include assessment, creating care plans, education, making referrals, advocacy and assistance with problem solving. Each task provided by the case manager was addressed on the survey (Appendix D) with a focus on how they involved the family in that specific task. For example, Question #4 asked about how often case managers involve families in the assessment process; question #7 asked about care planning and question #9 asked about how often different types of educational materials were provided. This framework organized survey

questions to explore how the needs of family caregivers were addressed through the services provide by case managers. The purpose of this study was to explore from the case managers' perspectives how they work with family caregivers in order to better understand the day to day services on behalf of the clients.

Methods

The purpose of this study was to explore from the perspective of the case managers how they work with family caregivers. Data for this study was gathered via electronic survey and was analyzed using descriptive statistics.

Sample

The sample that was surveyed included social workers who are providing case management services to people who are 65 and older. A list of agencies that provided services to the 65 and older population was created. The agencies' case management or social service directors were informed about the content of this study and asked if they would be willing to distribute an electronic survey to their staff. If they chose to participate, a letter of cooperation was requested (Appendix A). This letter, completed by the agency supervisor or program director, was submitted on agency letter head to confirm their participation and to ensure they understood the nature of the study. Five agencies agreed to participate in the study. This sample focused on community based agencies rather than larger, medically based health care systems.

Protection of Human Subjects

This study was reviewed and approved by a research committee and the Institutional Review Board at St. Catherine University prior to data collection. There were no known risks or direct benefits for participating in this study.

An email describing the study and its parameters and a link to the survey (Appendix B) was distributed to the supervisor or program director who then forwarded the email to the case management staff to make an independent decision about participation. Those who chose to participate clicked on a link in the cover letter which directed them to the survey (Appendix B). The link was emailed directly to the case managers at two agencies, with permission from the program supervisor, because of technical problems encountered with forwarding the link. The respondent's identity was anonymous to the supervisor or program director and to the researcher. The returned survey did not include any email/agency information by utilizing the anonymizing feature in Qualtrics. The survey data was kept in a file on a password protected computer and only viewed by the researcher. The data was destroyed by June 1, 2013.

Participation in this study was completely voluntary. Refusal to participate involved no penalties and participants were able to withdraw from the study at any time for any reason. Consent was obtained by participants completing and submitting the survey.

Data Collection

Instrument Development

The content of the survey questions was based on a review of the literature and framed by the tasks provided by case managers in relationship to their engagement with family caregivers of their older clients. Tasks provided by case managers include assessment, creating care plans, education, making referrals, advocacy and assistance with problem solving. Each task provided by case managers had an associated question or set of questions. For assessment and creating care plans, the case manager was asked how often the caregiver is invited to participate and the parameters of that participation from 1 (*never*) to 5 (*always*). Questions about creating care plans addressed method and frequency. Respondents were asked by what method they provide updates

and the frequency. Case managers were asked to respond about eight types of educational materials and their use with family caregivers. Similarly, eight types of problems were listed and case managers were asked how often they assist with the different types of problems from 1 (*never*) to 4 (*always*). For the task of advocacy, the case manager was asked how often they notify the caregiver when the client is having difficulty with a provider ranging from 1 (*never*) to 5 (*always*).

Data collection process

A cover letter (Appendix B) was sent to each agency supervisor or program director who agreed to participate (Appendix A) with a link to the survey which they then distributed to staff case managers. The link was emailed directly to the case managers at 2 agencies because the link could not be forwarded. Case managers made an independent decision about participation. The respondent's identity was anonymous to the supervisor or program director and to the researcher. The returned survey did not include any identifiable information by using the feature in Qualtrics that removes identifying information from responses. The survey link was hosted by Qualtrics and took approximately 5-10 minutes. The data collection took place January 28, 2013 to February 11, 2013. The response rate could not be calculated since the survey was distributed to the agency, not to the individual. The survey data was kept in a file on the researcher's password protected computer and was only viewed by the researcher. The data was destroyed by June 1st, 2013.

Data analysis

Data was exported from Qualtrics then analyzed using descriptive analysis through the SPSS data analysis program. The likert scale questions were analyzed by using frequency

distribution to describe the data. The qualitative data was analyzed by reviewing comments from respondents and picking out themes. All direct quotes are presented in *italics*.

