Long-Distance Caregivers: What Are Their Experiences with Formal Care Providers?

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Abstract

Objectives: Extensive literature has documented the experiences of informal caregivers and their interactions with formal care providers, yet this research is almost entirely limited to caregivers who live near their care-recipients. This study aims to describe long-distance caregivers' (LDC) experiences (e.g., satisfaction and challenges) with formal care providers. Subgroup differences were examined based on the care-recipient's (CR) dementia status and residential setting (community versus residential care).

Methods: Data were collected from 296 LDCs (M_{age}=56.64, SD=12.40) categorized into four subgroups based on CR dementia status and residential setting. Participants rated their overall satisfaction, satisfaction with communication and information, and described challenges faced in their interactions with formal care providers.

Results: Challenges related to formal care providers were significantly greater and satisfaction significantly lower among LDCs of CRs in residential care, irrespective of dementia status, when compared to LDCs of CRs in the community.

Conclusions: This study provides insights into the experiences of a growing segment of the caregiver population managing care from a distance, specifically in their interactions with formal care providers.

Clinical Implications: The results of this study point to the possible necessity for the development of novel interventions to improve and enhance communication and collaboration between FCPs and informal caregivers.

Keywords

Long-distance caregiving; formal care providers; caregiving; long-term care; nursing homes

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Introduction

Advanced age increases the likelihood of experiencing age-related illnesses that can interfere with the ability to independently care for oneself (Davis et al., 2011). The rapidly increasing older adult population, and the chronic nature of the healthcare challenges they face, places an increased demand on the healthcare system (Prince et al., 2016) and on unpaid caregivers who provide the bulk of help to older adults with chronic conditions (Pavolini & Ranci, 2008; Wolff et al., 2016). Although there are considerable differences in the appropriate terminology recommended to define these caregivers (e.g., Stall et al., 2020), which can include family and friends, they will be referred to as informal caregivers in this paper to be consistent with previous literature. For many, the informal caregiving experience is quite dynamic and complex as individuals learn to provide and monitor care for their loved ones, navigate the healthcare system, communicate with formal care providers (FCPs), and manage multiple responsibilities in addition to their role in providing care. Moreover, there is a strong empirical research base demonstrating the potential negative effects of caregiving, such as poorer health (e.g., Patterson & Grant, 2003; Son et al., 2007), well-being (Au et al., 2010; Haley et al., 2003; Herrera et al., 2013; Schulz & Martire, 2004), increased stress and burden (Davis et al., 2011), and financial strain (Reinhard et al., 2008). Although a myriad of research exists examining the effects of caregiving, this area of research has almost been entirely limited to caregivers who are geographically close to their care-recipient (CR).

Interactions among Informal Caregivers and Formal Care Providers

Information needs.

Informal caregivers, especially those who provide assistance to individuals with complex medical issues or cognitive impairment, often do not feel equipped with the proper information, skills, and training to provide optimal care (Bucher et al., 2001; Scherbring, 2002). A study involving informal cancer caregivers (Iconomou et al., 2001) found that a significant portion of caregivers expressed a need for more information from their CR's oncologists, and higher unmet information-related needs was associated with greater dissatisfaction with FCPs. Similarly, in a study of dementia caregivers, Jennings and colleagues (2015) found that caregivers frequently reported that they did not have contact with an FCP who could adequately help them navigate the CR's dementia-related behaviors, which may impact the caregiver's feelings of self-efficacy to provide quality and effective care. This further exemplifies the need for more relevant caregiver support services and suggests that "the current model of primary care does not facilitate adequately addressing the complexities of dementia care" (Jennings et al., 2015, p. 287).

Communication needs.

