

## Distance caregiving a family member with cancer: A review of the literature on distance caregiving and recommendations for future research

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### Abstract

Distance caregivers (DCGs) are a growing phenomenon in the United States. Family members are struggling to provide care to loved ones with chronic illnesses such as cancer, from a distance. Unlike local caregiving research, distance caregiving research is limited and inconsistent definitions of distance make it difficult to compare studies. To date, DCGs have not been afforded the opportunities for educational and emotional support that local caregivers have received from the health care teams. Because they are not usually present at medical appointments, DCGs do not receive first-hand information from the health care team about the patient's condition, disease progression, and/or treatment options. These caregivers report feeling left out of important family discussions. They experience anxiety related to the uncertainty of the family members' well-being and guilt related to not being available to help local caregivers more. The challenges of distance caregiving are especially evident when the distance caregiver has a parent with advanced cancer. Family-centered care, attending to the needs of the whole family regardless of their geographic location is critical for quality cancer care. In this manuscript, the sparse literature on distance caregiving is reviewed. Recommendations for future research and for the development of creative technologically advanced interventions for this underserved caregiving population are suggested.

**Key words:** Distance caregivers; Caregiving; Cancer caregivers; Long distance caregivers; Caregivers

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**Core tip:** Distance caregivers (DCGs) are an important subset of family caregivers who are understudied and receive little attention from clinical providers. The limited

research has identified that this growing population of caregivers experience anxiety, mood disturbances and distress, yet few, if any interventions for them exist. There is a need for more research to identify the benefits and burdens of DCGs and the impact of this burden on the caregivers, patient and family. Interventions providing support and education for this subset of caregivers must be designed and tested. Advanced technology offers unique strategies to deliver these interventions.

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## INTRODUCTION

With the increased mobilization of our society, the number of distance caregivers (DCGs) has continued to grow in the United States to represent about 7 million<sup>[1]</sup>, and is projected to double by 2020<sup>[2]</sup>. Approximately 15%-20% of all family caregivers are caring from a distance<sup>[3]</sup>. While much is known about local caregivers, research on distance caregiving is very limited. The negative physical and psychological impact of caregiving upon local family caregivers has been well established and various psycho-educational interventions have been tested to find meaningful approaches to minimizing these negative outcomes<sup>[4-6]</sup>. However, a subgroup of family caregivers - DCGs have been eliminated from most of the caregiving research and often find themselves marginalized in the clinical arena as well.

According to Bevan *et al*<sup>[7]</sup>, family members are the most important and frequent providers of informal care, yet they are rarely taken seriously. They are treated as secondary or informal caregivers even though some DCGs are the patient's primary caregiver<sup>[7]</sup>. This lack of recognition is especially difficult when the DCG's recipient is a family member with cancer and the DCG is dealing with worry and uncertainty associated with a life-threatening illness<sup>[8]</sup>.

What is known clinically is that DCGs are rarely able to attend medical visits regularly with their family member. Often DCGs are surprised at the physical and functional changes in their family member who is undergoing cancer treatment or struggling with advanced cancer. These changes can trigger DCG anxiety and distress which may be transformed into anger at the patient's care, questioning the current plan of care or demanding a second opinion<sup>[9]</sup>. DCG anger and distress can increase anxiety and distress in the patient, local caregivers, and health care team. In the clinical setting, some professionals dread the DCGs' visits and in the United States, professionals have labeled this distance caregiving phenomenon as "the daughter from California", or "the

son from New York", depending on the geographic location of the distance caregiver<sup>[9]</sup>.

## DEFINITION OF DISTANCE CAREGIVING

There is no consensus on the definition of distance caregiving. The common perception of a distance caregiver is one who lives far away and occasionally communicates with family members to see how their loved one is doing; however, evidence contradicts this assumption.

Several large national surveys of DCGs have reported that while, on average, DCGs do live far away (300-450 miles)<sup>[1,10]</sup>, over half of caregivers surveyed reported visiting the patient frequently (more than once/month)<sup>[11]</sup>.

The early work on distance caregiving was done with caregiving elders and parents with dementia and researchers used mileage to define distance caregiving. In 1988, Schoonover *et al*<sup>[12]</sup> studied adult children of 100 elderly mothers and described these caregivers as living more than 50 miles away.

Travel time, rather than mileage, has also been used to operationalize distance caregiving in research studies. However, travel time has not specified the means of travel, which complicates the generalizability of the studies. In a secondary cross-sectional analysis of the Family Caregiving Study, Wagner<sup>[1]</sup> defined DCGs ( $n = 200$ ) as those living at least 1 h away but found in their study that the DCGs lived an average of 304 miles from the care recipient. Random digit telephone dialing interviews conducted by the National Alliance for Caregiving and AARP in 2004<sup>[13]</sup>, and again in 2009<sup>[14]</sup>, uncovered that 15% and 13% of self-identified caregivers respectively were DCGs based on the definition of providing care and living more than one hour away.