Strengths and limitations

This study extends existing research that shows family members who are caregivers have a desire to be involved in the case management process by including case managers' voices about how they work with family caregivers. A limited number of participants narrowed the scope of responses. Response rates were likely compromised by the difficulty with the Qualtrics survey link.

Findings

The findings of this study begin with a description of the respondents. The respondents' answers to questions about their practice related to work with families will be presented as well as their comments.

Demographics

Demographic information for this study is show in Table 1. Of the 18 participants who completed the survey, most participants identified as an LSW (n=11). Three participants identified as an LGSW and one identified as an LISW. Half of the respondents have been a case manager for 0-3 years (n=9). Three have been a case manager 4-7 years, 3 for 8-11 years and 3 for 12 or more years (15+ years, 25 years, 29 years).

Table 1. *Demographics*

N=18				
Licensure Level		Years in practice		
LSW	10	M = 6.8 (S.D. =8.4)		
LGSW	3	<3	9	
LISW	1	4-7	3	
Other*	3	8-11	3	
		12+	3	

*BA in related field, no license, BA in psychology

Engaging Families in Assessment

The results for family engagement in assessment are shown in Table 2. Case managers invited caregivers to participate in the assessment *most of the time* (n=8) or *always* (n=8). Other case managers *sometimes* (n=7) or *most of the time* (n=11) complete the assessment with a caregiver present. Six case managers indicated they *never* provide a copy of the assessment to the caregiver and 7 indicated they *rarely* provide a copy of the assessment to the caregiver.

When asked to comment about their interaction with families, one case manager responded, “*If there is a caregiver involved and they show interest in attending meetings, I always invite them.*”

Table 2. *Engaging Families in Assessment, Creating a Care Plan and Method of Providing Updates*

N=18					
	Never	Rarely	Sometimes	Most of the time	Always
<i>Assessment</i>					
Invite caregiver to participate	0	1	1	8	8
Complete with caregiver present	0	0	7	11	0
Provide a copy to caregiver	6	7	0	3	2
<i>Creating a Care Plan</i>					
Invite caregiver to participate	0	2	3	11	2
Complete with caregiver present	0	0	8	10	0
Provide a copy to caregiver	2	2	3	5	6
<i>Method of Providing Updates</i>					
Email	0	4	10	3	1
Phone	0	0	2	15	1
Mail	0	5	9	3	1
In Person	0	3	11	4	0

Creating Care Plans

The results for caregiver involvement in creating care plans are shown in Table 2. A majority of case managers indicated that they invite the caregiver to participate in creating the care plan *most of the time* (n=11). Other respondents indicated that they complete the care plan with a caregiver present *most of the time* (n=10) and 8 respondents indicated they *sometimes* complete the care plan with a caregiver present. Of the respondents, 6 case managers reported that they *always* provide a copy of the care plan to the caregiver while others indicated they *never* (n=2) or *rarely* (n=2) provide a copy to the caregiver.

Method of Providing Updates

As show in Table 2, most case managers *sometimes* (n=10) provide updates to caregivers by email. Phone updates were completed *most of the time* by 15 respondents. Nine case managers indicated they *sometimes* provide updates to caregivers by mail and 11 case managers responded that they *sometimes* provide updates in-person. The most common method used to provide updates was by phone.

Table 3. *Frequency of Updates Provided to Caregivers*

N=18	
Never	1
Less than once a month	9
Once a month	4
2-3 times a month	2
Once a week	2

The frequency of updates provided to caregivers is shown in Table 3. Most case managers provided updates to caregiver *less than once a month* (n=9) or *once a month* (n=4). One case manager indicated *never* providing updates and other case managers indicated they provided updates *2-3 times a month* (n=2) and *once a week* (n=2).

