Long Distance Caregiving: An Evaluative Review of the Literature

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Abstract A comprehensive and evaluative review of empirical research published between 2000 and 2010 specific to long distance caregiving is provided to identify what is known about this subgroup of caregivers and to identify gaps in knowledge. We searched peer-reviewed journals included in the following databases: Academic Search Premier (EBSCO), PROQuest Direct, Social Work Abstracts, CINAHL, MEDLINE, and PsychInfo. Searches were restricted to English language publications between 2000 and 2010. Search terms included: 'review + caregiving + dementia', 'meta-analyses + caregiving + dementia,' 'caregiving + dementia + not institutional,' 'informal + caregiving,' 'family + caregiving', 'caregiving + technology'. Any searches including the term 'dementia' were repeated without that term. These same searches were repeated with the term 'distance' added to each. Empirical research specific to long distance caregiving is reviewed in detail. A brief review is provided of other closely related research. Long distance caregivers report being heavily involved in the care of their family member, regardless of distance and surprisingly, are often the only or primary caregiver. The specific needs for future research to inform best practice that goes beyond description of this important subgroup of caregivers is discussed.

Keywords Long distance caregiving · Review · Dementia · Older persons · Methodological issues

While a great deal has been written on many aspects of caregiving for older persons, very little empirical research has been published specific to informal care provided by families to its elderly relatives who are living at a great geographic distance from

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the caregiver. The number of families impacted by the need for long distance caregiving is substantial and is growing. The National Council on the Aging (1997) estimated that approximately 7 million persons were providing care for relatives who were living many miles away and projected that this number would double in 15 years.

There are many reasons for increased demands on families for caregiving to elderly members: shorter hospital stays (Davidhizar 1999), aging of the population with projections that 1 in 5 will be 65+ by 2030 (Hobbs and Damon 1999), and the fact that most elderly persons do not want to leave their own homes regardless of increasing geographic distance from family (McFarlane 1997). Greater longevity of human life, an increase in single parent families, delayed child bearing, and the economic need for two working adults also contribute to the increase in caregiving responsibilities for family members (Singer et al. 2001; Wilcox 1995). Further, the need for long distance caregiving is impacted by increased mobility of persons over age 65 with the number who moved across states increasing by 65% between 1982 and 1992 (Cole 1995). Although geographical proximity is not a prerequisite for maintaining close family bonds (Bengtson et al. 1996; Cicirelli 1995), it has been identified as an important issue in how families deal with their family responsibilities (Baldock 2000).

This paper provides a comprehensive and evaluative review of empirical research published between 2000 and 2010 specific to long distance caregiving in order to identify what is known about this subgroup of caregivers and to identify gaps in our knowledge. First, the broader context in which long distance caregiving takes place will be briefly discussed with key definitions as operationalized in this paper provided. After a review of the literature relevant to long distance caregiving, the role of research in informing best practices and issues in conducting needed future research are discussed in detail.

Context for Provision of Care from a Distance

Throughout our review and discussion, we acknowledge that the term caregiving covers a wide range of possible assistance, including, complete responsibility for care, provision of some financial support, arrangement for various levels of in-home care, regular visits and telephone calls, and oversight of medical care. Need for assistance is defined by ability to perform instrumental activities of daily living, such as, shopping, transportation, and meal preparation and other basic self-care tasks, such as, bathing, toileting, and dressing (Travis 1995).

Provision of care from a distance can reduce frequency of visiting and assistance with chores since certain activities and support tasks are simply not feasible when family members live far away. The quantity and quality of interactions may vary depending on distance and availability of resources to address the resulting barriers to care provision (Rossi and Rossi 1990; Silverstein and Litwak 1993; Lin and Rogerson 1995). Some families may find caregiving to be draining both emotionally and financially, particularly when an ill elderly parent is involved. Add distance to this equation and caregiving becomes much more complex. Although a great deal of research has been conducted on caregivers and the effects of this role on their lives



and health, very little of this research has included distance as a factor. It is not clear whether or not long distance caregivers and their experiences are different from their counterparts in important ways.

Conceptionalizations of Long Distance Caregiving

Just as there is no single agreed upon definition for informal caregiving, long distance caregiving has been defined in various ways. Generally, travel time more than 1 h has been considered a long distance for caregiving purposes (National Alliance for Caregiving 2004; Wagner 1997; Frankel and Dewit 1989). A caregiver has been defined as someone who was at least 18 years old who provided informal care to a relative or friend aged 50 or older during that last 12 months (National Alliance for Caregiving and the American Association of Retired Persons 1997). Some definitions of caregiving include younger persons as caregivers (e.g., aged 15 or older, Arno et al. 1999) or define care recipients as being older (e.g., 65 or older, Spector et al. 2000). And some previous definitions have included a specified minimum period of time as part of the definition of caregiving (e.g., three or more months, Spector et al. 2000; Arno et al. 1999).

