

**A psychoeducational intervention for early-stage caregivers of older Iowans: A pilot study**

by

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## ABSTRACT

Current literature on older adult care focuses on the burden of caregiving, predictors of institutionalization, caregiver impact on mental health, and usage of home and community-based care. However, gaps in literature exist regarding informal older adult caregivers' knowledge of home and community-based services and awareness of service availability in their community. The primary objective of this study was to test the efficacy of a one-session psychoeducational intervention for informal caregivers' of older Iowans aimed at increasing knowledge and awareness of long-term services and supports (LTSS) availability as well as caregiver feelings of preparedness. To conduct this study, a one-session psychoeducational workshop for caregivers was held in twelve communities across Iowa. Community organizations and faith-based groups were recruited to host each workshop, and the host organizations then recruited participants. The intervention workshop covered common caregiving concerns, locating resources locally, and designing a care plan. Results indicate that the intervention was effective in significantly improving caregivers' LTSS knowledge and awareness of availability. The intervention did have a positive effect for many caregivers in improving feelings of preparedness; however, the session was also associated with decreased self-efficacy for some caregivers. Age and education were related to caregiver outcomes and analyses suggest a more complex picture, particularly regarding self-efficacy. Further research specifically targeting underserved populations, as well as those in the early or pre-planning stages of caregiving, is needed to more fully understand prevention and intervention efforts aimed at enhancing care and improving caregivers' experiences.

## INTRODUCTION

In 2011 the economic value of institutional care in the United States, rather than home and community-based or informal long-term care, was estimated to be \$134 billion (Hagen, 2013). During the same year Medicaid and Medicare were the primary payer source for 77% of long-term care residents (The Henry J. Kaiser Family Foundation, 2011a). In the state of Iowa, the 2011 cost of long-term care spending by Medicaid was \$1.45 billion (The Henry J. Kaiser Family Foundation, 2011b), and Medicaid and Medicare were the primary payer source for 55% of nursing home residents (The Henry J. Kaiser Family Foundation, 2011a). These costs are expected to grow as Iowa's population of adults aged 65 and older is projected to increase from 452,888 in 2010 to 663,186 in 2030 and account for over 22% of Iowa's total population (Iowa Department on Aging, 2012).

Nationwide, Iowa has the second largest percentage of total population in nursing facilities, with more than 25,000 individuals in nursing facilities in 2011 (The Henry J. Kaiser Family Foundation, 2013). Unfortunately in Iowa many older adults are entering nursing facilities with low-care needs. Low-care need is defined as a resident who "does not require physical assistance in any of the four late-loss ADLs [activities of daily living] (bed mobility, transferring, using the toilet, and eating)" and who does not have any other specialty or complex classifications, such as Alzheimer's disease (Reinhard, Kassner, Houser, & Mollica, 2011b, p. 97). Nationally, Iowa has one of the highest percentages (17%) of nursing home residents with low-care needs, placing the state in the bottom 20% (Reinhard, Kassner, Houser, & Mollica, 2011a). This rank is distressing, as most older adults prefer home and community-based care over nursing facilities (Alexih & Blakeway, 2012).



Home and community-based care options allow older adults to age in place as most prefer, often at a lower cost than nursing care. For the purposes of this study, home and community-based services are defined as formal and informal services provided to older adults in their home or community rather than in institutional facilities. “On average, the Medicaid dollars that are required to support one adult in a nursing home are almost enough to support three adults with physical disabilities through home and community-based services” (Reinhard, Kassner, & Houser, 2011). In the state of Iowa, the 2013 median cost of nursing care was \$64,058 per year, while the median cost of homemaker services was \$46,767 per year (Genworth Financial, Inc., 2013).

One of the reasons older adults enter nursing facilities, rather than stay in the community as they would prefer, is many older adults and their caregivers do not understand the variety of home and community-based care options available to them (Alexih & Blakeway, 2012). In Iowa, this is due in part to the disjointed nature of the long-term services and supports (LTSS) system, which can be challenging to navigate (Iowa Association of Area Agencies on Aging, 2012). The state of Iowa’s Department of Elder Affairs (now the Department on Aging) also shares this viewpoint, stating, “Due to the fragmentation in public programs and information deficit, many Iowans currently lack access to quality information on community-based long-term care services. This long-standing condition is a significant factor in over-utilization of institutional care” (Iowa Department of Elder Affairs, 2008, p. 13).

The high cost of nursing care, coupled with the dramatic increase of the older adult population, make finding ways to address Iowa’s over-utilization of nursing care a pressing concern. In order to address the lack of understanding, I conducted a community-based one session workshop for early-stage informal caregivers in Iowa. The intervention was designed to

increase knowledge of the LTSS available in participants' communities while simultaneously providing caregivers with practical tips and tools for approaching the caregiving process and locating resources. The study hypotheses were threefold, such that the community-based intervention would increase caregivers' knowledge of local LTSS services and awareness of the availability of local providers, and would increase their short-term self-efficacy regarding their feelings of caregiving preparedness. A further hypothesis was that caregiver characteristics, care recipient characteristics, and location (rurality) would serve as predictors of caregivers' preparedness.

## LITERATURE REVIEW

### Knowledge and Caregiver Interventions

Long-term services and supports (LTSS) include “a broad spectrum of options for people who – because of ongoing disabilities and chronic conditions – require long-term assistance, delivered in settings that range from private residences to assisted living facilities and nursing homes” (Reinhard, Kassner, & Houser, 2011, p. 448). The use of educational programs as a means of increasing LTSS service use among caregivers has been documented as effective (Bass, McCarthy, Eckert, & Bichler, 1994). Psychoeducational interventions, which increase knowledge and teach specific skills, have been shown to be effective with caregivers (Coon & Evans, 2009). More specifically, programs designed to increase knowledge of local LTSS, including locating and utilizing services, facilitate use of LTSS (Bass, McCarthy, Eckert, & Bichler, 1994).

Although often referred to as informal or family caregivers, for the purpose of this study the term “caregiver” did not necessitate familial relation to the care recipient. An informal caregiver can be defined as an unpaid person who assists an individual with taking care of him/herself (National Alliance for Caregiving and the American Association of Retired Persons, 1997). A caregiver may also be the individual identified by the older adult as helping with their care, whether that individual is related to or a friend or neighbor of the older adult (Sebern, 2005). The profile of the average caregiver in the U.S. is “a 49-year-old woman who works outside the home and spends nearly 20 hours per week providing unpaid care to her mother for nearly five years” (Feinberg, Reinhard, Houser, & Choula, 2011, p. 1).

The current study’s intervention targeted caregivers, rather than the older adults themselves. According to Gaugler, family care is “key to the long-term care system” (2002, p.

205). Although caregivers were once seen as merely a resource for the older adult, they are now considered partners in care (Feinberg, Reinhard, Houser, & Choula, 2011). Informal caregivers often take on both the role of service provider and of decision maker (Feinberg & Whitlach, 2002). Moreover, caregivers “are actively involved in daily decisions, they play a key role in seeking help, they seek out new alliances, and they serve as intermediaries between the cared-for relative and his or her life environment” (Carpentier & Ducharme, 2007, p. 104). For this study, early-stage caregivers were originally defined as those caregivers in the first 12 months of providing care; however, not all intervention participants met this definition.

The study intervention also intended to focus on caregivers who were not married to or partners of the care recipient, as family caregivers are more likely to access information and referral services than spouses (Bass, McCarthy, Eckert, & Bichler, 1994); though again, not all participants were in this target group. Additionally, interventions are believed to benefit adult children caregivers more than spousal caregivers (Sorensen, Pinquart, & Duberstein, 2002). There are a number of reasons why spousal caregivers tend to derive less benefit from interventions. On one hand, spouses frequently have more experience caregiving, perhaps for their own parents, than adult children; and their increased coping and information gathering skills lead to a smaller intervention benefit (Sorensen, Pinquart, & Duberstein, 2002). Whereas on the other hand, spousal caregivers’ advanced age may increase their risk for their own health issues and increase their potential for decline in their social support network; which can reduce the potential benefit gained from interventions (Sorensen, Pinquart, & Duberstein, 2002).

A significant amount of research has been conducted which focuses on the experiences of older adults’ caregivers. In 1980, Zarit’s study on caregiver burden demonstrated that a critical step in effective community-based care for older adults with dementia was the provision of

support to the caregivers (Zarit, Reever, & Bach-Peterson, 1980). Similarly, Bass and Noelker (1987) found an individual's primary caregiver influences the use of home-based care, and that the caregiver's level of stress impacted the utilization of formal services. In 1999, Arno, Levine, and Memmott noted that caregiver support was greatly needed, as caregivers were poorly trained, seldom offered referrals to community-based services, and left to negotiate the complicated and fragmented LTSS system on their own (1999). A 2005 study by Gaugler determined that the use of in-home services by early-stage caregivers predicted a delay in the use of institutional care (Gaugler, Kane, Kane, & Newcomer, 2005). Furthermore, in 2011 Feinberg found that although family support was a key component of aging in place, the fragmented LTSS system had a significant impact on informal caregivers (Feinberg, Reinhard, Houser, & Choula, 2011). The LTSS system is described as fragmented because it is comprised of a multitude of agencies and providers, each with their own complex policies and requirements, providing distinct services to individuals who are frequently unfamiliar with or even unaware of their options.

### Self-efficacy and Caregiving

Although knowledge is a necessary component of success in any domain, including caregiving, knowledge alone is insufficient for proficient performance (Bandura, 1982). Bandura defines self-efficacy as "people's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives" (1994, p. 71). If individuals believe an activity exceeds their capability, they may put forth less effort, devote less time, or avoid the activity altogether (Bandura, 1982); whereas a belief in one's ability to accomplish the activity enhances both accomplishment of the task and personal well-being (Bandura, 1994).

In light of the research highlighting the importance of self-efficacy, a number of interventions have been developed for caregivers with this component in mind. For example, the Powerful Tools for Caregivers program was developed as an educational program for informal family caregivers and based on the model of self-efficacy (Boise, Congleton, & Shannon, 2005). The six-week Powerful Tools program is conducted throughout Iowa by Iowa State University's Human Sciences Extension and Outreach and focuses on self-care. A long-term action plan and tools such as family meetings, shared decision-making, and optimism are emphasized.

#### Other Factors Impacting Development of Caregiver Interventions

In a 2002 caregiver intervention meta-analysis, which included 38 studies using psychoeducational interventions, this type of intervention produced consistent and significant effects on outcome measures (Sorensen, Pinquart, & Duberstein, 2002). Sorensen and colleagues noted that several factors impacted the differentiation between intervention approaches including type of caregiver-care receiver relationship and care recipient needs (e.g., disease state). Sorensen's meta-analysis provides historical perspective on a variety of interventions including psychoeducational and self-efficacy interventions, and current interventions have built upon this knowledge.