Neuharth *et al*<sup>[15]</sup> used travel time to explore the role of adult children in caregiving decisions. They examined the association between caregiving responsibilities among siblings and travel time. They classified the distance as < 10 min, 11-30 min, 31-60 min, 61 min to 24 h, and 1 h or more. Not surprising, those requiring greater travel time to reach the parent provided less hands-on care. Similar to the Wagner<sup>[1]</sup> study definition of DCGs, Koerin *et al*<sup>[16]</sup> identified DCGs as those living more than 1 h away. However, they did report that their sample lived an average of 304 miles away from their ill loved one, which most likely exceeded the 1 h travel time if travel was by automobile.

A recent definition by Bledsoe *et al*<sup>[17]</sup> acknowledges that adding distance to caregiving increases the complexity of caregiving. The researchers operationalized the definition of DCG as: "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 caregivers cannot have daily face to face contact with the relative" (page 295).

While this definition may have been helpful in 2010, with the advent of face to face smart phone contact, it may not be applicable in the age of advancing technology. Following an extensive and systematic review

of the literature on long-distance caregiving, Cagle *et al.*<sup>[18]</sup> suggested that the definition by Parker *et al.*<sup>[19]</sup> is most comprehensive. It appears to be appropriate today and could apply to DCGs caring for a loved one with cancer. Their definition is: "Anyone (1) who provides informal, unpaid care to a person experiencing some degree of physical, mental, emotional, or economic impairment that limits independence and necessitates assistance; and (2) who experiences caregiving complications because of geographic distances from the recipient, as determined by distance, travel time, travel cost, personal mobility problems, limited transportation, and other related factors that affect the caregiver's access to the care recipient (page 391)".

Mazanec<sup>[20]</sup> conducted a small study ( $n = 80$ ) comparing anxiety and depressive symptoms in local and DCGs of parents with advanced cancer and initially defined distance caregiving by mileage, based on previous studies. However, DCGs and their care recipients self-reported that distance was not based on either mileage or travel time, rather on perception of being "at a distance". Those self-identified DCGs were living 1 h away or more, by automobile, making 2 h of travel time for a visit or medical appointment challenging. Many had to arrange child care or take time away from work, limiting their ability to visit as frequently as they would like to.

While there is not a consensus on how to define the distance in distance caregiving, it would seem that perception of distance by the caregiver or care recipient warrants the critical factor in defining distance. Based on the few studies that exist, it also seems that being 1 h or more away by any means of travel complicates the DCGs schedule and supports the perception that they are "long-distance" rather than local caregivers.

### Demographics and role of DCGs

The limited research that has been done has identified that the typical DCG is middle-aged, married, and has children<sup>[10,16,20]</sup>. Most DCGs provide care to a relative, usually a parent. Some studies found the majority of DCGs were female<sup>[13,20]</sup>, however, others have found the majority to be male<sup>[16]</sup>. Additional demographics show that most DCGs are employed full-time, are highly educated (college degree or more), and affluent<sup>[8,13,16]</sup>.

Because little is known about the distance caregiving experience, literature on local caregiving may help provide some insight as to the role of distance caregiving. A nonprofessional caregiver's role is to help someone with physical care or cope with disease<sup>[22]</sup>. The tasks associated with local caregiving are complex and include providing hands-on physical care, helping with daily and weekly household chores, transporting to medical appointments, managing financial affairs, and providing emotional support<sup>[23]</sup>.

DCGs are unable to provide hands-on physical care on a regular basis. However, they may be able to help with daily and weekly household chores from a dis-

tance if they have the resources to coordinate help for these chores and/or financially support hired help to assist the patient. Findings indicate that a majority of DCGs are significantly involved in not only making care decisions, but in managing daily aspects of their family member's care, such as arranging transportation, assisting with care coordination, and providing respite for local caregivers<sup>[10,11,24,25]</sup>. Many DCGs report taking over the management of the patients' financial affairs<sup>[15,26]</sup>. This eases the burden on local caregivers and gives the DCG a sense of involvement.

Probably the one of the most important roles of DCGs is that of providing emotional support to both the care recipient and the local caregivers. Providing emotional support from a distance can be a challenging responsibility, especially when the patient has advanced cancer and the entire family is struggling with the diagnosis, treatment sequelae, and prognosis. Knowing how to be an effective listener, provide hope while maintaining trust, and empower the patient to manage care takes skill. It is important to note that although caregivers have described the burdens associated with providing hands-on physical care or tangible assistance, many caregivers have reported that the provision of emotional support can be more burdensome than physical care<sup>[4,27]</sup>.