We operationalize *long distance caregiving* as the efforts made by family members to provide for the needs of elderly, often ailing relatives who reside at a location that is sufficiently geographically distant that the caregiver cannot have daily face-to-face contact with the relative. Our definition refers only to informal care that is provided to persons living outside institutions. We do not restrict the age of the caregiver, but generally are focused on care provided to persons over age 65 who need some sort of assistance to remain in their own homes.

Method

Search Strategy

Our search of the literature was guided by our operational definition for long distance caregiving. To locate all relevant empirical research, we searched peer-reviewed journals included in the following databases: Academic Search Premier (EBSCO), PROQuest Direct, Social Work Abstracts, CINAHL, MEDLINE, and PsychInfo. Searches were restricted to English language publications between 2000 and 2010. Search terms included: 'review + caregiving + dementia', 'meta-analyses + caregiving + dementia,' 'caregiving + dementia + not institutional,' 'informal + caregiving,' 'family + caregiving', 'caregiving + technology'. Any searches including the term 'dementia' were repeated without that term. These same searches were repeated with the term 'distance' added to each. This approach was taken in an attempt to locate any research that might include information pertinent to long distance caregiving even though the primary focus was on caregiving in more general terms. We also searched specialized websites, such as, http://www.aoa.gov/AoARoot/index.aspx [Administration on Aging], http://www.caregiving.org [National Alliance for Caregiving], and http://www.family caregivingcoalition.org.



Results

Before discussing in detail the few articles located that reported on empirical research specific to long distance caregiving, a brief review is provided of other closely related research.

Brief Overview of Research on Caregiving Non-Specific to Long Distance

Traditionally, much has been written on the possible negative impact of providing care to elderly family members without specifically addressing the distance factor (i.e., Neal et al. 1993; Ponzetti and Ponzetti 1999), and we found that that trend continues in more recent research. Research exists that examines determinants of satisfaction with care and emotional distress among informal carergivers (e.g., Mafullul and Morriss 2000); difference in stress responses in caregivers based on their relationship to the care recipient (e.g., wives versus daughters, King et al. 2002); and examination of factors that might influence caregiver stress and coping (e.g., Edwards et al. 2002; Davis et al. 2004; DiBartolo and Soeken 2003). The well-being of caregivers who are providing care in their own homes has been studied cross-sectionally (Beeson et al. 2000; Covinsky et al. 2003) and less often over time (Arai et al. 2002). Not all research is focused on possible detrimental impacts on caregivers. For example, Jenssen et al. (2004) found that caregivers place a great deal of value in their role and not all are depressed. Ingersoll-Dayton et al. (2001) found that most caregivers also received help from their aging parents. Most often the assistance received was in the form of emotional support, but the caregivers also received financial support, assistance with child care and help with household tasks.

Gender differences in the caregiver experience have been investigated (e.g., Gallicchio et al. 2002; lack of support for women caregivers, Neufeld and Harrison 2003; male caregivers compared to female, Cahill 2000; Kirsi et al. 2000). Examples exist of research with care recipients other than those with Alzheimer's Disease or other dementias (e.g., AIDS, advanced cancer, Flaskerud et al. 2000). A number of articles were located that provided results of research on stress for family caregivers who had placed their relative in a nursing home (i.e., Almberg et al. 2000; Bond et al. 2003; Edwards et al. 2002).

Another major segment in the existing literature consists of articles that are not empirical but provide information, describe skills, and/or attempt to provide support for either caregivers directly or to professionals who work with caregivers (e.g., Farran et al. 2004; online support for caregivers, Glueckauf and Loomis 2003; effective training, Hepburn et al. 2001).