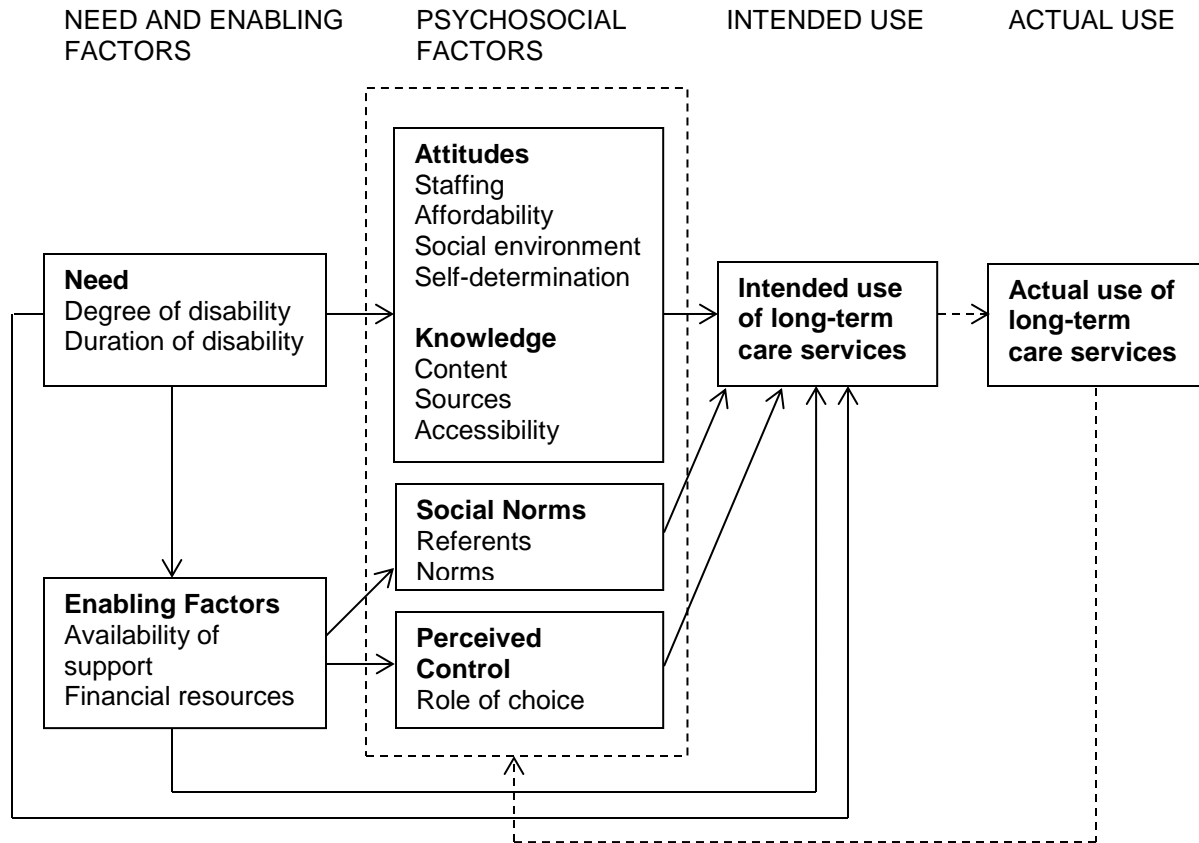
Many current interventions focus solely on individuals with Alzheimer's disease or other dementias and their caregivers. For example, the SHARE program (Supporting Health, Activities, Resources, and Education: The SHARE Program for Early-Stage Families), is designed to help participants learn about the symptoms of memory loss and plan for future care needs (Alzheimer's Association, 2013). The EPIC program, (Early-stage Partners In Care: The EPIC Project), helps prepare early-stage caregivers and care recipients for their Alzheimer's journey through education and communication (Coon, 2013). In the REACH program,

(Resources for Enhancing Alzheimer's Caregiver Health), caregivers learn stress management through class participation and home practice (Coon, 2013). And finally, the Learning to Become a Family Caregiver program was designed to transition individuals whose relative has been diagnosed with Alzheimer's disease in the last nine months to their new caregiver role (Ducharme, et al., 2011).

### Theoretical Perspectives

Older adults and their caregivers often lack awareness of long-term services and supports that would allow the care recipient to age in place. In 1967, Andersen and Anderson developed a health services use model based on the family as a unit, and this behavior model suggested that health usage was determined by predisposition, enabling and impeding factors, and care need (Andersen, 1995). Predisposition being ones likelihood to use a service without any outside factors, enabling and impeding factors the outside influences which increase or decrease likelihood, and care need being need for the service in the first place. The model has gone through a number of iterations, and the current psychosocial adaptation of Andersen's model of usage (Figure 1) demonstrates that knowledge plays a direct role in both the intended and actual use of LTSS (Bradley et al., 2002).

The content, sources, and accessibility of knowledge are important determining factors in both the actual and intended use of LTSS. Awareness of a LTSS service is a predictor of usage, and lack of awareness of LTSS options also predicts non-usage (Tang & Pickard, 2008). This reinforces the importance of knowledge, as in-home care usage by early-stage caregivers has been shown to delay institutionalization (Gaugler, Kane, Kane, & Newcomer, 2005); and family caregivers who attend educational programs are more likely to use support services after attending the program (Bass, McCarthy, Eckert, & Bichler, 1994).



*Figure 1.* Figure showing the role of psychosocial, need, and enabling factors in long-term care use. From “Expanding the Andersen model: The role of psychosocial factors in long-term care use,” by E. H. Bradley, S. A. McGraw, L. Curry, A. Buckser, K. L. King, S. V. Kasl, & R. Andersen, 2002, *Health Services Research*, 37(5), 1229.

There are many different reasons older adults and their caregivers lack knowledge about their LTSS options. Caregivers often indicate it did not occur to them to seek out LTSS in order to meet the care recipient’s needs (Casado, van Vulpen, & Davis, 2011). “This lack of awareness could have also been an underlying cause of two other often reported reasons – ‘no special reason or never thought of it’ and ‘service not available’” (Casado, van Vulpen, & Davis, 2011, p. 545). In Bradley’s 2002 study on psychosocial factors in long-term care use, caregivers responded:



“‘It’s information you don’t know, questions you don’t know to ask,’ and ‘I had a very hard time trying to find information when my dad came . . . it’s not as though they’re telling you everything, if you don’t know what to ask. Everybody says ask the right question. Well, you would if you knew it.’” (Bradley, et al., 2002, pp. 1231, 1236)

While other caregivers felt they had the facts, but didn’t know how to use them to make decisions: “I guess enough information is given, but it just goes in one ear and out the other. Here I am with guidance and a desk drawer [full of information] and I still don’t know what the hell to do.” (Bradley, et al., 2002, p. 1231).

### Study Rationale

Long-term care is expensive and most older adults would prefer to age in their own homes, yet Iowa ranks as one of the top states in the nation for nursing home residents with low-care needs. Studies have shown, and the state of Iowa concurs, that the complex and fragmented nature of the LTSS system is a major factor in the overutilization of nursing care. Families do not utilize services they cannot find or do not know how to use, thus nursing care moves from the option of last resort to the only realistic option. The study intervention attempted to address this problem by increasing caregivers’ knowledge of LTSS options in their area, and by increasing their short-term self-efficacy in their ability to design a care plan. In other words, by helping caregivers know what options are available to them, and by increasing their belief that they are capable of designing an effective care plan, we increase the likelihood caregivers will use home and community-based services rather than nursing care.

Caregiver interventions vary on several dimensions including audience (e.g., type of caregiver, duration of caregiving relationship) and target of the intervention (e.g., burden, self-care, knowledge). The study intervention differs from the previously noted interventions in a

number of ways. As shown in Table 1, most existing interventions focus specifically on families whose care recipients have Alzheimer's disease or dementia, whereas the proposed intervention was open to caregivers regardless of the care recipient's condition(s). Because participant recruitment was accomplished through community organizations and faith based groups, rather than through the Alzheimer's Association and/or medical facilities, a broad range of care recipient conditions was expected.

Another differentiation of this study is the criteria of early-stage. Of the existing interventions noted in Table 1, three are specifically geared for early-stage caregivers; however, they are restricted to Alzheimer's caregivers. Early-stage caregivers attempting to manage the dependencies of an individual with memory impairment or functional impairment requiring assistance with activities of daily living may find it difficult to establish successful care plans or care routines (Gaugler, Kane, Kane, Clay, & Newcomer, 2005). Additionally, the literature suggests that many families wait until the later stages of caregiving to utilize community-based services, which limits the potential benefits of the programming to the caregiver and to the care recipient (Gaugler, Kane, Kane, & Newcomer, 2005). Because educational programs increase service use (Bass, McCarthy, Eckert, & Bichler, 1994), by targeting early-stage caregivers we hoped to increase service use earlier in the caregiving process thus extending the service benefits for a longer duration.

Additionally, the existing interventions focus on self-care and burden alleviation for the caregiver, while the study intervention focused on LTSS knowledge and care plan design; thus filling the gaps left by the other studies. Although there are also small local programs and seminars which are designed to increase caregiver knowledge, these are generally put on by local or regional LTSS providers, and vary greatly in scope, quality, and consistency.

Table 1

*Existing Caregiver Interventions*

Intervention	Care recipient condition	Target Audience			Intervention Objective	
		Early-Stage	Burden/ Self-Care	Increase LTSS Knowledge		
Powerful Tools for Caregivers <sup>1</sup>	All Caregivers		X			
SHARE <sup>2</sup>	Alzheimer's/Dementia Caregivers	X	X	X		
EPIC <sup>3</sup>	Alzheimer's/Dementia Caregivers	X	X			
REACH <sup>2</sup>	Alzheimer's/Dementia Caregivers		X			
Learning to Become a Family Caregiver <sup>4</sup>	Alzheimer's/Dementia Caregivers	X	X	X		

*Note.* LTSS = Long-term services and supports. <sup>1</sup>The Power Tools for Caregivers intervention is from Boise et al. (2005); <sup>2</sup>The Supporting Health, Activities, Resources, and Education: The SHARE Program for Early-Stage Families and the Resources for Enhancing Alzheimer's Caregiver Health interventions are from Coon (2013); <sup>3</sup>The Early-Stage Partners In Care: The Epic project intervention is from the Alzheimer's Association (2013); <sup>4</sup>and the Learning to Become a Family Caregiver intervention is from Ducharme et al. (2011).

A strength of this study was its use of community organizations and faith-based groups. Churches, which exist in most communities, are often stable institutions at the center of the community with long-term active members (Campbell, et al., 2007; Peterson, Atwood & Yates, 2002). Churches often have access to individuals who may typically be underserved; and individuals who are part of neglected and underserved populations frequently have limited access to more traditional health program venues (Peterson, Atwood, & Yates, 2002). In addition, churches are quite effective in leading community level health programs, which attract community members in addition to church members (Peterson, Atwood, & Yates, 2002).

Another strength of this study was the psychoeducational class design. As seen in Table 2, the intervention curriculum was designed to increase knowledge of local LTSS providers, identify care needs, evaluate LTSS alternatives, and design a care plan. As part of the class, participants discussed different types of LTSS, some of which they may have been unfamiliar with; were provided with a list of local LTSS providers; and worked through hypothetical case

scenarios to identify care needs and propose potential care plans. The class design was intended to increase LTSS knowledge and short-term self-efficacy regarding care plan implementation.

### Research Questions and Hypotheses

The first specific aim of this study was to determine caregiver knowledge of local long-term services and supports on a pre/post intervention basis. I hypothesized that by participating in the proposed intervention program caregivers would increase their knowledge of local LTSS. The second specific aim was to determine if the proposed short-term intervention could improve caregiver self-efficacy in regards to locating and utilizing local long-term services and supports. I hypothesized that by identifying the care recipients care needs, evaluating types of local LTSS options, and designing a care plan; participants would increase their short-term self-efficacy regarding their ability to locate and utilize relevant LTSS. The third specific aim was to determine if specific caregiver or community characteristics were predictive of preparedness (e.g., caregiver age, sex, education, financial security, and caregiving duration; care recipient age, sex, general health condition, and rurality continuum).

Table 2

*Logic Model Showing the Impact of the Intervention Workshop*

Inputs	Intervention Components	Outputs	Outcomes	Long-term Impacts
Community organization provided list of local LTSS providers	Increase knowledge of local LTSS providers	Individual care plan	Increased knowledge of local LTSS providers	Decreased nursing home expenditures
Community organization provides classroom space	Identify care needs	List of LTSS providers for care plan	Increased caregiver short-term self-efficacy	Increased quality of life
Intervention participants recruited by community organization	Evaluate LTSS alternatives	List of LTSS service gaps in community	Increased utilization of LTSS	
Participant Time	Design a care plan		Delayed nursing home admission	

Note: LTSS = Long-Term Services and Supports

## METHODOLOGY

### Study Design

The study conducted in conjunction with the proposed intervention was an impact assessment, conducted as a nonrandomized quasi-experiment. As this was a pilot study, time and funding constraints prevented the use of a true randomized field experiment. The units of analysis in this assessment were at the individual level, and the program effect was noted using a pre-test/post-test design. The study used the Preparedness for Caregiving Scale (Zwicker, 2010) to assess caregiver self-efficacy, and a questionnaire using yes/no variables to assess caregiver LTSS knowledge. A series of demographic questions, including: age, sex, relation type, socioeconomic status, and existence of a care plan, were also included to permit understanding of the care relationship.