Similar to the critical need for information, a particular source of frustration for caregivers is the lack of communication and information provided by members of the formal health care system (Cagle & Munn, 2012; Edwards, 2014; Stajduhar et al., 2013; Wetle et al., 2005). Although not often perceived as such, informal caregivers represent an integral component of the primary care team in addition to FCPs, and enhanced coordination between caregivers and FCPs has been associated with better health outcomes for CRs (Koerin & Harrington,

2002; Gittel, 2000; Weinberg et al., 2007). Relatedly, Gittell's (2005) theory of relational coordination posits that effective coordination between caregivers and FCPs depends on frequent and high-quality communication characterized by shared goals, shared knowledge, and mutual respect, highlighting the caregiver as a member of the care team. However, FCPs – without malicious intent - tend to focus on solely addressing the needs of the patient while overlooking the needs of informal caregivers (Morris & Thomas, 2002; Stajduhar, 2003; Weinberg et al., 2007). Problems reported by caregivers related to FCPs include lack of time and skill in having conversations with family members, understaffing, and inadequate care provided to the CR (Shield et al., 2005; Wetle et al., 2005). These factors can contribute to increased psychological distress and feelings of uncertainty regarding the CR's health status (Bevan et al., 2011). In a study examining caregivers of patients who underwent knee surgery, Weinberg and colleagues (2007) found that higher levels of relational coordination (frequency of communication, quality of communication, and supportive relationships) between FCPs and caregivers was positively related to enhanced caregiver competency to provide and manage care at home. Additionally, CRs of caregivers who felt more prepared to provide care reported more freedom from pain, better functional status, and better mental health.

Advocacy and acknowledgement needs.

Caregivers of frail older adults, particularly of those with cognitive impairment, need to play an active role in care and serve as the CR's advocate. It is of critical importance for caregivers to have access to frequent and accurate information regarding the CR's health status in order to help with providing and arranging services for the most optimal care and making accurate and informed healthcare decisions. Moreover, caregivers can provide a wealth of information about the CR's history that may be important in establishing care plans and recognizing unmet needs in the CR (Edwards, 2014). However, caregivers are often overlooked as an important component in the effective delivery of person-centered care. A semi-structured qualitative study of informal cancer caregivers revealed that caregivers desired to be more "visible" in their interactions with FCPs (Harding et al., 2012). That is, caregivers want to be acknowledged by FCPs regarding their expertise in caring for the patient and wish to have more time and opportunity to express their concerns, advocate on behalf of the care-recipient, and discuss specific illness-related information with FCPs.

Challenges in long-term care.

Many informal caregivers at some point in their caregiving career may be faced with the difficult decision of needing to place their loved one in a long-term care facility. Often, this decision is inevitable because caregivers may experience challenges with meeting increasing care demands due to the progressive nature of their loved ones' chronic illnesses. Although there may be a shift in the caregiver's objective care responsibilities after a CR's placement in a long-term care facility, caregivers remain actively involved in the care-process (Ejaz et al., 2012). A wealth of research has examined satisfaction with FCPs in long-term care settings and despite the critical role residential facilities play in providing a range of care to the growing older adult population, these institutions tend to be under-resourced (Barken & Lowndes, 2018) and deal with consistent organizational-level issues such as staff burnout and high rates of turnover (Kemp et al., 2009). Family caregivers are often dissatisfied with

nursing home services due to understaffing, inadequate training/competence, impersonal care, and poor symptom management (Engel et al., 2006). Research has also shown that care provided to patients in nursing homes appear to be more task-centered than person-centered, which is likely related to staff workload, leaving minimal time to address the concerns of family members (Hertzberg et al., 2003; Liu et al., 2012). Evidence exists documenting the strong relationship between long-term care FCP communication with family caregivers, overall family satisfaction, and better patient outcomes (e.g., Engel et al., 2006; Liu et al., 2012; Majerovitz et al., 2009; Thompson et al., 2008). In a study investigating family satisfaction with nurse practitioners in nursing homes caring for persons with dementia at the end of life, Liu et al. (2012) found that communication (e.g., keeping family informed of changes in the CR's condition, giving families frequent opportunities to ask questions, and establishing ongoing relationships with FCPs) was a significant predictor of overall satisfaction with care.

Caregiving for a CR with cognitive impairment.