Four excellent recent reviews were located, but none included long distance caregiving. Gottlieb and Wolfe (2002) reviewed 17 empirical studies published 1984–2000 that examined coping strategies of caregivers to persons with dementia and impact on caregiver health and morale. They found that methodological issues across the studies made developing an overall conclusion problematic. In a similar review, Kneebone and Martin (2003) included 16 studies based on Lazarus and Folkman's (1984) stress and coping model among caregivers of people with dementia, and concluded that a general tendency toward problem-solving and acceptance is helpful to these caregivers. Houde (2002) provided a review of 36



studies from the CINAHL database (1997–2000) for the purpose of identifying methodological concerns in research on gender differences among caregivers. Houde cited the need for larger sample sizes, more well-controlled intervention studies, and additional analyses based on gender in future studies. Vitaliano et al. (2003) conducted a meta-analysis of 23 studies to determine the impact of providing care to persons with dementia on the health of the caregiver. They concluded that caregivers reported poorer health overall and took more medications than noncaregivers did.

Guidance for Long Distance Caregivers

As with caregiving in general, there are numerous examples of publications that attempt to provide support and strategies for the long distance caregiver (e.g., Harvard Women's Health Watch, April 2004; American Association of Retired Persons 1986; Heath 1993; Kalter 1997; Collins et al. 2003). Plowfield et al. (2000) do not provide any empirical data, but they do include distance as a factor when discussing the elements of a comprehensive, accurate geriatric assessment.

Distance from Care Recipient as a Factor

Although Hays (2002) provides an excellent review of the literature as it relates to living arrangements and health status in later life, the only inclusion of long distance caregiving is a reference to Greenwell and Bengtson's (1997) cross-sectional study of geographical distance and contact between older persons and adult children.

Neuharth and Stern (2002) included distance as one factor in research designed to model each adult child's caregiving decisions within the family context. This research applied structural modeling techniques to data from the 1982 and 1984 National Long Term Care Survey. Neuharth and Stern defined distance in terms of travel time to the care recipient in four categories: less than 10 min, 11–30 min, 31–60 min, 61 min up to 1 day, and 1 day or greater. They found that as distance increased the less care the child was willing to offer. Financial management was the most likely care to be provided from a distance.

Empirical Research Focused on Long Distance Caregiving

Seven studies providing results of research *specific* to long distance caregiving were located and are discussed in detail here. They consist of three exploratory qualitative studies with transnational families, a survey study modeling the effects of worry about parents by military personnel who live at great distances from their parents, two description studies based on national data sets (secondary analysis of the 1997 NAC/AARP national telephone survey and results of an online survey by the National Alliance for Caregiving), and a descriptive study based on demographic and service use data from the Los Angeles Alzheimer's Association. An additional eleven studies that report on empirical research on the use of various technologies to either support caregivers or care recipients are reviewed. Although none of this final group of studies specifically targets caregiving over a distance, they were included due to the assumption that the studied technologies would have value to long distance caregivers and their care recipients.



Transnational Families

Baldock (2000) conducted an exploratory study on caregiving from a distance by interviewing 12 persons who had immigrated to Australia several years previous. She found that these transnational migrants remained very much involved in providing care for their parents. Emotional support was the primary assistance given, most commonly through frequent telephone calls. These long distance caregivers typically planned much in advance for visits back home to their parents and used all available vacation or other leave for this purpose. Baldock found that caregiving from a distance seemed to diminish a gendered construct of caring, as both male and female caregivers retained close communication and support networks with their parents. An additional stress very specific to this group of long distance caregivers emerged in that Baldock found that this close contact with aging parents in their country of origin often led to ambiguity related to national identity for the caregivers.

An ethnographic exploration of long-distance caregiving among three cohorts of Italian migrants in Australia (Baldassar 2007) highlighted time as a key variable in studying transnational caregiving. This study was based on 80 qualitative interviews with family members in Australia and in Italy. Although the care exchanges did not remain static over time, findings indicated that distance did not reduce the families' understanding of obligations to provide care. Most families reported increase in the number and intensity of transnational contact as travel became safer and more affordable and communication technologies improved.

In a smaller, exploratory study Kodwo-Nyameazea and Nguyen (2008) examined caregiving attitudes and efforts among 5 Ghanaian immigrants living in the U. S. for their elder relative still residing in Ghana. This study applied grounded theory methodology to the qualitative interviews. The participants clearly perceived themselves as having continued obligation to provide some type of care to their parents in Ghana. Although the participants described gender-specific roles, caregiving activities were similar for male and female participants, consisting of sending money, phone calls and occasional visits.