### Psychoeducational Intervention

The intervention addressed three main areas: common concerns, locating community resources, and care plan design. The intervention was interactive, with opportunities for participants to ask questions, make suggestions, and interact with one another. The intervention was two hours and 15 minutes in duration, with 15 additional minutes allotted at the beginning and at the end of each intervention for survey completion. Prior to the pilot program implementation, the intervention program workshop materials were peer-reviewed by Iowa State University's Human Sciences Extension and Outreach. Human Sciences Extension and Outreach offers research-based educational programming to assist families in making informed and transformative decisions that improve their lives. Feedback from the peer-review process was incorporated into the workshop and it was deemed fit to proceed. As seen in Appendix A,

the study and intervention were reviewed was declared exempt by the Iowa State University's human subjects Institutional Review Board.

The intervention began with a group question and answer session regarding common caregiver concerns. Information, resources, and strategies were discussed for the listed concerns; and topics such as legal and financial matters, driving, falling, depression/anxiety, and dementia were covered. Participants had the opportunity to ask specific questions about each of the concerns or share strategies they may have used or heard of. Next, the participants discussed community resources, and a LTSS resource packet was distributed. Information gathered by the sponsoring community organization, if any, was also distributed at this time. The list of 26 service types was reviewed, and each type was discussed individually. Participants had the opportunity to ask questions about each service type or discuss the availability in the area. Participants were informed that the listing of service providers they received was neither comprehensive, nor an endorsement of any of the providers included.

For the purposes of this intervention, a care plan was defined as a written document which outlines the care recipient's goals, the personal or healthcare services the care recipient needs, how often the services are needed, who will provide the services, any equipment or supplies needed for the services, and how the services will help the care recipient reach their goals. As a group, the participants discussed a care plan using a sample scenario. Then participants broke into small groups for additional practice. Each small group was given unique sample scenarios and asked to design a care plan for each scenario. Each group then shared their plan and their decision-making rationale with the larger group. When the number of participants allowed it, multiple groups were given the same scenario so that the different strategies to the

same issue could be compared and discussed. Each group designed a care plan for at least two different scenarios.

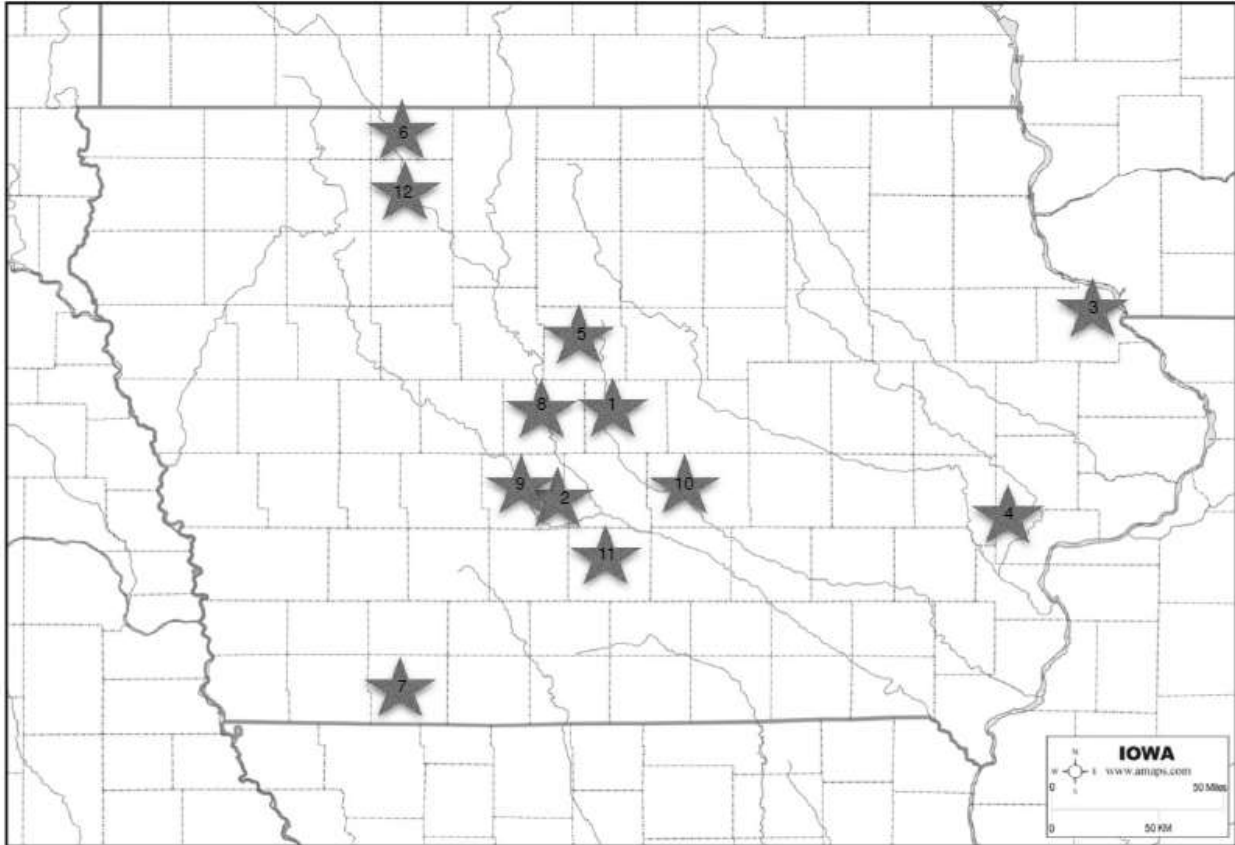
After the care plan practice, the final discussion was on caregiver burden. This discussion included information on the impact of caregiver burden, setting expectations, and finding/creating support within the community. After the intervention, participants were given the opportunity to ask additional questions and discuss individual concerns in a non-group setting.

As seen in Figure 2, the intervention class was designed to address the concerns facing caregivers due to the fragmented and complex nature of our LTSS system through a community-based approach. Community organizations provided the classroom space, and some also provided a LTSS service list. The participants, which were recruited by the organizations, used these inputs as part of the intervention. The intervention addressed the individual issue of lack of knowledge, which is a factor in intended and actual LTSS use. The intervention also addressed self-efficacy through skill practice and care plan design, which allowed participants the opportunity to implement their new knowledge. According to Bandura, task mastery is the most effective approach to building a strong feeling of efficacy (Bandura, 1994). By addressing these issues, the intervention program was intended to produce the short and long-term effects of increasing LTSS use, delaying nursing home admission, and improving quality of life while decreasing overall costs.

### Procedure

Community organizations and faith-based groups throughout Iowa were recruited to serve as host organizations for the workshops. In cooperation with Iowa State University's Human Sciences Extension and Outreach, organizations were engaged that have an active





*Figure 2.* Map of intervention locations across the state of Iowa.

interest in the caregiver population. The recruited organizations have members or serve individuals who are caregivers. Regional faith-based organizations were also contacted and encouraged to suggest or recruit member congregations that might wish to participate.

In the host role, organizations were asked to provide a list of LTSS providers in their area which corresponded to the 26 service categories included in the participant survey. The list was collected from the organizations that chose to prepare one, and the information was provided to participants as part of the intervention program. Area providers were also identified for each of the participating communities for all 26 service categories, and those lists were distributed to the participants and reviewed as part of the intervention. Host organizations each received electronic and printed marketing materials, and the organizations used those materials to market the

workshop and recruit participants. The host organizations and workshop leader worked together to schedule the workshops, and the organization provided an appropriate space to conduct the workshop.

On the date of each workshop, the workshop facilitator arrived early at the host organization's provided facility and set up necessary materials and equipment including a laptop, projector, and various government produced brochures on caregiving related topics. Upon arrival, participants signed an informed consent (Appendix B) and completed the pre-test survey. The pre-test surveys were collected from all participants prior to beginning the intervention portion of the intervention. The workshop leader conducted the intervention which covered practical tips, common caregiver concerns, information on local long-term care services and supports (including the materials provided by the community organization), and care plan design. Upon completion of the intervention, participants were given the post-test survey to complete.

### Participants

For the purposes of the study analysis, participants meeting the following study inclusion criteria were targeted for analysis: is currently providing care to an Iowa resident over the age of 60, has one year or less of caregiving experience, is not the spouse or life partner of the care recipient, is over 18 years of age, and does not receive pay for providing care. However, due to sample size workshop participants not meeting the inclusion criteria were analyzed as well. Participant demographics including caregiver and care recipient age can be seen in Table 3, and the characteristics of the caregiver relationship, including caregiving relationship and months of caregiving can be seen in Table 4.

To recruit the community organizations, local community and faith-based organizations throughout Iowa who have an existing ongoing interest in the caregiving population were contacted to identify groups who would be interested in hosting a workshop. Seventeen organizations were selected to serve as hosts. In order to be selected as a host, the organization had to be willing to actively market the workshop, able to recruit eligible participants, and able to provide an appropriate space for conducting the workshop. Selected organizations were asked to recruit 10-15 eligible participants for their intervention utilizing the marketing materials provided.

Individual participants for this intervention were recruited by the community organizations. Target participants for the workshop were informal non-spouse caregivers in their first year of caregiving, although other caregivers who wished to attend were not turned away. For the purpose of this study, the term “informal caregiver” refers to a friend or family member who provides unpaid care to an older adult. Interventions were comprised of 3-14 participants at 12 locations, for a total of 98 participants. The average intervention class size was six participants.

Because participants were recruited by organizations and faith-based groups in their community, a broad range of care recipient conditions was expected. Of 75 participants responding, 72 indicated that the individual they were caring for had at least one illness or condition. As seen in Table 5, care recipients represented all eight of the listed conditions or illnesses. Of the seven listed conditions, Alzheimer’s/Dementia had the highest number of care recipients listed at 30 or 30.6% of respondents, followed by Diabetes at 16.3% and Congestive Heart Failure at 11.2%. Additionally, 26 different conditions or illnesses were included in the “other” category including: Aging (5), Arthritis (3), Forgetful/Memory Loss (3), and

Table 3

*Participant Demographics*

	Caregiver			Care Recipient		
	<i>M</i>	<i>SD</i>	Range	<i>M</i>	<i>SD</i>	Range
Age (Years)	61.62	11.29	22-84	81.64	8.09	62-98
	%	N		%	N	
Sex						
Female	77.6	76		48.0	47	
Male	22.4	22		32.6	32	
Unknown				19.4	19	
Education						
Some High School	2.0	2		11.2	11	
High School Graduate	20.4	20		32.7	32	
Technical/Trade/Vocational Training	25.5	25		15.3	15	
Four Year Degree	29.6	29		15.3	15	
Graduate Degree	22.4	22		6.1	6	
Unknown				19.4	19	
Ethnicity						
White or Caucasian	98.0	96		81.6	80	
Multi-Ethnic	1.0	1				
Asian American	1.0	1		1.0	1	
Unknown				17.4	17	
Marital Status						
Married	78.6	77		39.8	39	
Widowed	10.2	10		35.7	35	
Divorced	7.1	7		5.1	5	
Never Married	4.1	4		1.0	1	
Unknown				18.4	18	
Employment Status						
Full-Time	37.8	37				
Part-Time	10.2	10				
Self-Employed	6.1	6				
Homemaker	2.0	2				
Retired	35.7	35				
Disabled	4.1	4				
Not Employed	4.1	4				
Underage Child in Household						
Yes	8.2	8				
No	91.8	90				
Household Income						
Less than \$25,000	8.2	8		29.6	29	
\$25,000 - \$49,999	18.4	18		10.2	10	
\$50,000 - \$74,999	31.6	31		14.3	14	
\$75,000 - \$99,000	10.2	10		3.1	3	
\$100,000+	17.3	17		4.1	4	

Table 3 continued

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Please tell me how well you think you (and your family) are now doing financially as compared to other people your age?		
Better	35.7	35
About the Same	58.2	57
Worse	6.1	6
How well does the amount of money you have take care of your needs?		
Very Well	50.0	49
Fairly Well	42.9	42
Worse	7.1	7
Do you usually have enough to buy those little "extras"; that is those small luxuries?		
Yes	86.70	85
No	12.20	12

---

Table 4

*Characteristics of the Caring Relationship*

	<i>M</i>	<i>SD</i>	Range
Length of Caregiving	22.00	26.48	0-96
Hours per Week Caregiving	25.78	53.78	0-168
Length of Time in Community	30.92	20.24	1-71
Other Caregivers Known	5.06	8.31	0-58
Service Type Knowledge (#)			
Pre-Test	16.83	6.25	0-26
Post-Test	25.51	1.57	17-26
Service Type Awareness of Availability(#)			
Pre-Test	12.47	6.11	0-26
Post-Test	23.89	5.14	0-26
Preparedness			
Pre-Test	23.17	6.18	10-37
Post-Test	27.63	4.75	15-40
	%	<i>N</i>	
Type of Relationship			
Child or In-law	58.14	50	
Grandchild	1.16	1	
Niece/Nephew	1.16	1	
Sibling	3.49	3	
Spouse or Partner	16.28	14	
Other	19.77	17	
Live Together			
Yes	26.50	26	
No	57.10	56	
Live in the Same Zip Code			
Yes	52.00	51	
No	29.00	28	
Feel Supported			
Very Supported	21.40	21	
Somewhat Supported	27.60	27	
Rarely Supported	10.20	10	
Not Supported at All	4.10	4	
Have a Care Plan			
Yes	8.20	8	
No	33.70	33	

*Note:* Values may not total to 98 due to missing data.