## BURDENS OF DISTANCE CAREGIVING

Much of the local caregiving research has focused on caregiver stress and burden. Caregiver burden is known to negatively influence the physical and psychological well-being of the caregivers<sup>[4-6]</sup>. Psycho-educational interventions have been designed to assist the local caregiver in the role and to provide support.

Like local caregivers, DCGs experience poor physical and psychological wellbeing related to caregiving. In addition, DCGs experience the added stressors associated with caring from a distance. Uncertainty as to when to visit, especially if resources for travel are limited, causes worry and distress. Additional financial burdens occur because of travel expenses and time away from employment. Psycho-educational and supportive interventions for DCGs are limited to popular press materials and internet websites for caregivers.

### Burden on DCG psychological well-being

Schoonover *et al.*<sup>[12]</sup> reported that more than half of the 50 DCGs studied reported feeling helpless and anxious and 80% reported "at least some strain" caused by living away from the patient. Koerin *et al.*<sup>[16]</sup> described that almost 80% of DCGs reported stress related to feelings of inadequacy regarding how to assess the status of their loved one and uncertainty regarding how their loved one is progressing in terms of their illness. These additional sources of stress are felt to relate to evidence that DCGs are at greater risk than local caregivers for unrelenting anxiety and mood disturbances<sup>[20]</sup>.

**Financial burdens of distance caregiving**

While a majority of DCGs are employed, almost 50% report having to rearrange their work schedules to accommodate activities related to caring for their loved one from a distance. Some have reported having to turn down a promotion and give up work benefits<sup>[16]</sup>. More than one-third report consistently missing days of work for caregiving responsibilities and in addition to lost work, they spend an average of \$400-\$700/month on travel and out-of-pocket expenses, depending on how far away they lived<sup>[16]</sup>. In a telephone survey of local and DCGs, DCGs had annual expenses of \$8728 compared to \$4570<sup>[28]</sup>.

**Distance caregiving burdens and cancer caregiving**

A diagnosis of cancer is a major life stressor for the person with cancer and the whole family, including those living far away<sup>[29,30]</sup>. With the advent of many new cancer treatment options, patients with advanced cancer and their families are struggling with the prolonged and difficult course of the disease. Caregiving burdens not only have increased in intensity, but are being experienced over longer periods of time. Depending on the type of cancer and expected disease trajectory, fears related to prognosis and treatment options are overwhelming. Caregivers worry that they may be unable to manage pain and symptoms<sup>[4-6]</sup>. While patients have reported fears of cancer recurrence and uncertainty about the future, so have their local family caregivers. DCGs of family members with cancer experience these same worries and fears but often with limited social support or support from the oncology team.

There is limited research available on DCG of patients with cancer. In the previously cited small study comparing local and DCGs, Mazanec<sup>[20]</sup> found that distance caregiving was statistically significantly associated with caregiver anxiety and total mood disturbance. In addition, the distress scores reported exceeded the threshold for requiring intervention as established by the National Comprehensive Cancer Network Distress Guidelines<sup>[21]</sup> and the distress scores of DCGs were higher than those of local caregivers.

In the qualitative component of this mixed-methods study, DCGs ( $n = 14$ ) described stress, uncertainty, guilt, and anxiety specifically related to their distant geographic location and in addition to the known stress of having a family member with advanced cancer. DCGs felt disconnected from their family and the oncology team, and "out of the loop" because they were not able to come to the cancer center with their parents or visit as often as they would like. Many struggled with anxiety over when to plan a visit, especially if travel resources were limited, if they would be able to get home quickly enough in time of need, or how to be helpful to their parents and local family members<sup>[8,20]</sup>. They relied on information from the patient and/or local caregivers and many DCGs believed information was withheld from them because their parents didn't want them to worry<sup>[8]</sup>.

**BENEFITS OF PROVIDING DISTANCE CAREGIVING**

Benefits of caregiving, in addition to the burdens, have been reported from research findings on local caregivers<sup>[5,6]</sup>. Like local caregivers, DCGs have reported finding meaning and purpose in providing care<sup>[1,8,10,24,25]</sup>. Some DCGs have described a sense of personal satisfaction from being a caregiver and others noted the commented on the rewards of fulfilling a responsibility to their family.

Interestingly, some DCGs of persons with cancer reported that there is a unique benefit to be a DCG in that they don't have to deal with the cancer on a daily basis like the local caregivers may have to. These DCGs remarked that their telephone conversations with their parent could be about "everyday" things like ball games and grandchildren's recitals<sup>[8]</sup>. They enjoyed having this long-distance relationship with their parents which offered them the opportunity to talk about life rather than illness.

**INTERVENTIONS FOR DISTANCE CAREGIVING**

Although a number of psychosocial and educational interventions have been developed to help local caregivers with their tasks and minimize their caregiver burden, little has been developed to assist the DCGs. The limited research has identified DCGs want to feel more connected to the patient, family, and health care team, have the same access to information about the patient's disease trajectory and treatment options that local caregivers have, and have a system of support for the unique needs of DCGs<sup>[8,20]</sup>.