Military Families

The stated goal of research by Parker et al. (2002) was to build upon Baldock's (2000) work and develop a model of the effects of worry about parents by military personnel who live at great distances from their parents. Active duty military are one of the largest groups of people who live at great distances from their parents, and they do so for most of their adult lives. Based on previous work by Baldock (2000) and Climo (1992), Parker et al. hypothesized that as worry about parents increased, military officers would increase the frequency of their telephone and written contact. They also expected that officers who were satisfied with parents' plans for future care would experience less worry. Parker et al. surveyed 277 senior ranking male officers between the ages of 40 and 49. All of the participants indicated that their parents lived at a distance of 90 or more miles away. The resultant structural equation model was found to fit the data reasonably well, but it only accounted for 8% of the variation in frequency of telephone and mail contacts. Participants with



more siblings tended to contact their parents less frequently, while officers reporting excellent relationships with their parents tended to have more frequent contact. The model accounted for about 31% of the variance in worry about parents, but worry was not found to be a significant mediator of frequency of telephone, email or mail contacts with parents. Parker et al. (2002) found that regardless of their reported level of worry of parents' well-being contact by telephone, mail, or e-mail occurred on an almost weekly basis.

Findings from National Data Sets

Koerin and Harrigan (2002) conducted a secondary analysis of the 1997 NAC/AARP national telephone survey of family caregivers for older adults, focusing their study on long distance caregivers. Long distance caregivers were defined as those living more than 2 h from the care recipient. Of the 1,509 surveys in the original survey, 109 met the criteria for this subsample. Their goals were to describe long distance caregivers and the recipients of their care, to identify what types of care were given, to describe stress reported by the caregivers, and to identify what resources were utilized.

Koerin and Harrigan found that most long distance caregivers were middle-aged (M=42 years) women (56%) who were married (65.1%) and often had children or grandchildren in their households (50%). The subsample was ethnically diverse due to oversampling conducted to construct the sample for the original study (32.1%) were white; 33.9% were Asian; 22% were Hispanic, and 11/9% were African American). Generally, long distance caregivers reported higher levels of education and income than other caregivers (52%) of long distance caregivers had a college degree or some graduate study compared to 29% of all caregivers in the sample). A surprisingly high number of long distance caregivers reported that they were the primary caregiver (11%) or shared primary care equally with another person (21%).

There was a wide range in age (50 to 98 years) among care recipients with the average age being 77.6 years. Most caregivers were providing care to a relative (5.5% were non-relatives) usually a parent (mother, 39.4%; father, 13.8%; grandmother, 13.8%). Approximately 25% of the respondents reported that the main illness or problem of the care recipient was aging, and 19% reported that their care recipient suffered from Alzheimer's Disease.

Caregivers reported providing transportation assistance (67.9%), financial management (66.1%), housework assistance (64.2%), grocery shopping (63.3%), and arranging for outside services (56.9%). Many respondents also reported providing assistance with ADL's, for example, giving medications (37.6%), assistance with getting in and out of beds and chairs (36.7%), and assistance in getting dressed (29.4%).

While only 10% of the respondents reported physical or mental problems as a result of their caregiving, over half said they had given up vacations, hobbies or other leisure activities. Just over half (54.1%) of the caregivers were employed full-time and 16.5% were employed part-time. Of those employed, 43.2% reported missing work and 34.1% had taken a leave of absence to provide care. Long distance caregivers reported both difficulties and rewards associated with their role. Distance from the care recipient was the most frequently cited difficulty (20.2%). Watching the deterioration of the loved



one's health (13.8%) and demand on their time (11.0%) were also commonly cited burdens. Respondents reported experiencing rewards as well with 19.3% finding personal satisfaction in their caregiving role, 18.3% experienced a positive sense of family loyalty and giving back, and 18.3% experienced appreciation from the care recipient. The four most frequently used resources were assistive devices (38.3%), home modifications (34.5%), personal care or nursing services (25.5%), and financial information (20.4%).

An online survey (National Alliance for Caregiving 2004) was conducted specifically aimed at learning more about the challenges of long distance caregiving and developing a profile of the caregiver. Participants (n=1,130) were providing care for persons 55 and older "who has chronic physical, cognitive or mental health problems" and who lived at a distance of more than 1 h travel time from the caregiver (p. 4). Recruitment was accomplished through email invitations to a larger sample of 79,851 persons who had previously agreed to participate in online surveys. The goals of the survey were to investigate the effect of distance and status of caregiver as only, primary or one of several caregivers; possible effects on caregiver's employment; availability of any work place accommodations; extent of out-of-pocket expenses; and possible effects on caregiver's health.

In contrast to Koerin and Harrigan's (2002) findings, caregivers in this sample were more likely to be men (58%), with an average age of 51, 27% reported a child under age 17 at home, and were married (approximately 75%). Participants were primarily white (95.5%) with 2% being Hispanic, 2% African American, and 0.5% were Asian. Similar to Koerin and Harrigan's findings, respondents were a highly educated group (70% had a college degree or some graduate study), and they were affluent (50% reported income of \$75,000 or more).