Table 5

*Care Recipient Condition or Illness*

Condition Type	%	<i>N</i>
Alzheimer's Disease/Dementia	30.60	30
Cancer	1.00	1
Congestive Heart Failure	11.20	11
COPD	8.20	8
Diabetes	16.30	16
Parkinson's Disease	3.10	3
Stroke	8.20	8
Other	28.60	28
	<i>M</i>	<i>SD</i> ; Range
Total Conditions	1.40	.75; 0-4

*Note:* COPD = Chronic obstructive pulmonary disease.

Weak/Feeble (2). The majority of care recipients had one or two reported illnesses or conditions (one 48%; two 18.4%), and no participant reported a care recipient with more than four conditions or illnesses.

The participants attended the intervention in 12 different communities representing various levels of rurality throughout Iowa. As seen in Table 6, levels of rurality range from two metro-counties in metro areas of 250,000 to 1 million population; to nine completely rural or less than 2,500 urban population, not adjacent to a metro area. However the starting level of two may be somewhat misleading. The second location is listed as a two on the Rural-Urban Continuum Code because the location of the intervention was just over the border between Polk and Dallas counties. Had the intervention taken place one block to the east, the starting code would have been a one, counties in metro areas of 1 million population or more. Outside of code one, the only two continuum codes not represented were code five, nonmetro – urban population of 20,000 or more, not adjacent to a metro area; and code eight, nonmetro – completely rural or less than 2,500 urban population, adjacent to a metro area. Additionally, as seen in Figure 2, the locations of the interventions were primarily in central Iowa with some locations along the outer borders of the state.

The care recipients also represented a variety of ruralities across Iowa. As seen in Table 7, care recipients resided in every continuum code except five and eight. The largest percentage of care recipients resided in continuum code six, nonmetro - urban population of 2,500 to 19,999, adjacent to a metro area. Additionally, as shown in Table 4, 52% of caregivers and care recipients live in the same zip code, with 26.5% living in the same household.



Table 6

*Intervention Locations and Rural-Urban Continuum Codes*

Location	Zip Code <sup>1</sup>	County <sup>2</sup>	City Population <sup>2,3</sup>	County Population <sup>2</sup>	Continuum Code <sup>4</sup>	Continuum Code Number <sup>4</sup>
1	50010	Story	61,792 <sup>2</sup>	92,406	Metro - Counties in metro areas of fewer than 250,000 population	3
2	50325	Dallas	16,590 <sup>2</sup>	74,641	Metro - Counties in metro areas of 250,000 to 1 million population	2
3	52040	Dubuque	4,115 <sup>3</sup>	93,653	Metro - Counties in metro areas of fewer than 250,000 population	3
4	52776	Muscatine	3,726 <sup>3</sup>	42,745	Nonmetro - Urban population of 20,000 or more, adjacent to a metro area	4
5	50130	Hamilton	1,193 <sup>3</sup>	15,673	Nonmetro - Urban population of 2,500 to 19,999, adjacent to a metro area	6
6	50514	Emmet	913 <sup>3</sup>	10,302	Nonmetro - Urban population of 2,500 to 19,999, not adjacent to a metro area	7
7	50851	Taylor	1,359 <sup>3</sup>	6,317	Nonmetro - Completely rural or less than 2,500 urban population, not adjacent to a metro area	9
8	50036	Boone	12,629 <sup>2</sup>	26,364	Nonmetro - Urban population of 2,500 to 19,999, adjacent to a metro area	6
9	50003	Dallas	4,047 <sup>3</sup>	74,641	Metro - Counties in metro areas of 250,000 to 1 million population	2
10	50208	Jasper	15,136 <sup>2</sup>	36,641	Nonmetro - Urban population of 2,500 to 19,999, adjacent to a metro area	6
11	50125	Warren	15,108 <sup>2</sup>	47,336	Metro - Counties in metro areas of 250,000 to 1 million population	2
12	50536	Palo Alto	3,811 <sup>3</sup>	9,815	Nonmetro - Urban population of 2,500 to 19,999, not adjacent to a metro area	7

Note. <sup>1</sup> United States Zip Codes. (2014). *Zip Codes Database (Data File)*. Retrieved from <http://www.unitedstateszipcodes.org>;

<sup>2</sup> United States Department of Census. (2013). *State & County Quick Facts (Data File)*. Retrieved from

<http://www.quickfacts.census.gov>; <sup>3</sup> United States Census Bureau. (2013). *Population (Data File)*. Retrieved from <http://www.census.gov/popest/data/datasets.html>;

<sup>4</sup> United States Department of Agriculture: Economic Research. (2013). *2013 Rural-Urban Continuum Codes (Data File)*. Retrieved from <http://www.ers.usda.gov>

## Measures

No validated scale was located to measure knowledge of and awareness of availability of long-term services and supports; however, the measure which was used to test this hypothesis was adapted from the Community Resource Scale. The Community Resource Scale was developed to assess participant knowledge of community resource existence, access to the resources, and usage of the resources (Toseland, Rossiter, Peak, & Smith, 1990). The Cronbach alpha for the access scale, in which caregivers indicated yes or no when asked if they “knew how to access” the 13 resources listed, was .88 (Toseland, Rossiter, Peak, & Smith, 1990, p. 212). Other scales were also considered for adaptation to measure this hypothesis, including resource generators and support network name generators, but the measures were rejected due not only to the complexities of quantifying change in the generated named resources, but also to the difficulties of applying validity from a social network measure to a service resource scale.

The Knowledge of Long-Term Services and Supports Scale (Toseland, Rossiter, Peak, & Smith, 1990; Appendix D) was used to assess caregiver knowledge of LTSS. The 26-item scale gauged participants’ knowledge of various LTSS service types via two variables, “Do you know what this service is?” and “Do you know if this service is available in your area?”.

Table 7

<i>Care Recipient Zip Code Rurality Continuum</i>		
<i>Continuum Code</i> <sup>1</sup>	<i>N</i>	<i>%</i>
1	2	2.04
2	17	17.35
3	8	8.16
4	9	9.18
6	28	28.57
7	12	12.24
9	2	2.04

*Note.* <sup>1</sup> United States Department of Agriculture: Economic Research. (2013). *2013 Rural-Urban Continuum Codes (Data File)*. Retrieved from <http://www.ers.usda.gov> .

Examples of the 26 service type items include: adult day center, bill payer, and respite care.

Responses to the first variable were provided on a yes/no scale, where yes had a value of one and no had a null value. Thus, the range of scores for each participant's summed total score could fall between zero and 26, with zero indicating no knowledge of any listed LTSS and 26 indicating knowledge of all the LTSS listed.

Responses to the second variable were yes, which has a value of one; no, which had a value of two; or I don't know, which had a value of three. Responses to the second variable were recoded so that yes had a value of one, no had a value of one, and I don't know had a null value. The variables were recoded to align with the original Community Resource Scale from which this variable was adapted. Recoding the scale allowed the variable to be summed so that yes or no would both indicate awareness of the existence or non-existence of a resource in the community, while I don't know indicated a lack of awareness. Thus, the range of scores for each participant's summed total score could fall between zero and 26, with zero indicating no awareness regarding LTSS availability and 26 indicating awareness of availability of all of the LTSS listed.

The Preparedness for Caregiving Scale (Zwicker, 2010), was utilized to assess self-efficacy. This nine-item scale gauged caregivers' feelings of preparedness. Example measures from the scale, which can be found in Appendix C, include: "How well prepared do you think you are to take care of your family member's physical needs?", "How well prepared do you think you are for the stress of caregiving?", and "Overall, how well prepared do you think you are to care for your family member?" (Zwicker, 2010).

Responses were given on a five point scale, and were summed to reflect perceptions of preparedness. The values range from one, indicating does not feel prepared, to five, indicating

feels very prepared. The range of scores for each participant could fall between eight and 40, and the higher the score, the higher the caregiver's feelings of preparedness. The Preparedness for Caregiving Scale has a moderate to high reported internal consistency (Zwicker, 2010), with Cronbach alphas ranging from 0.88 to 0.93 (Schumacher, et al., 2008). Additionally, construct validity is evidenced by the negative correlation between caregiver worry and preparedness (Archbold, Stewart, Greenlick, & Harvath, 1990).

The following demographic covariates were tested to determine prediction of preparedness: caregiver age, sex, education, financial security, and caregiving duration; care recipient age, sex, general health status, and rurality continuum. These covariates, as found in Appendix E, were selected for their potential as predictive measures. Age was selected based on the anticipation that older caregivers, who may be less comfortable with technology, were less likely to be knowledgeable about local LTSS providers; and would therefore have lower feelings of preparedness prior to the intervention than younger caregivers. Education and financial security were selected with the expectation that less educated caregivers with fewer financial resources would be less knowledgeable about local LTSS providers, thus having lower feelings of preparedness than their more educated and financially secure counterparts. Caregiving duration was selected because it was anticipated that the longer a caregiver has been providing care, the higher their feelings of preparedness would be prior to the intervention. Care recipient age and general health status were selected with the expectation that older frailer adults would be in need of more services, thus creating lower feelings of preparedness in their care giver. Finally, rurality was selected because it is anticipated that the more rural, and therefore potentially isolated, caregivers would have lower feelings of preparedness prior to the intervention than caregivers who live in larger communities.

## RESULTS

Prior to analyses, the data were cleaned, checked for missingness and outliers, and summed scores created for the Knowledge of Long-Term Services and Supports Scale and the Preparedness for Caregiving Scale (Zwicker, 2010). Descriptives were ascertained and then analyses were conducted to address the three research questions using IBM SPSS Statistics Version 22, with significance set at  $p \leq .05$ .

### Missing Data

Unfortunately, there was a fair amount of data missing from the survey responses. First, regarding the question, “How long have you been a caregiver for this individual?” thirty-six respondents left the answer blank. Based on conversations with participants as the forms were completed, it is believed that a large number of the participants who reported zero months were either very-early stage caregivers who did not consider the current level of assistance they provided as classifying themselves in the caregiver category; or, alternatively they were preparing to care for a specific individual but were not yet providing any care. Another 17 participants indicated that they had been a caregiver for zero months. Again, based on conversations with the participants during form completion, it is estimated that up to 75% of these participants were also very-early stage caregivers who did not yet consider their activities as caregiving. Between the two groups, the non-responders and then zero responders, it is estimated that less than ten were individuals who either were not caregivers at all, (e.g. – they were pastors or other professionals who supported caregivers), or they had already completed their caregiving role. For example, one individual indicated that although her mother had passed away, she was attending the workshop to see how she had done as a caregiver. As a result of not

being a caregiver, or not yet identifying as a caregiver, these participants did not respond to questions related to care recipients.

Additionally, there were a number of participants who did not complete sections of the pre-tests or post-tests. As more sections were missing in the pre-tests than in the post-tests, a large portion of the missing data is attributable to participant fatigue. It appears that some participants either ran out of time or desire to complete the pre-test prior to the intervention. These were generally not the same individuals who did not complete the post-test in its entirety.