Advancing technology should be able to provide the needed support to DCGs. The world-wide internet offers the best alternative to in-person support. While no one has examined the use of telemedicine with the patient and caregiver population, there is literature addressing the use of this type of technology for physician-to-patient communication in various settings as for patient-to-family communication in the home and in long-term care facilities for patients with dementia<sup>[31,32]</sup>. The key benefits of the use of telemedicine in these situations were a sense of closeness<sup>[32]</sup>.

While significant evidence exists that distance caregiving is a growing phenomenon-one that brings untoward negative effects-little empirical work exists that examines feasible approaches to minimizing these negative effects upon these vulnerable caregivers. A recent pilot study ( $n = 7$ ) using video-conferencing, offered DCGs the opportunity to communicate with their loved one, the local caregiver, and members of the healthcare team-in "real time" during oncology office visits. The researchers examined the effect of this intervention upon patient and distance caregiver anxiety and distress while also determining if the intervention was feasible and acceptable within the healthcare system<sup>[33]</sup>.

The pilot study utilized a convenience sample of patients with advanced brain or lung cancer from a large Midwestern National Comprehensive Cancer Center. All individuals enrolled in this pilot study received the videoconference link for smart phone or tablet and were connected electronically into a single office visit that included the patient, oncologist, nurse, and local and distance caregiver. The average age of the patients was 60 and DCGs was 42. Most of the patients were female and most of the DCGs were male. The majority of patients and caregivers were Caucasian (71.4%) and married (85.7%; 57.1% respectively). Although only 28.6% of patients were employed, 100% of DCGs were employed. The average distance between the patient and DCG was 1059 (819.7) miles.

Although the pilot sample size was small, significant reductions in DCG anxiety and distress from pre- to post-videoconference meeting were identified. The pilot demonstrated the feasibility as well as the efficacy of the intervention but did not examine whether efficacy was maintained over time. Oncologists' reports of acceptance were very high, with scores averaging 2.83 (0.41) on a 1-3 scale when asked if they would like to use this technology with more patients. Anecdotal comments from oncologists included these: (1) "This was extremely helpful as this patient has some cognitive and compliance issues and his wife works out of town, *etc.* and I could tell that she really appreciated this aid"; and (2) "I was afraid that this would take more time - having another person involved in the office visit, *etc.* I found that I spent less overall time since the DCG didn't call me after the meeting asking questions and asking for clarification<sup>[32]</sup>.

## FUTURE RESEARCH

Much work remains to be done to understand the benefits and burdens associated with distance caregiving and to develop interventions to address those burdens. As the phenomenon continues to grow, supports must be put in place to deal with the stressors of this new role and to meet the educational needs of DCGs as we have done for local caregivers.

Research that has been done has often been limited to surveys and secondary analyses of large data sets with the inconsistent operationalization of distance. Most of the work has been descriptive and has been done with DCGs of elderly parents or patients with dementia. Although there is still a need for descriptive studies with larger sample sizes from different populations, it is time to move beyond the descriptive. Research is needed to demonstrate the effects of the known DCG anxiety, mood disturbances and distress on the patient and local caregiver. Quality cancer care addresses the needs of the whole family, regardless of the geographic location of the family members.

Longitudinal research and mixed methods approaches will give us the information we need to prioritize DCG needs over the patient's disease trajectory. This

is especially critical for DCGs of patients with cancer, who now are living longer and have the potential for more intense and burdensome caregiving needs. The findings from this work could lay the groundwork for interventional research for DCGs of patients with cancer and other life-limiting chronic illnesses.

Most importantly, intervention studies, using a randomized controlled design are needed to advance the caregiving science. Knowledge gained from psychoeducational interventions for local caregivers can be applied to DCGs. Advanced technology can provide the strategies for delivering these interventions. Development of evidence-based DCG internet services can provide educational and social networking resources to DCGs around the clock, every day of the week. Caring from Afar<sup>[2]</sup> is an example of a web-based connection, but few DCGs are aware of its availability and to date, no research has been done on its effects on caregiver psychological wellbeing.

The Douglas *et al.*<sup>[33]</sup> pilot study demonstrated the feasibility of using advanced technology to connect DCGs with family and the health care team. Interventions using smart-phones and/or tablets have the potential to decrease anxiety and distress for not only the DCGs but also for the patients and local caregivers. Larger randomized controlled trials comparing usual care for DCGs with a psychoeducational program including web-based resources and smart-phone/tablet connections into the health care system are needed. Although there are challenges with privacy and institutional firewalls, the benefits of integrating this level of family care far outweigh the challenges. The potential for providing family-centered care through the use of technology is within our reach.

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