Most long distance caregivers (76%) in this survey reported providing care to a parent, step-parent or parent-in-law. Even though the average distance from care recipient was 450 miles and 7.23 h of travel time one-way, 23% of the caregivers reported that they were the only (5%) or primary care provider (18%). In fact, caregivers who reported being the only provider lived on average 424 miles from the care recipient. When caregivers were *not* the only care provider, greater distance was associated with less frequent personal visits, fewer hours spent helping around the house, but did not affect hours spent arranging for or monitoring care provided by another. Long distance caregivers also reported regular personal contact with the care recipient with 65% reporting at least monthly visits, 17% reported visiting once a week and another 17% visited more than once a week. Many caregivers (72%) reported that they spent an average of 22 h per month providing assistance with Instrumental Activities of Daily Living (i.e., transportation, grocery shopping, housework, or managing medications). Caregivers (46%) also spent time arranging for needed services or monitoring the care received (49%).

Most caregivers were employed; 62% full-time and 18% part-time. Half of the respondents reported making some type of work accommodations and the type of accommodation was affected by distance with those living at a greater distance more often reporting missing entire days of work. An average of 20 h of missed work per month was reported. Those caregivers (5%) who reported being the only care provider were the most affected. Distance was a factor in the pattern of work accommodations experienced. Those caregivers living at a greater distance were



more likely to take unpaid leave, turn down a promotion, lose work benefits, and miss days at work.

Financial costs of caregiving varied by distance with those living 1 to 3 h away reporting an average of \$386 and those living more than 3 h away reporting an average of \$674 per month for care, travel, and phone expenses. A more recent telephone survey (Evercare and National Alliance for Caregiving 2007) found that long distance caregivers (i.e., living 20 min or more away) had the highest annual expenses (\$8,728) compared to those caregivers living with their family member (\$5,885 and those living nearby (\$4,570)).

Eighteen percent of caregivers reported that their health had been negatively impacted. With one exception, the distance reported by respondents did not differ by gender or age. Caregivers age 65 and older tended to live closer to the care recipient.

Gender differences in the care situation and some work-related factors emerged. Women were more likely to be the only or primary caregiver and reported missing more work per month than men (24 h vs. 17). Women spent more time helping around the house (23.5 vs. 21 h per month) and more time assisting with personal care (14.5 vs. 11 h per month). Women spent more money on average per month than men on services needed by the care recipient (\$751 vs. \$490). Women were more likely than men to report that they had reduced their work to part-time and that they were considering leaving work completely.

Comparison on Demographics and Service Use

Watari et al. (2006) compared demographic data and service use among survey respondents who were either long distance (n=90) or local caregivers (n=187) who had contact with the Los Angeles Alzheimer's Association (LAAA). Surveys were anonymous and were administered through mail or e-mail. Long distance caregiving was operationalized as living outside Los Angeles County while providing care to someone with Alzheimer's or related problems who lived in Los Angeles County. The LAAA provided a long distance caregiver program that consisted of consultation with a professional family consultant who acted as a liaison between caregiver and recipient, provision of a printed or web-based community service resource guide, access to a website with information on how to obtain local services, legal consultation via telephone for assistance with applicable laws, financial and care planning, and the Safe Return program for individuals with dementia who wander or become lost.

Over 70% of the caregivers (long distance and local) were women with an average age in the early 50 s. Most care recipients were women (66%), with an average age in the late 70 s. Caregivers differed on level of education and relationship to care recipient. There were more long distance care givers with graduate degrees, and long distance caregivers were more likely to be providing care to a parent. Long distance care recipients were more likely to receive a pension. While the largest percentage of long distance and local care recipients lived with a spouse, significantly more long distance care recipients lived alone compared to local care recipients. In contrast to local caregivers who were more likely to be referred by their physician, long distance caregivers were more likely to be referred to LAAA by another Alzheimer's chapter or the phone book. Long distance and



local caregivers did not differ on the number (on average 2 to 3) or type of services (written materials, web site, and Helpline) received from LAAA. However, long distance caregivers rated satisfaction with services higher, and the overall service satisfaction rating was statistically significant. The two groups of caregivers did not differ in their reports of unmet service needs; in-home care, adult day care, and emotional support were the most frequently reported. On the other hand, they did differ on reported barriers to services. Family disagreement about care was much more frequently cited as a barrier among long distance caregivers. They also reported a lack of information on Alzheimer's disease and of course, distance as a barrier more often than local caregivers. Local caregivers were more likely to report feeling overwhelmed.