After looking at the nature of the missing data (i.e. - missing whole measures not just a few things), and examining its effects on an already small sample size, the missing data caused a substantial reduction in size for some measures. After consultation with a statistician, it was decided it was imprudent to employ any statistical methods to replace or estimate missing data. As a result, some analyses which were originally proposed to include care recipient characteristics were not included as originally intended.

### Descriptives

LTSS Knowledge. The Knowledge of Long-Term Services and Supports Scale was summed in two categories, caregiver knowledge of the service type and caregiver awareness of the service in their area. As seen in Table 8, the mean value of caregiver knowledge on the pre-test was 16.83, with a minimum value of zero, a maximum value of 26, and a standard deviation of 6.25. On the post-test, the mean value of caregiver knowledge was 25.51, with a minimum value of 17, a maximum value of 26, and a standard deviation of 1.57. On the pre-test for Knowledge of Service Type, participants had the least amount of knowledge about Consumer Directed Attendant Care (.15), and the most knowledge about Assisted Living Facilities (.98). On the post-test, participants still had the least amount of knowledge about Consumer Directed

Table 8

*Knowledge of Service Type*

Service Type	Pre-Test Proportion	Post-Test Proportion
Adult Day Center	0.84	1.00
Assisted Living Facility	0.98	1.00
Bill Payer	0.43	0.98
Case Management - Private	0.30	0.97
Case Management - Public	0.33	0.96
Chore Services	0.58	0.99
Consumer Directed Attendant Care	0.15	0.88
Continuing Care Community	0.36	0.93
Counseling/Emotional Support	0.72	0.98
Errands and Shopping	0.71	1.00
Financial Management	0.59	0.95
Legal Assistance	0.71	0.99
Information and Referral	0.48	0.95
Home Health Aide	0.93	0.99
Home Delivered Meals	0.94	1.00
Homemaker Services	0.71	0.98
Medication Aide	0.53	0.98
Nursing Care - In Home	0.84	0.99
Nursing Care - Facility	0.97	1.00
Nursing Care - Skilled Facility	0.93	1.00
Nutrition Counseling	0.68	0.99
Personal Care Services	0.54	0.98
Personal Emergency Response Device	0.83	0.98
Remote Electronic Monitoring	0.50	0.93
Respite Care	0.75	0.99
Transportation	0.83	1.00
Total Score ( <i>SD</i> ; Range)	16.83 (6.25; 0-26)	25.51 (1.58; 17-26)

*Note:* No=0; Yes=1; Proportion represents percentage of caregivers who indicated they did have knowledge of the stated service type.

Attendant Care, but at .88 rather than .15. On the post-test participants had the greatest amount of knowledge (1.00) of the following service types: Adult Day Center, Assisted Living Facility, Errands and Shopping, Home Delivered Meals, Nursing Care – Facility, Nursing Care – Skilled Care, and Transportation. The service type with the greatest amount of change in knowledge was Consumer Directed Attendant Care. On the pre- test, the mean score was above .90 for five service types: Assisted Living Facility, Home Health Aide, Home Delivered Meals, Nursing Care – Facility, and Nursing Care – Skilled Care. These five service types increased the least between pre-test and post-test, with mean differences ranging from .02 for Assisted Living Facility to .07 for Nursing Care – Skilled Care.

Awareness of LTSS Availability. As seen in Table 9, the mean value of caregiver awareness on the pre-test was 12.47, with a minimum value of zero, a maximum value of 26, and a standard deviation of 6.11. On the post-test, the mean value of caregiver awareness was 23.89, with a minimum value of zero, a maximum value of 26, and a standard deviation of 5.14. On the pre-test for Awareness of Service Type Availability, participants had the least amount of awareness about Consumer Directed Attendant Care (.10), and the most awareness about Nursing Care – Facility (.95). On the post-test, participants still had the least amount of knowledge about Consumer Directed Attendant Care, but at .73 rather than .10. On the post-test participants had the greatest amount of knowledge (.99) of the Nursing Care – Skilled Facility. The service type with the greatest amount of change in knowledge was Case Management – Public, which went from .18 to .89. In awareness, only Assisted Living Facility and Nursing Care – Facility had a mean score above .90 in the pre-test and increased by less than a mean of .1 in the post-test.



Table 9

*Awareness of Service Type Availability*

Service Type	Pre-Test Proportion	Post-Test Proportion
Adult Day Center	0.57	0.92
Assisted Living Facility	0.94	0.98
Bill Payer	0.23	0.89
Case Management - Private	0.17	0.85
Case Management - Public	0.18	0.89
Chore Services	0.37	0.88
Consumer Directed Attendant Care	0.10	0.73
Continuing Care Community	0.28	0.86
Counseling/Emotional Support	0.45	0.92
Errands and Shopping	0.33	0.92
Financial Management	0.26	0.90
Legal Assistance	0.45	0.93
Information and Referral	0.31	0.89
Home Health Aide	0.79	0.92
Home Delivered Meals	0.78	0.94
Homemaker Services	0.52	0.89
Medication Aide	0.25	0.87
Nursing Care - In Home	0.67	0.95
Nursing Care - Facility	0.95	0.98
Nursing Care - Skilled Facility	0.88	0.99
Nutrition Counseling	0.40	0.93
Personal Care Services	0.26	0.93
Personal Emergency Response Device	0.64	0.93
Remote Electronic Monitoring	0.32	0.79
Respite Care	0.57	0.95
Transportation	0.66	0.95
Total Score ( <i>SD</i> ; Range)	12.47 (6.11; 0-26)	23.89 (5.14; 0-26)

*Note:* No=0; Yes=1; Proportion represents percentage of caregivers who indicated they did have awareness of availability of the stated service type.

Self-reported Preparedness to Caregive. Caregivers were asked a series of eight questions on a five point scale which were summed to calculate total caregiver preparedness. The highest possible score was 40, indicating total preparedness, and the lowest possible score was eight, indicating no feelings of preparedness. As seen in Table 10, on the pre-test, the mean value of caregiver preparedness was 23.17, with a minimum value of 10, a maximum value of 37, and a standard deviation of 6.18. On the post-test, the mean value of caregiver preparedness was 27.63, with a minimum value of 15, a maximum value of 40, and a standard deviation of 4.75. In the in the preparation for caregiving scale (Table 10), the third question was “How well prepared do you think you are to find out about and set up services for him or her?” This question went from a pre-test mean of 2.87 to a post-test mean of 3.66, the highest degree of change (.79) in mean from pre-test to post-test. The question with the smallest degree of change was “How well prepared do you think you are to take care of his or her emotional needs?” at .33. Question eight, “Overall, how well prepared do you think you are for the stress of caregiving?” went up by .74, only .05 less than the degree of change in question three regarding setting up services.

#### Association between primary study variables

Pearson correlation was used to assess the association between the primary study variables (see Table 11). As expected, pre-test awareness of LTSS availability and feelings of preparedness are significantly associated with knowledge of LTSS on the pre-test; and post-test caregiver preparedness was associated with feelings of preparedness on the pre-test. Results also indicate that pre-test awareness of LTSS availability is associated with pre-test caregiver perception of preparedness. Interestingly, caregiver financial insecurity and care recipient age were not associated with knowledge, awareness, or feelings of preparedness.

Table 10

*Preparation for Caregiving*

Preparation Question	Pre-Test			Post-Test		
	<i>M</i>	<i>SD</i>	Range	<i>M</i>	<i>SD</i>	Range
1. How well prepared do you think you are to take care of your family member's physical needs?	2.86	1.06	1-5	3.30	0.79	2-5
2. How well prepared do you think you are to take care of his or her emotional needs?	2.86	0.88	1-5	3.19	0.73	2-5
3. How well prepared do you think you are to find out about and set up services for him or her?	2.87	1.11	1-5	3.66	0.75	1-5
4. How well prepared do you think you are for the stress of caregiving?	2.75	1.01	1-5	3.26	0.78	2-5
5. How well prepared do you think you are to make caregiving activities pleasant for both you and your family members?	2.93	0.87	1-5	3.37	0.72	1-5
6. How well prepared do you think you are to respond to and handle emergencies that involve him or her?	3.07	1.00	1-5	3.53	0.77	2-5
7. How well prepared do you think you are to get the help and information you need from the health care system?	3.03	1.05	1-5	3.77	0.74	2-5
8. Overall, how well prepared do you think you are to care for your family member?	2.86	0.89	1-5	3.57	0.75	2-5
Sum	23.17	6.18	10-37	27.63	4.75	15-40

Table 11

*Correlation Table Indicating Association between Primary Study Variables*

Variables	1	2	3	4	5	6	7	8	9	10	11	12	13
1. CG Age (years)													
2. CG Sex (1=Male; 2=Female)	-0.08												
3. CG Education	-0.19	-0.11											
4. CG Financial Insecurity	-0.03	0.10	-0.31**										
5. CR Age (years)	0.18	-0.06	-0.05	0.04									
6. CR Sex (1=Male; 2=Female)	-0.16	-0.36**	0.12	0.07	0.04								
7. CR Health	0.02	0.09	0.04	0.00	0.11	-0.05							
8. CR Rurality	0.08	0.10	0.03	0.02	0.05	-0.07	0.16						
9. Knowledge of LTSS (Pre)	0.00	0.03	0.21	-0.02	-0.11	0.15	0.10	0.14					
10. Knowledge of LTSS (Post)	-0.13	0.03	0.16	0.13	0.13	0.00	0.24*	-0.07	0.22				
11. LTSS Availability (Pre)	0.02	0.07	-0.01	0.04	0.00	0.05	0.05	0.15	0.79**	0.27*			
12. LTSS Availability (Post)	-0.12	0.03	0.02	0.11	-0.04	-0.03	0.17	0.08	0.39**	0.47**	0.41**		
13. Preparation for Caregiving (Pre)	0.05	-0.15	-0.06	-0.07	-0.04	0.38**	0.03	0.15	0.43**	0.09	0.51**	0.24*	
14. Preparation for Caregiving (Post)	-0.21*	0.02	0.12	-0.07	-0.16	0.31**	-0.12	0.16	0.28*	0.14	0.24*	0.40**	0.65**

*Note:* LTSS = Long-term services and supports. Higher rurality scores indicate decrease in population and distance from metropolitan areas. Higher health scores indicate poorer general health.

### Investigating Pre-Post Change

The first research question addressed caregivers' knowledge of long-term services and supports. There were two dependent variables in this specific aim, number of service types caregivers had knowledge of and awareness of service type providers in their area. Repeated-measures analysis of variance (ANOVA) were utilized to examine change in the two measures on a pre-post basis and to determine group differences. Covariates included caregiver age, sex, education, and financial insecurity. All main effects and two-way interactions between time and the covariates were tested.

In the repeated-measures ANOVA for the first dependent variable LTSS knowledge, there was a main effect of time,  $F = 11.98(1, 62)$ ,  $p = .001$ , and a main effect education,  $F = 5.67(1, 62)$ ,  $p = .02$  (Table 12). Post-hoc pairwise comparisons indicated that post-test knowledge ( $M = 25.51$ ) was significantly greater than knowledge at pre-test ( $M = 17.19$ ),  $p \leq .001$ . In addition, there was a significant interaction of time and education  $F = 5.67(1, 62)$ ,  $p = .02$ . Additionally, there was a trend indicating a potential interaction of time and caregiver age,  $F = 2.81(1, 62)$ ,  $p = .099$ .

A second repeated-measures ANOVA test was conducted to investigate change in pre-post awareness of LTSS availability. As shown in Table 13, the results revealed a main effect of time [ $F = 4.08, (1, 60)$ ,  $p = .048$ ], indicating a significant increase from pre-test ( $M = 12.85$ ) to post-test ( $M=24.11$ ),  $p \leq .001$ .