Education Materials Provided to Caregivers

The use of education materials with family caregivers is shown in Table 4. Most respondents *sometimes* (n=9) provide disease specific education materials. Education materials about community resources were used *most of the time* by 9 case managers. Materials about education programs were provided by case managers *sometimes* (n=6) and *most of the time* (n=5). Case managers reported that they *sometimes* (n=6) and *most of the time* (n=6) provide education materials about coping skills. Education materials about end of life decision making were used to some degree by most of the respondents: *sometimes* (n=5), *most of the time* (n=5) and *always* (n=4). Eight case managers *sometimes* provided education materials about legal resources. Respondents indicated they *sometimes* (n=7) and *most of the time* (n=4) provide education materials to caregivers about financial resources. Similarly, other case managers indicated they *sometimes* (n=7) and *most of the time* (n=4) provide education materials to caregivers about caregiving resources. The respondent who indicated that he/she never provided education materials has been a case manager for less than 2 years.

Table 4. *Education Materials Provided to Caregivers*

N=18					
	Never	Rarely	Sometimes	Most of the time	Always
Disease specific	1	3	9	4	1
Community resources	1	1	5	9	2
Education programs	1	5	6	5	1
Coping skills	1	4	6	6	1
End of life decision making	1	3	5	5	4
Legal resources	0	3	8	5	2
Financial resources	1	3	7	4	3
Caregiving resources	1	3	7	4	3

Assisting Caregivers with Problem Solving

The results for frequency of assistance with problem solving are showing in Table 5. Case managers *sometimes* (n=4), *always* (n=4) and *most of the time* (n=9) assisted caregivers with problem solving related to transportation. Eleven respondents indicated that they assist caregivers with problem solving related to equipment *most of the time*. Other case managers assisted caregivers with housing related problem solving *always* (n=5) or *most of the time* (n=9). Case managers assisted with problem solving related to employment *most of the time* (n=6). Case managers indicated that they assist caregivers with problem solving related to finances *most of the time* (n=10). A majority of respondents indicated that they assist caregivers with problem solving related to home care services *most of the time* (n=13). Other respondents indicated that they assist caregivers with problem solving related to medical needs *always* (n=5) or *most of the time* (n=11). Other case managers reported that they assist caregivers with problem solving related to family conflict *always* (n=4) or *most of the time* (n=7).

Table 5. *Assisting Caregivers with Problem Solving and Caregiver Involvement when Making Referrals*

		N=18				
		Never	Rarely	Sometimes	Most of the time	Always
<i>Problem Solving</i>						
	Transportation	0	1	4	9	4
	Equipment	0	1	2	11	4
	Housing	1	0	3	9	5
	Employment	5	4	1	6	2
	Finances	1	2	2	10	3
	Home care services	0	0	1	13	14
	Medical needs	0	0	2	11	5
	Family conflict	1	4	2	7	4
<i>Referrals</i>						
	Obtain caregiver input when making a referral	0	1	4	8	5
	Notify caregiver when a referral is made	0	1	5	4	8
	Notify caregiver when client is having difficulty with a provider	0	2	4	5	7

Caregiver Involvement when Making Referrals

As shown in Table 5, respondents indicated they *always* (n=5) or *sometimes* (n=8) obtain caregiver input when making a referral. Case managers indicated that caregivers are notified *most of the time* (n=4) or *always* (n=8) when a referral is made. Other respondents *most of the time* (n=5) or *always* (n=7) notify the caregiver when the client is having difficulty with a provider. One case manager commented, *“I have families/client’s pick their own providing agencies and perform the steps necessary to begin services.”*

Case Manager Comments about Family Involvement in Case Management

When offered the opportunity to comment on their work, respondents addressed the client’s role in determining whether and how family caregivers are involved. Two major factors emerged from the comments section of the survey. First, respondents noted that family involvement ...*always depends on the situation*. Other respondents’ comments expressed these conditions:

- *Truthfully, all of the preceding questions should be preceded with: It depends. As privately hired, fee for service geriatric care managers, it is almost always caregivers who hire us. So problem identification, goal setting, problem solving often involves caregivers input and opinion, and the level of their involvement in providing the solution is unique to each situation.*
- *Families are often the main contact for persons who are not capable of making their own decisions, and for persons with development disabilities.*
- *Every family is different and needs something different. Most often with seniors families are involved and educated regarding senior resources.*
- *If there is a caregiver involved and they interest in attending meetings, I always invite them.*

Secondly, family involvement should be determined by the client. Two respondents’ spoke to this point of view. One stated, ...*I leave it up to the client to determine the amount of*

involvement the client wants. While another commented that, *It always depends on....what the client wants. We will have the families and caregivers be as involved in everything as the client would like.* Of the 6 respondents who commented on their work with families, 5 have been a case manager for 6 years or more and 4 hold an LSW or higher.