The need for information and transparent communication for caregivers is heightened when providing care to CRs with conditions, such as dementia, that result in increasing dependency, impairment, and communication difficulties through the disease's progression (Gittell, 2005). As the CR's condition worsens, caregivers may be hypervigilant in monitoring care and advocating on the CR's behalf. Dementia caregivers have been consistently shown to experience higher levels of burden and worse mental and physical health compared to non-dementia caregivers (e.g., Karg et al., 2018; Pinquart & Sorenson, 2007). Caregivers for CRs in the community are required to monitor the provision of direct care needs, but also ensure the provision of emotional support to the CR. Dementia caregivers in the community report a lack of transparency in information and communication with FCPs, as well as difficulties in navigating dementia-related behavioral symptoms and obtaining training, referrals, and access to services. These challenges reported with FCPs, in turn, have been related to increased levels of caregiver burden (Silva et al., 2013; Singh et al., 2014). Furthermore, these feelings may be exacerbated when persons with dementia enter long-term care facilities, where care tends to be more structured and task-oriented, which may contribute to lower feelings of satisfaction with FCPs (Bauer, 2006; Barken & Lowndes, 2018). In long-term care, family members are important contributors to the quality of care a resident receives, and they often remain actively involved in many aspects of care following placement (Bauer, 2006; Gaugler & Kane, 2007; Roberts & Ishler, 2018). For dementia caregivers, family members must rely on staff for information about the residents, who are often unable to report for themselves. Further, the behavioral symptoms frequently manifested by dementia may lead to more tense interactions with FCPs about care (Robison et al., 2007). Thus, there is reason to hypothesize that caregivers with CRs who have dementia will be less satisfied with communication with FCPs, and this may be exacerbated when a CR is in a long-term care facility.

Focus on Long-Distance Caregiving – Study Purpose

A myriad of research has examined the potential consequences of caregiving, but the existing work in this area has been almost entirely limited to geographically proximate caregivers. Long-distance caregivers (LDCs) – caregivers who do not live geographically

close to their CR - comprise a growing sub-population of caregivers who remain largely understudied in the caregiving literature. Our increasingly mobile society, along with declines in birthrates and increased population migration, has shifted the structure of care provision with more individuals providing care from afar than ever before (Benefield & Beck, 2007; Koerin & Harrington, 2002). In the United States, approximately 10% of all caregivers and 9% of dementia caregivers live more than two hours away from their CR (Alzheimer's Association, 2010; NAC & AARP, 2009); and roughly one-fourth of LDCs reported being the primary or only caregiver for a CR (Metlife & NAC, 2004). Although LDC is an understudied phenomenon, the limited research in this area indicates that the assistance provided (e.g., financial management, emotional support, personal care, decision-making) by LDCs when compared to proximate caregivers are relatively similar (Baldock, 2000; Roff et al., 2007; Vezina & Turcotte, 2010). However, the specific experiences of LDCs and their interactions with formal care providers have not been examined

The limited research conducted on LDCs has found that LDCs also report equal or greater levels of emotional stress compared to proximate caregivers. Thompsell and Lovestone (2002) reported that despite having equal levels of distress compared to geographically proximate caregivers, LDCs have lower access to information and are more frequently dissatisfied with the information that is received. Distance can potentially add an additional barrier to accessing frequent and consistent communication with FCPs regarding the CR's condition, making it much more difficult to monitor and ensure optimal care. However, despite the literature that exists on caregivers' satisfaction with communication and information, relatively little is known about the specific experiences of LDCs with FCPs. It is also unknown how these experiences of LDCs with FCPs may be differentially influenced based on whether the CR has a diagnosis of dementia, and whether the CR lives in residential care or in the community. Thus, the purpose of the current study is to describe and explore LDCs' experiences (e.g., overall satisfaction and challenges) with their CRs' FCPs. We investigated LDC subgroup differences in their experiences with FCPs based on CR cognitive status and residential setting. Specifically, these groups are defined as: 1) LDCs of CRs with dementia living in residential care; 2) LDCs of CRs with no dementia living in residential care; 3) LDCs of CRs with dementia living in the community; and 4) LDCs of CRs with no dementia living in the community.