The second research question addressed change in caregiver feelings of preparedness. A third repeated-measure ANOVA test was conducted to test change in caregivers' perceptions of preparedness. As shown in Table 14, these results revealed that while the intervention did not

Table 12

*Analysis of Variance – Knowledge of Service Types*

Variable	<i>df</i>	MS	<i>F</i>	$\eta^2$	<i>p</i>
Time	1	207.14	11.98	.162	$\leq .01$
Age	1	13.87	0.65	.010	.42
Sex	1	12.91	0.60	.010	.44
Education	1	130.93	6.13	.090	.02
Financial Security	1	26.49	1.24	.020	.27
Time x Age	1	48.50	2.81	.043	.10
Time x Sex	1	3.95	0.23	.004	.63
Time x Education	1	98.08	5.67	.084	.02
Time x Financial Security	1	9.65	0.56	.009	.46
Error	62	17.29			

*Note:* Sex (1= Male, 2=Female); Financial Security (1= Very well, 3=Poorly).

Table 13

*Analysis of Variance – Awareness of Service Type Availability*

Variable	<i>df</i>	MS	<i>F</i>	$\eta^2$	<i>p</i>
Time	1	77.19	4.08	.064	.05
Age	1	12.79	0.29	.005	.59
Sex	1	33.89	0.78	.013	.38
Education	1	62.30	1.43	.023	.24
Financial Security	1	35.15	0.81	.013	.37
Time x Age	1	20.39	1.08	.018	.30
Time x Sex	1	0.64	0.03	.001	.86
Time x Education	1	6.89	0.36	.006	.55
Time x Financial Security	1	0.47	0.03	.000	.88
Error	60	18.94			

*Note:* Sex (1= Male, 2=Female); Financial Security (1= Very well, 3=Poorly).

Table 14

*Analysis of Variance – Feelings of Preparedness*

Variable	<i>df</i>	MS	<i>F</i>	$\eta^2$	<i>p</i>
Time	1	5.13	0.52	.006	.47
Age	1	26.24	0.53	.006	.47
Sex	1	26.84	0.54	.007	.47
Education	1	0.01	0.00	.000	.99
Financial Security	1	10.52	0.21	.003	.65
Time x Age	1	48.94	4.97	.057	.03
Time x Sex	1	30.76	3.12	.037	.08
Time x Education	1	31.15	3.16	.037	.08
Time x Financial Security	1	1.17	0.12	.001	.73
Error	82	9.85			

*Note:* Sex (1= Male, 2=Female); Financial Security (1= Very well, 3=Poorly).

have a main effect, age and time were significantly related [ $F = 4.97 (1, 82), p = .03$ ], and to a lesser extent sex and education were also related.

### Predicting Caregiver Preparedness

Finally, a block multiple regression analysis was conducted to identify categories of predictors of change in caregiver preparedness. The first block of predictors included caregiver pre-test preparedness. The second block of predictors focused on caregiver characteristics (i.e., sex, age, education, and financial security). The third block of predictors included care recipient characteristics (i.e., age, sex, general health status, and caregiving duration). The final block included a community-level characteristic (i.e., care recipient community rurality continuum).

As shown in Table 15, the results indicated that inclusion of blocks one and two were significant. Addition of blocks three and four were not significant additions to the model. Thus, the second model was accepted. Within the second model, pre-test preparedness and caregiver age were found to be significant predictors of post-test preparedness; while sex, education, and financial security were not. Additionally, the second model offers insight into much of the variability of caregiver preparedness. Although we see that care recipient health is a significant predictor of post-preparedness, we cannot include this individual predictor as the block three as a whole was not a significant predictor of post-preparedness.

Table 15

*Results of Block Regression Examining Predictors of Caregiver Perception of Preparedness*

Model	<i>R</i>	<i>R</i> Square	Adjusted <i>R</i> Square	Std. Error of the Estimate	Change Statistics				
					<i>R</i> Square Change	<i>F</i> Change	<i>df</i> 1	<i>df</i> 2	Sig. <i>F</i> Change
1	.636 <sup>a</sup>	.404	.393	3.78605	.404	36.592	1	54	≤.001
2	.748 <sup>b</sup>	.560	.516	3.38146	.156	4.424	4	50	.004
3	.783 <sup>c</sup>	.613	.538	3.30333	.054	1.598	4	46	.191
4	.784 <sup>d</sup>	.615	.529	3.33299	.002	.185	1	45	.669

*Note:* <sup>a</sup> Predictors: (Constant), Pre-Test Preparedness; <sup>b</sup> Predictors: (Constant), Pre-Test Preparedness, Caregiver Financial Security, Caregiver Sex, Caregiver Age, Caregiver Education; <sup>c</sup> Predictors: (Constant), Pre-Test Preparedness, Caregiver Financial Security, Caregiver Sex, Caregiver Age, Caregiver Education, Care Recipient Health, Caregiving Duration, Care Recipient Age, Care Recipient Sex; <sup>d</sup> Predictors: (Constant), Pre-Test Preparedness, Caregiver Financial Security, Caregiver Sex, Caregiver Age, Caregiver Education, Care Recipient Health, Caregiving Duration, Care Recipient Age, Care Recipient Sex, Care Recipient Zip Continuum



## DISCUSSION

The complex and disjointed nature of Iowa's LTSS system makes it quite challenging for older Iowans and their caregivers to access the information which would allow them to build a comprehensive care plan utilizing home and community-based services. The primary objective of this study was to test the efficacy of a one-session psychoeducational intervention aimed at increasing knowledge, awareness of LTSS availability, and caregiver feelings of preparedness.

### Assessing Intervention Effectiveness: LTSS Knowledge

The first research question assessed self-reported knowledge and awareness of 26 different long-term services and supports types. Both the knowledge and the awareness questions had a main effect of time. Participants who attended the intervention increased their self-reported knowledge and awareness of LTSS availability in their area by attending the intervention workshop.

On the pre-test for knowledge of service type, one caregiver (1.4% of the respondents) did not have knowledge of any of the service types, and five caregivers (6.9% of the respondents) had knowledge of all 26 of the service types. Whereas, on the post-test one caregiver had knowledge of 17 service types (1.1% of the respondents), and 75 caregivers had knowledge of all 26 service types (84.3% of the respondents). This impact was not significantly impacted by age, sex, financial security or rurality. The impact was significantly impacted by education level. Those with higher levels of education were more likely to be impacted by the intervention. Because the total possible score was 26, we see that with a post-test mean of 25.51, almost all of the participants understood what all of the 26 service types were. Nonetheless, as the assessment was based only on self-report, participants understanding of the service types may not have been accurate, even if they felt they understood the types. Future research could

examine accuracy by conducting a true test of caregiver knowledge of service types.

Additionally, while a possible trend was indicated with the interaction of time and caregiver age, future research is needed to determine if the trend was in fact genuine.

#### Assessing Intervention Effectiveness: LTSS Awareness of Availability

On the pre-test for awareness of service type availability, two caregivers (2.8% of the respondents) did not have awareness of any of the service types in their area, and two caregivers (2.8% of the respondents) had awareness of all 26 of the service types. However, on the post-test, only one caregiver had awareness of zero service types (1.3% of the respondents), and 48 caregivers had awareness of all 26 service types (63.2% of the respondents). The impact of the workshop on awareness was not significantly impacted by age, sex, education, financial security or rurality. This assessment was again based only on self-report, which presents the issue of perception of awareness versus actual awareness. Future research could test the accuracy of awareness against actual availability in the community after verifying actual participant knowledge of the service types. Additionally, participants had varying understandings of what “your area” meant in the question. Future research would need to offer additional clarification around the definitions of “area” to better frame the question for participants.

#### Assessing Intervention Impact on Feelings of Preparedness

Although perceptions of preparedness went up across the board for caregivers, and each individual question increased in mean value, not every individual increased their level of preparedness. Of the 88 participants who completed this portion of the survey, 11 or 12.5% of participants actually decreased preparedness. Another five participants, or 5.7%, neither increased nor decreased their level of preparedness. The biggest drop in preparedness was 8 points, and the biggest increase was 18 points, with a standard deviation of 4.79. Overall

attending the intervention did not significantly increase participants' perceptions of preparedness. Although a one-session intervention would not necessarily cause an immediate increase in feelings, certain participants did demonstrate increased feelings of preparedness, while others demonstrated decreased feelings of preparedness. Those that decreased in feelings of preparedness, which could potentially have been caused by feeling overwhelmed by the new information, could have affected the significance of the results. Although it is difficult to assess if a one-session intervention could truly impact feelings of preparedness, future research could follow participants for a period of time to assess long-term efficacy and determine if LTSS was utilized.

#### Predictors of Caregivers' Preparedness

Three categories of predictors of caregiver preparedness were assessed. The first category of predictors focused on caregiver characteristics, the second on care recipient characteristics, and the third on community-level characteristics. Caregiver age was a significant predictor of preparedness. There was also a trend for females and those with higher levels of education to feel more prepared. Care recipient characteristics were not predictive of preparedness. Caregiver knowledge prior to the intervention was also predictive of caregiver preparedness. The community-level characteristic of rurality continuum was not predictive of caregiver preparedness.

#### Reaching Caregivers, Particularly those Underserved

The typical caregiver who attended the Caregiver Beginnings Workshop was a 61 year-old Caucasian female with a bachelor's degree. She is married, works full-time, and does not have any children living at home. Her household income is between \$50,000 and \$74,999, and she feels her financial situation is "about the same" as other people her age. She has been

providing care for almost two years and spends about 25 hours a week caregiving. She has lived in her community for about 30 years and knows approximately five other caregivers. She does not have a care plan in place, and feels “somewhat supported” in her caregiver role.

The typical care recipient is an 81-year-old Caucasian female being cared for by her daughter or daughter-in-law, and although they do not live together they do reside in the same zip code. She is slightly more likely to be married than widowed, has a high-school education, and a household income of less than \$25,000.

Although this workshop was designed to target early-stage caregivers, and had hoped to reach underserved populations by utilizing churches and other community organizations, this was not the outcome that was achieved. As part of the intervention design, the host organizations were asked to recruit participants. Most organizations did this by posting flyers (Appendix F) in their communities and inserting information into area bulletins or newsletters. As a result many of the attendees were not among the underserved populations. Although it seems intuitive that those with a higher level of education would be more likely to seek out additional information and resources (such as informational workshops), the proportion of highly educated participants was surprising nonetheless.

In this workshop, just over 50% of caregivers had either a bachelor’s degree or a graduate degree; however, in Iowa as a whole, only 25.3% of Iowan’s have a bachelor’s degree or higher (United States Census Bureau, 2014). Only 2% of the caregivers in attendance did not have a high school degree, and more than 75% of caregivers had some level of education after high school. Interestingly, education was a predictor of increase in knowledge, with a higher level of education predicting a greater increase in knowledge.

The recruitment process used by most of the community organizations was to post flyers in their location as well as place notices in bulletins and newsletters. Although this method utilized the resources provided to the organizations by the intervention facilitator, it did not achieve the intended outcome of recruiting those in greatest need of information. The use of community organizations and faith-based groups as hosts was intended to attract participants who were from underserved populations. However, because the organizations chose to use broad public methods for disseminating the information, rather than individually targeting those who might be in need of the service as was hoped, the outcome was not achieved.

There was at least one participant whose background aligned with that of an underserved population. This individual was a married 22-year-old female with at least one child at home. She was a multi-ethnic high school graduate who was not currently employed and has a household income of less than \$25,000. She was caring full-time for her mother-in-law who lived with her, and she had been providing care for five months. This participant registered for the workshop after seeing a flyer posted in the community, and was not affiliated with the host organization. Although the participant outcome was not achieved using host organizations, this participant may shed light on recruitment tactics for future research. Future research could utilize additional sources of participants, including employers, community-based and social media advertising, and public health organizations.

#### Limitations and Considerations

For the purposes of this study, early-stage caregivers were considered those in the first 12 months of caregiving. However, due to the small sample size which was partially attributable to low registrations and workshop cancellations, all participants were analyzed regardless of caregiver duration. Of the 98 total participants, 53.2% were in their first 12 months of

caregiving. However, this number may also be somewhat misleading. Of the 53.2%, 27.4% or 17 individuals listed zero months of caregiving. Based on conversations during the interventions, it is estimated that approximately 25% of those 17 had already completed caregiving or were working with caregivers and simply looking for additional information. It is believed that the remainder of the individuals with zero months of caregiving anticipated becoming caregivers in the near future.