Discussion

The purpose of this study was to explore from case managers' perspectives how they work with family caregivers. A discussion about respondents' answers to questions about their practice related to work with families and their comments will be presented.

Engaging Families in Assessment

The results of this study indicate that case managers involve caregivers in the assessment process by inviting them to participate in the assessment or completing the assessment when a caregiver is present (Table 2). One third of social worker participants in a study by Kelsey and Laditka (2007) reported that assessments are critical to good care and that family support is important. Family involvement in assessment can help remind the client of questions that need answers or help clarify aspects of existing services (Purk & Richardson, 1994). There was no previous literature that indicated whether or not case managers were providing a copy of the assessment to the caregiver, which may be reflective of the variations across agencies in terms of how assessments are conducted.

Creating Care Plans

Over half of the respondents indicated that they invite the caregiver to participate in creating the care plan (Table 2). Port et al. (2011) noted that family involvement is important in creating care plans as they often possess knowledge of their loved one's psychosocial history. Previous research also indicates that creating a care plan is often the task of a case manager (Boyd et al., 1996; Abramowitz et al., 1998; Koenig et al., 2011). In comparison to this study

(Table 2), previous literature did not indicate how often caregivers wanted updates or by what method, but emphasized the important of an individualized care plan based on the clients' situations (Kelsey & Laditka, 2009; Pashby et al., 2009).

Education Materials Provided to Caregivers

Case managers provide education materials to caregivers in the areas of disease specific information, community resources, education programs, coping skills, end of life decision making, legal resources, financial resources and caregiving resources (Table 4). These findings are congruent with past literature demonstrating that families value education in these areas (Dobrof et al., 2002; Waldrop, 2006; Kelsey & Laditka, 2009; Pashby et al, 2009). Care managers in a study by Kelsey and Laditka (2009) reported that they frequently educated caregivers about what to expect in the future from their loved one's illness.

Assisting Caregivers with Problem Solving

Respondents indicated that they assist caregivers with problem solving related to basic needs (Table 5). These results are connected with previous findings that case managers working with families whose loved one has complex medical needs are more likely to spend time addressing needs related to medical problems, supportive services and employment (Abramowitz et al., 1998). When working with stroke survivors, case managers assisted with problem solving related to basic needs such as transportation, finances, housing, equipment and employment (Claiborne, 2006). Caregiver assistance with problem solving can establish a stronger relationship between client and caregiver, and most clients desire more family involvement than they experience (Botelho et al, 1996).

Caregiver Involvement when Making Referrals

Case managers indicated that they involve caregivers in the referral process (Table 5). Previous literature does not directly describe the level of caregiver involvement in making referrals but indicated that making referrals is often a task of the case manager (Boyd et al., 1996; Claiborne, 2006). Some case manager respondents indicated they notify the caregiver when the client is having difficulty with a provider (Table 5). This finding is congruent with previous studies that indicate social workers are often in the role of mediator (Claiborne, 2006; Kelsey & Laditka, 2009; Koenig et al, 2011).

Case Manager Comments about Family Involvement in Case Management

According to respondents in this study, family involvement should be determined by the client and family involvement depends on the situation. Similarly, in a study by Kelsey and Laditka (2009), care managers emphasized the importance of treating clients as individuals, recognizing that each client is unique and that if able, the client should always be the first decision maker. The findings of this study and the previous research by Kelsey and Laditka (2009) both emphasize the importance of client centered practice and putting the client's needs first.

Implications for Social Work Practice

Social workers are trained to view a person in their environment and as a member of a system, not just as an individual. Most case managers who participated in this study identified as being a social worker (Table 1) and were likely trained from a person in environment/systems theory perspective. By viewing our clients as part of a family system, social workers can help meet the client's needs by meeting the family needs as they are involved with the care of their loved one. By involving families with tasks such creating care plans, providing education and

problem solving, case managers may be assisting families by helping them cope more effectively with caregiving.