Empirical Research on the Use of Technology

A wide range of technological devices and services are now available that may be of assistance to those who provide caregiving from a distance (See Smith 2008 for an overview). Supportive technologies can be seen as falling into several major categories: (a) assistive devices, e.g., medicine dispensers, safety alarms; (b) telecare technology, e.g., use of ordinary phones for telephone support groups, video phones, telemonitoring using electronic stethoscopes or vital sign sensors; (c) computer-based services, e.g., health information available on Internet, web-camera conferences for family members, (d) "smart home" sensors that can identify activity patterns and alert caregivers; and (e) robotic assistants that can assist with numerous tasks, such as housekeeping, mobility, and communication.

Although many of these technologies seem ideally suited to both improving the care received and providing support for long distance caregivers, much of the published research does not specifically address caregiving over a great distance. Therefore, research included in this review was chosen based on likely relevance to long distance caregiving regardless of specific inclusion of the distance factor.

In a descriptive study primarily focused on use of portable aids for walking (e.g., canes and walker) and environmental modifications, Freedman et al. (2005) found that the independent use of such assistive devises had increased substantially between 1992 and 2001, while the number of older people dependent on personal care for activities of daily living declined. No studies specific to long distance caregiving could be located; however, this finding leads to speculation that the recipients of long distance caregiving would benefit from access to appropriate assistive devices and environmental modification.

Videophone technology has been tested for usability with older persons. For example, Parker Oliver et al. (2005) tested technical acceptability, operational effectiveness, and clinical appropriateness of videophones in a convenience sample of 12 older (average age 85 years) participants residing in assisted living. Overall, this technology was well received in this small sample of seniors. Eleven of the participants were able to use the videophones follow simple verbal instructions. Only one participant found the equipment difficult to use due to interference from hearing aids. Most participants reported being comfortable with the videophones and 91% indicated that they would use in their homes if requested by their health care provider. However, the authors noted that videophones would not be appropriate for persons with severe vision or hearing impairment.



Demiris et al. (2008) conducted a small scale, exploratory study on the impact of videophone use between distant caregivers of residents in long term care. The sample consisted of four residents and six family members. All participants were asked to conduct at least one video-call per week and complete a technical quality report following each call. After 3 months use of the videophones, participants were interviewed and the interview transcripts were analyzed using a qualitative approach. The average technical quality rating was 94.75% out of 100%. All participants indicated that they found seeing their family member's face helpful in having a sense of closeness. Many participants were able to use the videophone to include the resident in other family interactions, such as, when a grandchild visited the distance caregiver. Family members reported that the videophone helped in assessing the condition of the resident and helped reduce their guilt about moving loved one into a long term care facility. Residents reported a reduction in feelings of isolation and loneliness. This study highlights the potential for videophone use among long distance caregivers whose care recipients are in their own homes, as well as, the need for additional research with this group.

Video conferencing or online support groups may be useful to long distance caregivers. Although not specifically addressing distance caregiving, the use of an online discussion group was found by Marziali and Donahue (2006) to be as effective as in-person group support. The online group participants demonstrated a significant decrease in caregiver stress. However, the high dropout rate (54%) in the control group requires that these results be viewed with caution.

An innovative application of older technology is the use of telephone support groups. Smith and Toseland (2006) conducted a random control test of 12 week group program with 36 spouses and 61 adult children. The participants were assigned to either the Telephone Support Group (TSG) or usual services as offered by the senior services center. The TSG was a manualized program consisting of check-in, practice of emotion-focused and then problem-focused coping strategies, and provision of support during each session. The results indicated that TSG was more effective for adult child caregivers than usual services in reducing burden, relieving depression, increasing social support, and knowledge and use of community services. There were no significant differences found for the spouse caregivers. This study employed a strong methodology and the findings are informative. However, as is common in the published literature on caregiving, geographic distance was not included in the demographics or as a study factor. The authors did note that the adult children caregivers often did not live with the care recipient.