Alternatively, another 36 individuals or 36.7% of the total participants did not list any months of caregiving, but rather left the question blank. Again based on conversations which occurred during the intervention, it is anticipated that the majority of these individuals were anticipating become caregivers in the near future, either for a spouse or parent (in-law), but had not yet begun providing activities which they considered as qualifying them as caregivers.

Despite attempting to reach a representative sample of caregivers in Iowa, perhaps with a bias towards those groups most traditionally underserved, this was not the outcome. Most participants had more education than the average Iowan. Due to the broad public methods of advertising used by host organizations, participants self-selected. This self-selection reinforces the intuitive notion that those with higher levels of education are more likely to seek out additional resources. Future research would need to utilize a more targeted method of recruitment to ensure a more representative sample or a sample targeted at underserved groups.

When reviewing the measures of knowledge and awareness of availability it is important to note that these measures were self-reported. Although participants indicated that they had knowledge of a specific service type, no assessment was done to determine if that knowledge was accurate. Additionally, when assessing awareness of availability, no comparison was done

against services actually available in the communities, so this self-report may also have been inaccurate.

Another item of note is that people considered “their area” differently when determining whether or not a service was available in their area. For the purposes of the service type list provided to participants by the facilitator during the intervention, “their area” was considered to be approximately 30 miles surrounding the intervention location. As indicated by the survey results, some individuals did not consider anything outside of their city boundaries in “their area.” There were additional problems with this particular measure as well, including the wording of the question. It stated, “Do you know if this service is available in your area?” However, in addition to not specifying the range of “your area,” it did not specify who “your” was. It is not helpful to know if the service is available in the caregivers’ area, as the care recipient is the individual in need of the service.

When the LTSS service lists were put together, all of the host communities had services available within 30 miles of their location for the vast majority of services. Some notable exceptions to this were both adult day centers and continuing care retirement communities. These two options were only available near urban areas. In some instances, communities were up to two and a half hours away from the nearest adult day center or continuing care retirement community.

Additionally, not everyone agreed on the definition of the service types. One example of this was the continuing care retirement community (CCRC). Many indicated that if an establishment offered both assisted living and nursing facilities they were a continuing care facility. For the purposes of the list provided by the intervention, only those locations specifically calling themselves a continuing care retirement community, the vast majority of

which charged an upfront buy-in fee, were considered as CCRCs for the list. Another example was assisted living facilities. While almost all participants felt they had knowledge of assisted living facilities (.98 pre-test mean; 1.00 post-test mean), no clarification of the specific distinctions between assisted living and other service types was provided. This was due in part to the vast differences between different providers of the assisted living service; however, this lack of clarification could have impacted the results. Measures could be improved by offering further clarity around service type and service area.

### Future Directions

#### Further research

Should additional research on this intervention be conducted, it would behoove researchers to ask the following: “Are you a paid caregiver,” “Do you know what an Area Agency on Aging (AAA) is,” “Did you have a secondary caregiver,” and “Where does the care recipient live?” Additionally, it would be helpful to list in-law and other ethnicity as separate caregiver statuses.

It would also be interesting to look into the congruence between the caregiver and the care recipient to determine how much this impacted results. If caregivers were more likely to have similar socio-economic status as the care receiver, did this impact their level of preparedness? Were caregivers with significantly different socioeconomic statuses more likely to be more or less prepared than those who have similar statuses?

Another point of interest may be to look at the list of services available in each community and compare that to the level of knowledge individuals in those communities had on a pre- and post-test basis. In addition to obtaining their zip codes, it would be helpful to ask about the distance between the caregiver and the care receiver. Caregiver’s residing in the same



community as their care recipient should theoretically have a higher level of awareness of services available than caregivers not residing in the same community.

Along the same lines, it would be helpful to understand the congruence, or lack thereof, of caregiver awareness of service type availability and the actual availability of said service. Although lists of service providers were created for each community, these lists were not comprehensive. If a comprehensive list was created it could be compared to awareness of availability. Furthermore, it would be helpful for researchers to ask participants how they gained their awareness of service availability. This would allow program directors and policy makers to understand effective means of reaching this elusive group.

Another item which was not addressed in this analysis was the distinction between spouse and non-spouse caregivers. Prior research indicates that non-spouse family caregivers are more likely to access information and referral services than spousal caregivers (Bass, McCarthy, Eckert, & Bichler, 1994). Although the sample size of this study was not large enough to separate spousal and non-spousal caregivers statistically, this would be an area to direct future research.

The low sample size of this intervention may have also impacted the predictors of preparedness on a post-test basis. Although care recipient health was shown as a significant indicator of feelings of preparedness in the post-test, the individual predictor could not be utilized as the block it was contained in was not a significant predictor of post-preparedness. When looking at preparedness as a whole, some participants had an increase in feelings of preparedness and others had a decrease after attending the intervention. A larger sample size may have provided the ability to further investigate this issue and determine the strength of care recipient health relating to caregiver feelings of preparedness.

### Implications for practice and policy

Based on the results of this study, it would behoove programs and providers servicing older adults and their caregivers to expand their educational programming surrounding service type and availability. Even a minimal one-session intervention has a significant impact on caregiver knowledge of service types, and research has shown that knowledge of a service increases the likelihood of usage of that service (Bass, McCarthy, Eckert, & Bichler, 1994).

As indicated in future research, it would be helpful if policy makers could understand the interaction between service type awareness and actual service type availability. This would allow gaps in awareness to be assessed, but would also provide insight into service type availability gaps that may be able to be addressed with economic development policies. In order to build an effective policy which addresses the underutilization of home and community-based care, policy makers need to understand the full picture of knowledge, awareness, and availability. While this pilot study begins to address these issues, and provides a starting point for future research, it is only a starting point. It is hoped that the results of this study may enable expanded research into programming which can improve and streamline Iowa's information and referral infrastructure, providing Iowans with the tools they need to make informed long-term services and supports decisions.

## CONCLUSION

The system of long-term services and supports (LTSS) in Iowa is fragmented and difficult to navigate. As such, this pilot study was developed to determine if a one-session psychoeducational intervention could increase caregivers' knowledge of different LTSS service types and their awareness of service availability. The study also aimed to determine if the intervention increased caregiver feelings of preparedness and determine what factors might predict feelings of preparedness.

Results of the study indicate that the intervention was effective in significantly improving caregivers' LTSS knowledge and awareness of LTSS availability. Caregivers began the intervention with very little knowledge of the service types, some with no knowledge. It is important that the intervention was able to increase knowledge, as knowledge of LTSS service types was associated with higher awareness of availability and increased feelings of preparedness. As knowledge and awareness of LTSS has been shown to increase utilization of services, the potential to increase knowledge with a one-session intervention may provide needed insight into programmatic and policy considerations for Iowa moving forward.

Although the study indicated the intervention was effective, further research is needed to better understand the predictors of knowledge, awareness, and preparedness. Additionally, further research needs to explore ways to reach those in the very early stages of caregiving who do not self-identify as caregivers. As Iowa's population ages, caregiving will continue to play an increasingly important role in Iowa's economic future and Iowans' quality of life. Interventions such as this, which address the complexities family caregivers face when navigating the LTSS system, can make a positive impact on Iowa and the lives of Iowans moving forward.

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## APPENDIX A HUMAN SUBJECT EXEMPTION

**IOWA STATE UNIVERSITY**  
OF SCIENCE AND TECHNOLOGY

Institutional Review Board  
Office for Responsible Research  
Vice President for Research  
1138 Pearson Hall  
Ames, Iowa 50011-2207  
515 294-4566  
FAX 515 294-4267

**Date:** 2/25/2014  
**To:** Nichole Seedorf  
5107 Briarwood Dr  
Ankeny, IA 50021  
**CC:** Dr. Jennifer Margrett  
4380 Palmer  
**From:** Office for Responsible Research  
**Title:** A psychoeducational intervention for early-stage caregivers of older Iowans: A pilot study  
**IRB ID:** 14-008  
**Study Review Date:** 2/25/2014

The project referenced above has been declared exempt from the requirements of the human subject protections regulations as described in 45 CFR 46.101(b) because it meets the following federal requirements for exemption:

- (1) Research conducted in established or commonly accepted education settings involving normal education practices, such as:
  - Research on regular and special education instructional strategies; or
  - Research on the effectiveness of, or the comparison among, instructional techniques, curricula, or classroom management methods.
- (2) Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey or interview procedures with adults or observation of public behavior where
  - Information obtained is recorded in such a manner that human subjects cannot be identified directly or through identifiers linked to the subjects; or
  - Any disclosure of the human subjects' responses outside the research could not reasonably place the subject at risk of criminal or civil liability or be damaging to their financial standing, employability, or reputation.

The determination of exemption means that:

- **You do not need to submit an application for annual continuing review.**
- **You must carry out the research as described in the IRB application.** Review by IRB staff is required prior to implementing modifications that may change the exempt status of the research. In general, review is required for any modifications to the research procedures (e.g., method of data collection, nature or scope of information to be collected, changes in confidentiality measures, etc.), modifications that result in the inclusion of participants from vulnerable populations, and/or any change that may increase the risk or discomfort to participants. Changes to key personnel must also be approved. The purpose of review is to determine if the project still meets the federal criteria for exemption.

Non-exempt research is subject to many regulatory requirements that must be addressed prior to implementation of the study. Conducting non-exempt research without IRB review and approval may constitute non-compliance with federal regulations and/or academic misconduct according to ISU policy.

Detailed information about requirements for submission of modifications can be found on the Exempt Study Modification Form. A Personnel Change Form may be submitted when the only modification involves changes in study staff. If it is determined that exemption is no longer warranted, then an Application for Approval of Research Involving Humans Form will need to be submitted and approved before proceeding with data collection.

Please note that you must submit all research involving human participants for review. **Only the IRB or designees may make the determination of exemption**, even if you conduct a study in the future that is exactly like this study.

Please be aware that **approval from other entities may also be needed**. For example, access to data from private records (e.g. student, medical, or employment records, etc.) that are protected by FERPA, HIPAA, or other confidentiality policies requires permission from the holders of those records. Similarly, for research conducted in institutions other than ISU (e.g., schools, other colleges or universities, medical facilities, companies, etc.), investigators must obtain permission from the institution(s) as required by their policies. **An IRB determination of exemption in no way implies or guarantees that permission from these other entities will be granted.**

Please don't hesitate to contact us if you have questions or concerns at 515-294-4566 or IRB@iastate.edu.



## APPENDIX B INFORMED CONSENT DOCUMENT

**Title of Study:** A psychoeducational intervention for early-stage caregivers of older Iowans: A pilot study

**Principal Investigator:** Nichole L. Seedorf

This form describes a research project. It has information to help you decide whether or not you wish to participate. Research studies include only people who choose to take part—your participation is completely voluntary. Please discuss any questions you have about the study or about this form with the project staff before deciding to participate.

### **INTRODUCTION**

The purpose of this study is to determine if a community-based intervention will increase caregivers' knowledge and utilization of local long-term services and supports providers and increase their short-term self-efficacy regarding their ability to design an effective care plan. You are being invited to participate in this study because you are currently providing unpaid care to an Iowa resident over the age of 65 who is not your spouse or life partner, and you began providing the care within the last 12 months. You should not participate if you do not wish to be a part of the research study.

### **DESCRIPTION OF PROCEDURES**

If you agree to participate, you will be asked to attend a one-time workshop lasting approximately two and a half hours. You will be given a short survey, which should take no more than 15 minutes to complete both at the beginning and at the end of the workshop. The survey will include a series of questions regarding your knowledge of long-term services and supports available in your area and your feelings of preparedness for caregiving. The anonymous surveys will also include general demographic information for both you as the care provider and also your care recipient. Your participation will last for approximately two and a half hours.

### **RISKS**

There are no foreseeable risks at this time from participating in this study.

### **BENEFITS**

If you decide to participate in this study the only direct benefit to you will be any knowledge gained during the course of the workshop. It is hoped that the information gained in this study will benefit society by advancing our understanding of long-term services and supports knowledge in Iowa.

## **COSTS AND COMPENSATION**

You will not have any costs from participating in this study. You will not be compensated for participating in this study.

## **PARTICIPANT RIGHTS**

Participating in this study is completely voluntary. You may choose not to take part in the study or to stop participating at any time, for any reason, without penalty or negative consequences. You can skip any questions that you do not wish to answer.