Implications for Policy

Implications for policy can best be viewed from an agency perspective. As multiple respondents commented and as was found in a previous study, family involvement depends on what the client prefers and is unique to each situation. When developing an agency policy about communicating with families, it would be beneficial to keep the guidelines flexible and develop communication guidelines based on the clients' needs and their unique situation rather than have a communication policy that is to be used with all family caregivers. For example, case managers who have clients with complex medical needs may be in communication with caregivers more frequently than those who do not have clients with complex medical needs.

Implications for Research

As the results of this study indicated, most case managers have contact with family caregivers. Based on this finding, it would be beneficial to further explore how case managers are involving families in tasks of case management and what methods of communication are most effective. This could be completed through a survey that captures more respondents or qualitative study to explore in depth the experiences of case managers who work with families.

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Letterhead**Date****Name/name of agency****Address****Phone**

Dr. Carol Kuechler
School of Social Work
University of St. Thomas/St. Catherine University

Dear Dr. Kuechler,

I am writing to acknowledge our agency's support of the clinical research project of Kelsey Myers, being conducted under your supervision. I give Kelsey Myers permission to conduct research with social workers by inviting them to participate in a survey to explore the extent to which case managers are involving families in the care coordination process, and acknowledge that there are no risks for participating in this study.

Upon approval of the St. Catherine University Institutional Review Board, Kelsey Myers will send me a link to a survey by email that I will distribute to social workers at **name of agency** who are case managers for those ages 65 and older. The social workers will make their decision regarding completion of the survey, and that participation is voluntary. No one at the agency knows who chooses to participate and response to the researcher will be anonymous, so it will not affect their status at our agency.

I am aware that this research is a part of her clinical research paper, which will be published and presented to the public on Monday, May 20, 2013. I understand that there are no anticipated risks to our organization or our clients. I understand that expected benefits include increased knowledge about to what extent case managers are involving families in the care coordination process. The direct benefits to **name of agency** include an invitation to the presentation on Monday, May 20, 2013 and a written summary of the researcher's findings.

Sincerely,

Name/Signature

**Working with Family Caregivers: Case Manager's Perspectives
IRB#12-N-71**

Dear Social Work Practitioner:

You are invited to participate in a research study to explore from the case manager's perspective how you work with family caregivers for people ages 65 and older. This study is being conducted by Kelsey Myers, a graduate student at the School of Social Work at St. Catherine University/University of St. Thomas, under the supervision of Dr. Carol Kuechler, a faculty member at the school. You were selected as a possible participant in this research because of your involvement with the State of Minnesota Board of Social Work and your experience as a social worker and case/care manager. Please read this form and ask questions before you agree to be in the study.

Upon review of the literature about case managers and families, few studies were found that directly explored how case managers involve families in the care coordination process. Families expressed a need for services that case managers can provide such as education and assistance with problem solving. This project will explore how case managers are providing services to families from the case manager's perspectives. Approximately 30 people are expected to participate in this research.

If you decide to participate, you will be asked click on a link below to complete a survey consisting of questions related to how case manager's work with family caregivers. The survey will take 5-10 minutes to complete and will be available through February 4th, 2013.

There are no known risks and no direct benefits to you for participating in this study.

No information obtained in connection with this research study can be identified with you. Your results will be kept anonymous and confidential. The Qualtrics survey is set up so that Qualtrics does not link emails to the results. In any written reports or publications, no one will be identified or identifiable and only group data will be presented.

Participation in this research study is voluntary. Your decision whether or not to participate will not affect your future relations with St. Catherine University or the University of St. Thomas in any way. If you decide to participate, you are free to stop at any time without affecting these relationships. Completion of the survey implies consent.

If you have any questions, please feel free to contact me, Kelsey Myers, at myer2153@stthomas.edu. If you have any additional questions, my faculty advisor, Dr. Carol Kuechler at cfkuechler@skate.edu and/or (651) 690-6719, will be happy to answer them. If you have other questions or concerns regarding the study and would like to talk to someone other than the researchers, you may also contact Dr. John Schmitt, Chair of the St. Catherine University Institutional Review Board, at (651) 690-7739.