Methods

Participants

Data for the current mixed-method study came from a larger cross-sectional study on LDC (Horowitz: R21-AG050018; *N*=304). Participants were recruited from multiple sources: aging service organizations (45%), researchmatch.org, a large national database of persons interested in research participation (41%), professional networks, participant referrals, and an existing pool of research participants involved in an aging study, with the latter three sources comprising 14% of the sample. Both English and Spanish-speaking caregivers were included. Recruitment letters or emails were sent to potential participants from all sources describing the study and eligibility criteria. The study team contacted prospective participants by telephone, or were contacted by them, after the initial letter or email.

The telephone eligibility screening determined if potential participants 1) have primary or equally shared responsibility for the care of an older adult relative, 2) the relative is functionally impaired (difficulty with 2 tasks of activities of daily living - e.g., bathing, dressing, etc.), or unable to do at least 1 without assistance, and 3) live 2 hours travel from the CR. The amount and/or type of care provided was not an eligibility criterion in order to represent the full range of caregiving involvement. Individuals who met eligibility criteria and provided informed consent then participated in a telephone survey that lasted approximately one hour.

The sample in the current study consisted of 296 LDCs falling into four subgroups of LDCs based on CRs' living arrangement and cognitive status: 1) a CR in a residential facility with a diagnosis of dementia (n= 58); 2) a CR in a residential facility with no dementia diagnosis (n = 65); 3) a CR with a dementia diagnosis living in the community (n = 49); and 4) a CR with no dementia diagnosis living in the community (n= 124). Eight participants in the original study sample (N=304) were excluded from the analysis due to missing data. Across groups, LDC participants were between the ages of 25–86 years (M_{age}=56.64, SD=12.40), with 73% of the sample consisting of females. See Table 1 for sample characteristics organized by subgroup. The study was approved by the Internal Review Boards of the institutions where the study was conducted.

Measures

LDC sociodemographic and health-related characteristics.

Single items were used to assess LDC age, gender, education, race/ethnicity, along with relationship and distance to the CR. CR dementia status was assessed with a one-item question: "To the best of your knowledge, has your (…) been diagnosed with any type of dementia?" Similarly, the CR's residential setting was assessed with a single item asking LDCs if the CR currently lives in a residential facility (i.e. nursing home, assisted living) or in the community.

Overall satisfaction with FCPs.

Two items were administered to measure satisfaction with FCPs. The first item asked participants how satisfied they are in general with the care that the CR is currently receiving from health care providers. The second item assesses the level of LDC satisfaction with communication and information received from health care providers. For both items, response options ranged from 0 = very dissatisfied to 5 = very satisfied.

Challenges related to FCPs.

Challenges experienced with FCPs were assessed qualitatively. Participants were given an open-ended question asking about the types of challenges they have experienced related to LDC.

Data Analysis

Descriptive statistics were computed for all study variables to check for normality in the distribution of data. Then, a series of between subjects' one-way ANOVAs were conducted

to examine group differences on overall satisfaction with care and overall satisfaction with FCP-related communications and information received among the four LDC subgroups. For each ANOVA, the assumption of homogeneity of variances using Levene's test was not met ($p<.05$). Thus, Welch's ANOVA was instead used as this test is unaffected by unequal variances and exhibits nearly equivalent statistical power with the classic ANOVA (Delacre et al., 2019). Games-Howell tests were used to examine post-hoc comparisons. Thematic coding, using Atlas.ti 8 software for qualitative data analysis, was conducted by two members of the study team to identify emergent themes in the open-ended item assessing challenges related to LDC. Because we were interested in quantifying the data to compare challenges among our four subgroups, the total number of challenges mentioned related to FCPs and the specific challenges mentioned (e.g., dealing with inadequate care) were recorded and used in the current analysis. As previously noted, because the assumption of homogeneity of variances was not met, a Welch's ANOVA was then conducted to examine group differences in the frequency of reported challenges relating to FCP, followed by $\chi2$ tests to examine differences in the proportion of the two challenges most frequently mentioned by LDCs among the four groups of LDCs.