If you have any questions *about the rights of research subjects or research-related injury*, please contact the IRB Administrator, (515) 294-4566, [IRB@iastate.edu](mailto:IRB@iastate.edu), or Director, (515) 294-3115, Office for Responsible Research, Iowa State University, Ames, Iowa 50011.

## **CONFIDENTIALITY**

No records identifying participants will be kept. However, federal government regulatory agencies, auditing departments of Iowa State University, and the Institutional Review Board (a committee that reviews and approves human subject research studies) may inspect and/or copy the anonymous records for quality assurance and data analysis. These anonymous records may contain private information.

To ensure confidentiality to the extent permitted by law, the following measures will be taken: collected information will be kept in a locked filing cabinet and only accessible to the program personnel. Computer files will be kept on a password protected removable drive which will also be kept in a locked filing cabinet. Data will be kept for five years before it is destroyed. If the results are published, your identity will remain confidential.

## **QUESTIONS**

You are encouraged to ask questions at any time during this study. For further information *about the study*, contact Nichole Seedorf at [nseedorf@iastate.edu](mailto:nseedorf@iastate.edu) or Dr. Jennifer Margrett at 515-294-3028 or [margrett@iastate.edu](mailto:margrett@iastate.edu).

## **CONSENT AND AUTHORIZATION PROVISIONS**

Your signature indicates that you voluntarily agree to participate in this study, that the study has been explained to you, that you have been given the time to read the document, and that your questions have been satisfactorily answered. You will receive a copy of the written informed consent prior to your participation in the study.

**PARTICIPANT NAME (Printed):** \_\_\_\_\_

**PARTICIPANT SIGNATURE:** \_\_\_\_\_

**DATE:** \_\_\_\_\_

## APPENDIX C PREPAREDNESS FOR CAREGIVING SCALE

**YOUR PREPARATION FOR CAREGIVING**

We know that people may feel well prepared for some aspects of giving care to another person, and not as well prepared for other aspects. We would like to know how well prepared you think you are to do each of the following, even if you are not doing that type of care now.

	Not at all prepared	Not too well prepared	Somewh at well prepared	Pretty well prepared	Very well prepared
1. How well prepared do you think you are to take care of your family member's physical needs?	0	1	2	3	4
2. How well prepared do you think you are to take care of his or her emotional needs?	0	1	2	3	4
3. How well prepared do you think you are to find out about and set up services for him or her?	0	1	2	3	4
4. How well prepared do you think you are for the stress of caregiving?	0	1	2	3	4
5. How well prepared do you think you are to make caregiving activities pleasant for both you and your family members?	0	1	2	3	4
6. How well prepared do you think you are to respond to and handle emergencies that involve him or her?	0	1	2	3	4
7. How well prepared do you think you are to get the help and information you need from the health care system?	0	1	2	3	4
8. Overall, how well prepared do you think you are to care for your family member?	0	1	2	3	4
9. Is there anything specific you would like to be better prepared for?					

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*Note.* From "Preparedness for caregiving scale," by D. Zwicker, 2010, *The Hartford Institute for Geriatric Nursing, New York University, College of Nursing.*

## APPENDIX D KNOWLEDGE OF LONG-TERM SERVICES AND SUPPORTS SCALE

The following list of service types includes many of the services you may encounter or require as a caregiver. Please provide an answer for each of the services types listed, even if you do not use the service now or do not expect to use the service in the future.

Service Type	Do you know what this service is?		Do you know if this service is available in your area?		
	Yes	No	Yes it is	No it's not	I don't know
Adult Day Center	Yes	No	Yes it is	No it's not	I don't know
Assisted Living Facility	Yes	No	Yes it is	No it's not	I don't know
Bill Payer	Yes	No	Yes it is	No it's not	I don't know
Case Management - Private	Yes	No	Yes it is	No it's not	I don't know
Case Management - Public	Yes	No	Yes it is	No it's not	I don't know
Chore Services	Yes	No	Yes it is	No it's not	I don't know
Consumer Directed Attendant Care	Yes	No	Yes it is	No it's not	I don't know
Continuing Care Community	Yes	No	Yes it is	No it's not	I don't know
Counseling/Emotional Support	Yes	No	Yes it is	No it's not	I don't know
Errands and Shopping	Yes	No	Yes it is	No it's not	I don't know
Financial Management	Yes	No	Yes it is	No it's not	I don't know
Legal Assistance	Yes	No	Yes it is	No it's not	I don't know
Information and Referral	Yes	No	Yes it is	No it's not	I don't know
Home Health Aide	Yes	No	Yes it is	No it's not	I don't know
Home Delivered Meals	Yes	No	Yes it is	No it's not	I don't know
Homemaker Services	Yes	No	Yes it is	No it's not	I don't know
Medication Aide	Yes	No	Yes it is	No it's not	I don't know
Nursing Care - In Home	Yes	No	Yes it is	No it's not	I don't know
Nursing Care - Facility	Yes	No	Yes it is	No it's not	I don't know
Nursing Care - Skilled Facility	Yes	No	Yes it is	No it's not	I don't know
Nutrition Counseling	Yes	No	Yes it is	No it's not	I don't know
Personal Care Services	Yes	No	Yes it is	No it's not	I don't know
Personal Emergency Response Device	Yes	No	Yes it is	No it's not	I don't know
Remote Electronic Monitoring	Yes	No	Yes it is	No it's not	I don't know
Respite Care	Yes	No	Yes it is	No it's not	I don't know
Transportation	Yes	No	Yes it is	No it's not	I don't know

*Note.* Adapted from "Comparative effectiveness of individual and group interventions to support family caregivers," by R.W. Toseland, C.M. Rossiter, T. Peak, and G.C. Smith, 1990, *Social Work*, 35(3), p. 212.

## APPENDIX E DEMOGRAPHIC QUESTIONS

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 Pre-Test
 

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Thank you for participating in our survey. The following questions are designed to provide information about the survey participants as a group and will not be used to identify individuals. All responses are anonymous and confidential. In this survey, all references to the caregiver refer to the individual providing or arranging care; and all references to the care receiver refer to the older adult in need of care.

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Please answer the following questions about yourself:

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- 1 What is your zip code? (XXXXXX)
  - 2 How long have you lived in this community? (X Year(s))
  - 3 What is your age? (XX)
  - 4 Sex? (Male/Female)  
 What is your current marital status? (Married/Living with an unmarried partner/Widowed/Divorced/Separated/Never married)
  - 5
  - 6 Does anyone under the age of 18 live in your household? (Yes/No)  
 What is the highest level of education you completed? (X Grade/HS Graduate or GED/Technical or Trade or Vocational training/Four year degree/Graduate degree)
  - 7
  - 8 What is your ethnic background? (White or Caucasian/Black or African-American/Asian American/Hispanic or Latino/American Indian/Other)
  - 9 What is your current employment status? (Employed full-time/Employed part-time/Self-employed/Homemaker/Retired/Disabled/Not employed)
  - 10 Please tell me how well you think you (and your family) are now doing financially as compared to other people your age?<sup>1</sup> (Better/About the same/Worse)
  - 11 How well does the amount of money you have take care of your needs?<sup>1</sup> (Very well/Fairly well/Poorly)
  - 12 Do you usually have enough to buy those little “extras”; that is those small luxuries?<sup>1</sup> (Yes/No)
  - 13 What is your relationship to the care receiver? (Child/Grandchild/Niece or Nephew/Sibling/Spouse or Partner/Neighbor/Other, please define)
  - 14 Do you and the care receiver live in the same household? (Yes/No)  
 For the following questions, a caregiver is defined as someone who assists an older adult with one or more Activities of Daily Living (Bathing, Dressing, Toileting, Transferring, Continence, and Feeding) or Instrumental Activities of Daily Living (Telephoning, Shopping, Food Preparation, Housekeeping, Laundry, Transportation, Medication, and Finances).
  - 15 How long have you been a caregiver for this individual? (X Months)
  - 16 How many hours a week do you provide care for this individual? (X Hours)  
 How much support do you feel for your caregiver role?<sup>2</sup> (Very supported/Somewhat supported/Rarely supported/Not supported at all)
  - 17
-

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18 How many other caregivers of older adults do you know? (XX)

For the following question, a care plan (which may or may not be written down), outlines what personal or healthcare services the care recipient needs, how often the services are needed, who will provide the services, any equipment or supplies need for the services, and how the services will help the care recipient reach their goals.

19 Has a care plan been created for the care recipient's current needs? (Yes/No)

---

Please answer the following questions about your care recipient:

---

1 What is the care recipient's zip code? (XXXXXX)

2 What is the care recipient's age? (XXX)

3 What is the care recipient's gender? (Male/Female)

4 What is the care recipient's marital status? (Married/Living with an unmarried partner/Widowed/Divorced/Separated/Never married)

5 What is the highest level of education the care recipient completed? (X Grade/HS Graduate or GED/Technical or Trade or Vocational training/Four year degree/Graduate degree)

6 What is the care recipient's ethnic background? (White or Caucasian/Black or African-American/Asian American/Hispanic or Latino/American Indian/Other)

7 In general, would you say the care recipient's health is:<sup>3</sup> (Excellent/Very good/Good/Fair/Poor)

8 What condition or illness is the care recipient suffering from, if any? (i.e. - Alzheimer's/Dementia, Cancer, Congestive Heart Failure, COPD, Diabetes, Parkinson's, Stroke, etc.)

9 Is the total monthly income of the care recipient less than \$2,130.00? (Yes/No)

10 Is the care recipient's total amount of resources (savings accounts, annuities, etc.) less than \$2,000 individually, or \$3,000 jointly? (Home and automobile are not included in this amount.)

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Post-Test

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Thank you for participating in our survey. The following questions are designed to provide information about the survey participants as a group and will not be used to identify individuals. The financial information requested will be used to better understand the needs of different groups of caregivers. All responses are anonymous and confidential. In this survey, all references to the caregiver refer to the individual providing or arranging care; and all references to the care receiver refer to the older adult in need of care.

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1 If you had a care plan prior to attending this workshop, did your care plan change?

2 If so, how did it change?

3 What is your care recipient's total household income? (Less than \$25,000/\$25,000 to \$49,999/\$50,000 to \$74,999/\$75,000 to \$99,999/\$100,000+)

4 What is your total household income? (Less than \$25,000/\$25,000 to \$49,999/\$50,000 to \$74,999/\$75,000 to \$99,999/\$100,000+)

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*Note.* <sup>1</sup> The measure is from the Multidimensional Functional Assessment: The OARS Methodology (Pfeiffer, 1975); <sup>2</sup> The measure is from the Caregiver Self-Assessment for the Caregiver of a Veteran Needing Long Term Care (United States Department of Veterans Affairs, 2013); <sup>3</sup> The measure is from the SF-12 Short-Form Health Survey.

## APPENDIX F MARKETING MATERIALS

## Are you a family caregiver?

Provide rides to appointments? - Assist with legal/financial issues?

Help with grocery shopping or homemaking? - Identify care options?



As your parents age, you know they need some assistance. *Do you know where to start?*

The **Caregiver Beginnings Workshop** is an introductory workshop covering a variety of caregiving topics, including: preventing falls, talking about driving, locating resources, and designing a care plan. Participants will leave the workshop with a better understanding of a variety of long-term services and supports, along with specific information on the resources in their community. Participants will also have the opportunity to design a care plan for their unique situation during the workshop. A brief survey will be given at the beginning and end of the workshop to test the workshop's impact.

Date: Sunday, August 17th

Time: 2:00 – 4:30 PM

Location:

Cost: FREE

RSVP:

## ACKNOWLEDGEMENTS

I wish to acknowledge the support I have received which made this research possible. First and foremost, I wish to thank my advisor, Dr. Jennifer Margrett. Without her patience, persistence, and understanding this project could not have been completed. I also wish to thank my committee members, Drs. Mack Shelley and Rick Dark, for their valuable insights and contributions. Additionally, I wish to acknowledge the financial support of the Interdisciplinary Graduate Studies Fellowship which allowed this research to be conducted. Finally, I wish to thank Ralph for his support in completing the final phases of this project; and Abigail and Brady for their unwavering support and patience throughout this adventure.