Beauchamp et al. (2005) evaluated the effectiveness of an internet-based support program for employed persons providing care to family members with dementia. The study employed a random control design with 299 family caregivers assigned to either the internet delivered intervention or a waitlist condition. The intervention was 'Caregiver's Friend: Dealing with Dementia,' which is a multimedia program with text material and videos that model caregiving strategies. This intervention is personalized through the inclusion of participant's responses to a questionnaire that then provides a list of links with in the program relevant to that person's situation. The results are promising. After an average exposure time to the program of 32 min, seven of the tested outcome variables (depression, anxiety, stress, caregiver strain,



self-efficacy, intent to seek help, perception of caregiving) showed statistically significant improvement 1 month later. Consistent with these results, the participants reported high levels of satisfaction with the program. This study did not specifically address long distance caregiving, but it seems likely that internet-based programs would be equally convenient and effective for caregivers regardless of their proximity to care recipients.

Whenever implementing a new delivery format for an intervention, such as virtual psychotherapeutic support groups, many questions arise concerning the clinicians' ability to transition to the use of new technology. Damianakis et al. (2008) conducted a qualitative analysis of survey responses from a group of clinicians (n=8) who conducted weekly support groups with caregivers of family members with chronic illnesses via online video conferencing. All clinicians had been trained in the group intervention and received minimal technology training. The respondents were overall positive about delivering the support group in this format and perceived the online groups to be comparable to face-to-face therapeutic groups. Results indicated that online group approach required more engagement with group members in the pre-group phase and responsiveness to members' frustrations with the technology.

Finally, some research has been conducted on whether or not caregivers would accept technological aids to caregiving. Kinney et al. (2003) conducted two series of focus groups (n=26 and n=16) with primary caregivers for relatives with dementia to explore the use of electronic technology as a way to support caregivers. Kinney et al. found that caregivers endorsed the use of some type of visual monitoring system as an effort to bridge geographic distance. Proximal caregivers expressed the need for caregivers at a distance to literally see what was happening to their loved ones. They felt that this would be a much more effective way to communicate the changes their parents were experiencing.

Smart home monitoring systems are one of the newer technologies that are being implemented. Ohta et al. (2002) reported on a system using infrared sensors designed to follow room to room movement and then report changes in typical movement patterns to a family caregiver by telephone or email. The participants were eight older adults (average age 81 years) and were mostly female (87.5%). They found a very high rate of signal accuracy (error rate below.06%) in detecting unusual movement patterns. This is a very small sample, but the results are promising. This type of technology could be very useful to long distance caregivers provided caregivers have ready access to local resources to respond to care recipients' urgent needs.

Japan and Germany are perhaps the leaders in the development of robots and thus also lead the way in development of caregiving robots, so-called 'care bots' (Decker 2008). In the U.S., the Department of Veteran Affairs has developed an 'intelligent' walker that provides navigational support for persons with visual impairment (Mathews 2006). Field studies in retirement communities have indicated general acceptance of a version of 'intelligent walker' and of a robot that can navigate independently and uses voice and head gestures to guide residents who have difficulty finding their way, but the care recipients have also expressed the desire that robots be improved so that they can be more aware of and responsive to the user's needs (Mathews 2006).

In Germany, a technologically sophisticated robot (Care-O-Bot) has been developed that acts as an assistant for household chores and home care for elderly



or disabled persons to support independent living in their own homes (Decker 2008). The Care-O-Bot is mobile and uses cameras and a laser scanner. It is controlled by a detachable touch screen panel and by voice commands using a microphone. This robot has extensive multi-functionality and can perform household tasks (e.g., fetch-and-carry duties, basic cleaning), act as a mobility aid by allowing the care recipient to move behind the robot, act as a communication tool with an on-board camera system and videophone, act as a remote monitor of vital functions (i.e., pulse and blood supply) and can independently contact a physician or other outside resource in case of an emergency.

Decker (2008) also provides a detailed and thought provoking discussion of the many possible ethical issues in the implementation of such highly autonomous assistive robots. For example, the use of learning algorithms that make robots more responsive and useful to care recipients brings up issues of conflicts between the manufacturer and the end user as to what types of learning are important, how much flexibility is needed, etc. Furthermore, is it ever ethical to replace a caregiver with a robot? Decker cites current professional nursing guidelines that specifically prohibit the replacement of caregivers with robotic assistants. However, as the assistive robot technology continues to develop and costs to family caregivers for paid in-home care and for nursing home care continue to rise, this ethical issue will no doubt need to be confronted repeated.

Summary of Findings

Much of the research reviewed here provides descriptive information about long distance caregivers. The 'typical' long distance caregiver included in these studies is a middle aged woman (56% of Koerin and Harrigan's 2002 sample) or man (58% of sample in survey by National Alliance of Caregiving 2004) with a high level of education and income. Most caregivers were employed and reported several ways their work was impacted. An average of 20 h of missed work per month was reported, and those caregivers living at greater distance were more likely to take unpaid leave, turn down a promotion, and lose work benefits (National Alliance for Caregiving 2004).