Results

Satisfaction with FCPs

Overall satisfaction with FCPs.—On a descriptive level, LDCs with CRs in residential care reported the lowest overall satisfaction with FCPs, particularly LDCs with CRs in residential facilities without a dementia diagnosis. However, a one-way between subjects' ANOVA using Welch's adjusted F ratio (1.90) revealed no significant differences across subgroups for overall satisfaction with FCPs, Welch's $F(3, 124.14) = 1.90$, $p=.14$.

LDC satisfaction with information and communication.—When examining ratings of satisfaction with communication and information received from FCPs, LDCs of CRs with dementia living in the community reported the highest level of satisfaction, and LDCs of CRs without a dementia diagnosis in residential care reported the lowest. A one-way ANOVA using Welch's adjusted F ratio (3.80) indicated that there was a significant effect [Welch's $F(3, 128.47) = 3.80$, $p<.05$] for satisfaction with communication and information across groups. Games-Howell post-hoc analyses revealed that LDCs who provide care for a CR in a residential facility *without* a diagnosis of dementia ($M=3.05$, $SD=1.90$) were significantly less satisfied with FCP-related communication and information compared to LDCs who care for a CR *with* dementia residing in the community ($M=4.06$, $SD=1.47$). Group differences also emerged between LDCs caring for a CR in a residential facility *without* a dementia diagnosis ($M=3.05$, $SD=1.90$) and those caring for CRs with no dementia living in the community ($M=3.84$, $SD=1.61$) – the latter group reported significantly higher satisfaction with FCP communication and information when compared to the former.

Challenges related to FCPs

Number of challenges.—In response to the open-ended question assessing the types of challenges that LDCs face in providing care from a distance, participants mentioned

between 0 and 3 challenges specifically relating to FCPs (M=.31, SD=.61, See Table 1). Across groups, 224 participants (76%) did not mention any challenges specific to FCPs, while 72 LDCs (24%) reported at least one FCP-related challenge. Of these participants, 54 LDCs (75%) mentioned one challenge, 15 LDCs (21%) mentioned two challenges, and 3 LDCS (4%) mentioned three challenges related to FCPs. Using thematic coding to identify emergent themes, the two most common challenges to emerge relating to FCPs were difficulty dealing with inadequate care (n=30, 9.9%) and difficulty communicating and receiving information from FCPs (n=61, 16.8%). To provide qualitative examples of the FCP-related challenges that LDCs experienced, illustrative quotes were selected and are depicted in Table 2.

The variable representing FCP-related challenges was skewed (2.08) and kurtotic (4.11). This variable was transformed using the square root transformation method and was used in subsequent analyses. To assess group differences in the total number of FCP-related challenges reported by LDCs, a one-way ANOVA using Welch's adjusted F ratio (11.34) was conducted and revealed statistically significant group differences [Welch's F(3, 116.90)=11.34, p<.001]. Games-Howell post-hoc analyses indicated significant differences between LDCs of a CR with dementia living in a residential facility (M=.43, SD=.55) and without dementia residing in the community (M=.11, SD=.34), with the former group reporting significantly more challenges related to FCPs. Furthermore, LDCs of a CR with no dementia in a residential facility (M=.48, SD=.56) reported significantly more challenges compared to LDCs of CRs with no dementia living in the community.

Dealing with inadequate care.—In addition, chi-square tests were performed to examine the proportion of LDCs across groups who reported dealing with inadequate care. Results showed that a significantly greater proportion of LDCs who provide care for a CR in a residential facility, with (33%) or without (37%) dementia, reported that dealing with inadequate care was a challenge compared to LDCs with CRs living in the community, both with (20%) and without (10%) dementia ($\chi 2$ = 14.85, p<.01).

Difficulty communicating and receiving information.—A chi-square test was conducted to assess the proportion of LDCs who reported challenges related to difficulty communicating and receiving information from FCPs, and similarly found that a greater proportion of LDCs who provide care for a CR in a residential facility, with (34%) or without (38%) dementia reported having difficulty communicating and receiving information from FCPs compared to LDCs who provide care for CRs with (10%) or without (18%) dementia in the community ($\chi 2$ = 23.18, p<.001).