Thank you for your participation.

Please click here to begin:

Sincerely,

Kelsey Myers
MSW Graduate Student
University of St. Thomas and St. Catherine University
myer2153@stthomas.edu

Working with Family Caregivers: Case Manager's Perspectives Survey

You are invited to participate in an online survey conducted by Kelsey Myers, a graduate student in the School of Social Work at St. Catherine University and the University of St. Thomas, supervised by Dr. Carol Kuechler, a faculty member of this school. The purpose of this study is to explore from the case manager's perspective how they work with family caregivers. Your responses will be anonymous; no email or account information will be recorded. The survey will be available until January 15th, 2013. Your participation is greatly appreciated!

Q1 I agree to participate in this survey:

- Yes (1)
- No (2)

If Yes Is Selected, Then Skip To What is your current licensure title? If No Is Selected, Then Skip To End of Survey

Q2 What is your social work license?

- LSW (1)
- LGSW (2)
- LISW (3)
- LICSW (4)
- Other, please specify (5) _____

Q3 How long have you been a case manager?

Q4 How often do you:

	Never (1)	Rarely (2)	Sometimes (3)	Most of the Time (4)	Always (5)
Invite the caregiver to participate in the assessment (1)	<input type="radio"/>				
Complete an assessment with a caregiver present (2)	<input type="radio"/>				
Provide a copy of the assessment to the caregiver (3)	<input type="radio"/>				

Q5 How often do you provide updates to family caregivers?

- Never (1)
- Less than Once a Month (2)
- Once a Month (3)
- 2-3 Times a Month (4)
- Once a Week (5)
- 2-3 Times a Week (6)
- Daily (7)

Q6 How often do you use the following methods to communicate with family caregivers?

	Never (1)	Rarely (2)	Sometimes (3)		
Email (1)	<input type="radio"/>				
Phone (2)	<input type="radio"/>				
Mail (3)	<input type="radio"/>				
In-person (4)	<input type="radio"/>				

Q7 How often do you:

	Never (1)	Rarely (2)	Sometimes (3)	Most of the Time (4)	Always (5)
Invite the caregiver to participate in creating a care plan (1)	<input type="radio"/>				
Create a care plan with a caregiver present (2)	<input type="radio"/>				
Provide a copy of the care plan to the caregiver (3)	<input type="radio"/>				

Q8 How often do you provide caregivers with the following education materials:

	Never (1)	Rarely (2)	Sometimes (3)	Most of the Time (4)	Always (5)
Disease specific (1)	<input type="radio"/>				
Community resources (2)	<input type="radio"/>				
Education programs (3)	<input type="radio"/>				
Coping skills (4)	<input type="radio"/>				
End of life decision making (5)	<input type="radio"/>				
Legal resources (6)	<input type="radio"/>				
Financial resources (7)	<input type="radio"/>				
Caregiving resources (8)	<input type="radio"/>				

Q9 How often do you:

	Never (1)	Rarely (2)	Sometimes (3)	Most of the Time (4)	Always (5)
Obtain caregiver input when making a referral (1)	<input type="radio"/>				
Notify the caregiver when a new referral is made (2)	<input type="radio"/>				
Notify the caregiver when your client is having difficulty with a provider (3)	<input type="radio"/>				

Q10 How often do you invite caregivers to assist with problem solving related to:

	Never (1)	Rarely (2)	Sometimes (3)	Most of the Time (4)	Always (5)
Transportation (1)	<input type="radio"/>				
Equipment (2)	<input type="radio"/>				
Housing (3)	<input type="radio"/>				
Employment (4)	<input type="radio"/>				
Finances (5)	<input type="radio"/>				
Home care services (6)	<input type="radio"/>				
Medical needs (7)	<input type="radio"/>				
Family conflict (8)	<input type="radio"/>				

Q11 Is there anything else you would like to add about how you involve families in the case management process?

Thank you for taking the time to complete this survey. Your participation is greatly appreciated!

Sincerely,

Kelsey Myers

End of Survey