The reported high levels of education and income may be a sampling artifact and in any case, leave us wondering about how low income families are dealing with this issue. Although Kinney et al.'s (2003) work focused on families providing care to a relative with dementia, it provides a starting point to further investigate the use of electronic technology in providing long distance care *and* preserving work productivity.

Long distance caregivers report being heavily involved in the care of their family member, regardless of distance. In contrast to Neuharth and Stern's (2002) finding that willingness to offer caregiving decreased as distance increased, other research specifically focused on long distance caregiving found a wide range of care being provided over sometimes very long distances. Surprisingly, in one survey 5% of respondents reported being the only and 18% the primary care provider to relatives who lived on average 424 miles away (National Alliance for Caregiving 2004). All studies reported frequent contact by telephone or mail.

New and emerging technologies, such as, detailed monitoring through the use of 'smart homes' and assistive robots seem ideally suited to care recipients who have



caregivers living at a distance. Research to date indicates that such assistive technologies are effective in addressing some care needs and are likely to be accepted by care recipients. Yet, consistent with other parts of the research literature reviewed, distance was not seen as a central factor in any of the reviewed studies on assistive technologies. Most research in this emerging field is focused on acceptance of various technologies by care recipients or the effectiveness of a particular technology in meeting certain care needs. While this approach is critical to the continuing development of assistive technologies, many other questions await attention

Future Research to Inform Best Practices in Long Distance Caregiving

A more thorough, contextualized approach is needed in future research to gain an increased understanding of what the long distance caregiver, the recipient of care, and their families are experiencing throughout the stages of this process. There are many limitations to the body of research reviewed here. Many of the studies were qualitative in nature. A qualitative approach has much to offer in exploring a new area, but the field now needs to move on to tests of effectiveness for interventions for long distance caregivers. Most quantitative studies reviewed were descriptive in nature. Descriptive data regarding long distance caregivers is necessary but not sufficient to guide policy or practice. With the exception of two national level descriptive studies, the sample sizes were very small. Finally, there is little research with long distance caregiving as its focus, and we consistently encountered research on caregivers or care recipients that did not include distance as a factor in the study.

The focus of this review was on research related to aspects of the long distance caregiver. However, many other important aspects of the long distance caregiving situation have not been explored sufficiently and contextual factors have not always been included in research. For example, in many families the ownership of primary caregiver role may be in dispute. It may be that there are other relatives who live in close proximity, but are more distant in the caring process. What, if any, family, community, or other cultural dynamics are reducing the role of geographically closer sources of support and increasing the role of the primary long distance caregiver?

In spite of the many obstacles to including cognitively impaired persons in the research process (i.e., Snyder et al. 2001) or persons who may be dealing with more than one serious, chronic illness, the person receiving care must be considered as part of any future explorations of this topic. Understanding care recipients' role in the unfolding process of caregiving and care receiving is critical. The current and past family and community roles of the person now designated as patient, client, or care recipient will be an important component here.

Other issues that need to continue to be explored are possible gender and ethnic differences. In earlier research, it has been noted that female relatives, generally daughters, have taken on a larger role of caretaking of older relatives. The findings related to long distance caregivers reported here are mixed. While Baldock (2000) concluded that gender was not a factor when providing care over very large distances, the survey conducted by the National Alliance for Caregiving (2004) found several differences by gender in the care situation and in impact on employment.



Conclusion

The results of this evaluative review of recent empirical research specific to long distance caregiving indicate that we have some valuable descriptive information about this subgroup of care providers. On the other hand, more research needs to be conducted to fill in the gaps in knowledge regarding the needs of people who give their resources, i.e., time, money, and material support to others from a distance. Future research should include the voices of the persons who are providing the care, as well as, those persons receiving the assistance. It may be that those being cared for have a different perspective on their own needs and the role of their caregivers and could be valuable in shedding light on this subject. What we learn from such research will better enable those within the human service arena to provide for the needs of long distance caregivers. Further, the results of such research could help inform us about creative approaches employers could implement to allow their employers to continue to be productive while caring for their elderly relatives and thus, benefit both parties. Certainly, many people relish the time spent with their frail loved ones, but it is nevertheless an often arduous task. Challenges associated with this caregiving role are greatly complicated by the need to provide care from a distance and are deserving of focused research.

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