Discussion

The current study sheds light on LDCs' perceptions of satisfaction and challenges experienced with FCPs, adding to the emerging body of literature on the experience and impact of LDC. Study results showed that there were no subgroup differences identified for overall satisfaction with FCPs. However, we found that LDCs who provide care for a CR in a residential care facility, irrespective of dementia status, reported more challenges and lower levels of satisfaction with communication and information received from FCPs when

compared to LDCs of CRs, with or without dementia, living in the community. Along the same lines, LDCs who provide care for a CR, both with and without dementia diagnoses, living in a residential facility were more likely to report inadequate care and difficulty communicating and receiving information from FCPs as major challenges when compared to LDCs of a CR, both with and without dementia, living in the community. The findings about challenges that LDCs experience regarding FCPs are in line with previous literature on geographically proximate caregivers (e.g., Engel et al., 2005; Wetle et al., 2005).

It is not surprising that prior research has shown that LDCs may experience equal or greater levels of emotional stress compared to proximate caregivers (Thompsell & Lovewell, 2002). The necessity of dealing with and managing formal care from afar may add to the stress experienced by LDCs. The addition of distance as a barrier to effective communication between LDCs and FCPs makes it much more difficult to foster connections with FCPs. Alternatively, FCPs may hold the perception that LDCs are not actively involved in the care process because LDCs may not able to be physically present at appointments, care-plan meetings, etc. at the same frequency as geographically proximate caregivers, which can potentially shed light on how miscommunication can originate between FCPs and LDCs. Overall, LDCs with CRs with and without dementia living in residential care reported lower satisfaction and a greater number of challenges with FCPs. As noted in prior work (e.g., Hertzberg et al., 2003; Liu et al., 2012), residential care facilities tend to be more task-centered rather than patient centered, and institutional barriers, such as time restrictions, hinder the consistent flow of communication between FCPs and LDCs. LDCs, because of their less visible physical presence, may therefore be left out of the direct communication loop. This could be a source of frustration and may add an additional layer of complexity for LDCs in navigating their caregiving role because they are not receiving information about the CR's condition and care from FCPs. A particularly interesting finding that emerged in the current study is that satisfaction with information and communication was lowest for LDCs who care for a CR in a residential facility *without* a diagnosis of dementia. This finding may seem counterintuitive given that it is typically assumed that caregivers who hold more responsibility (e.g., for a person with cognitive impairment) may exhibit lower levels of satisfaction. However, it is possible that communication is a significant barrier in CRs without dementia in residential care because in the absence of cognitive impairment, FCPs may instead be discussing and addressing issues directly with the CR. This may add additional complexity for LDCs in navigating their caregiving role because they are not receiving direct information from the FCP, and the information may instead be communicated by the CRs. As previously mentioned, Gittell's (2005) theory of relational coordination suggests that caregivers and FCPs must both commit to shared goals, shared knowledge, and mutual respect in order to achieve effective coordination between the formal and informal care networks. Thus, despite distance being a barrier to in-person communication, FCPs and LDCs must prioritize effectively communicating with one another through other means, such as virtual or electronic correspondence and technological resources (e.g., using Skype to participate in care plan meetings), to support LDCs and facilitate communication with FCPs, for the benefit of the CR.

The results of the current study should be considered in the context of its limitations. Study participants were partly recruited using convenience sampling, which possibly limits the

generalization of findings. Further, the items assessing satisfaction and challenges in LDCs asked participants about their experiences with FCPs in general. Future research would benefit from the examination of LDCs' interactions with different groups of FCPs (e.g., physicians, direct care staff). Additionally, although the purpose of the current study was to descriptively define and compare LDC interactions with FCPs, future research should also utilize multivariate analyses to further examine these relationships. Furthermore, although the current findings shed light on the challenges that LDCs experience, it should also be noted that only slightly more than one-third of our sample spontaneously specified challenges related to FCPs when asked in general about challenges associated with long-distance caregiving. Although a small number of LDCs endorsed challenges related to FCPs, the current findings nonetheless highlight that these sources of frustration do exist for LDCs.

Despite its limitations, our study provides insight into the experiences of a growing number of caregivers who organize and provide care from a distance and highlights several important implications. FCPs, particularly those who are involved in the provision of residential long-term care, need to be cognizant of the changing demographic of caregivers and work to provide more, in-depth information to caregivers who provide care from afar. Consistent with a patient-centered care approach, personalized care provided to the CR would be more efficient if these specialized care plans consider the importance of the caregiver, regardless of proximity, as a member of the primary care team to provide the most optimal quality of care to CRs. Moreover, FCPs should also dedicate increased time and effort to engage in consistent conversations regarding the CR's care with informal caregivers, especially when the primary caregiver lives a significant distance away from the CR and the facility s/he resides in.

The current study is novel in highlighting the experiences of a unique, but ever-growing population of caregivers, provides insight on the challenges that LDCs face with the healthcare system, and is important for the purpose of designing interventions to foster connections between LDCs and FCPs. Interestingly, a recent thematic synthesis found that in some instances, FCPs felt unsure or unable to effectively collaborate with informal caregivers, suggesting that strategies for supporting FCPs to support informal caregivers should be a priority in the educational curricula of healthcare professionals, with a particular focus on the diverse needs of proximate as well as LDCs (Hengelaar et al., 2018). In conclusion, the results of our study can be used in the design of interventions targeting the improvement of staff-caregiver communication and relationships in residential care facilities, with a particular focus on LDCs.

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Clinical Implications

- LDCs of older adults living in residential settings, when compared to LDCs of older adults living in the community, experience greater issues around satisfaction with care provided to their relative.

- The experiences of LDCs with FCPs documented in this study point to the possible necessity for the development of novel interventions designed to improve and enhance communication and collaboration between FCPs in residential care and informal caregivers. Such interventions could, for example, include awareness training for FCPs that outlines how to regularly engage with informal caregivers and the details FCPs should communicate to informal caregivers about their CR's care provision and health status.

Table 1.

Sample Characteristics for LDC Subgroups

Variable	Dementia Diagnosis/Residential Facility (n = 58)			No Dementia Diagnosis/Residential Facility (n = 65)			Dementia Diagnosis/Community (n = 49)			No Dementia Diagnosis/Community (n = 124)		
	%	M	SD	%	M	SD	%	M	SD	%	M	SD
Age		60.63	10.20		60.54	10.88		56	13.05		53	12.80
Gender (female)	70.7			66.2			71.4			78.2		
Race/ethnicity												
White	64.9			69.2			77.1			71		
Black or African American	15.8			12.3			4.2			12.9		
Hispanic	17.5			12.3			10.2			8.9		
Asian or Pacific Islander	0			0			2.1			4		
Other	1.8			6.2			6.3			3.2		
Education												
GED/High school graduate	5.2			13.8			12.2			0		
Some college	20.7			20			0			21		
College graduate	36.2			24.6			32.7			28.2		
Graduate school	37.9			41.5			55.1			50.8		
CG self-reported health		4.07	0.72		4.06	0.73		4.37	0.76		4.19	0.70
CG Relationship to CR												
Spouse	0			0			0			0		
Child	68.9			49.2			81.6			79		
Sibling	8.6			21.6			8.2			6.4		
Other	22.4			29.3			10.1			14.4		
Distance from CR (miles)		1064.34	1074.04		985.50	960.69		826.63	1070.40		865.26	1153.83
Travel time (hours)		9.91	10.43		6.00	3.93		7.08	10.60		6.40	6.33
CR health		2.67	1.11		2.46	0.99		2.73	1.02		2.80	0.90
Overall satisfaction with FCPs		4.05	1.41		3.63	1.75		4.29	1.30		4.13	1.30
Satisfaction with FCP communication and information		3.66	1.71		3.05	1.90		4.06	1.47		3.84	1.61
Frequency of reported challenges related to FCPs		0.48	0.68		0.54	0.70		0.29	0.70		0.13	0.44

Variable	Dementia Diagnosis/Residential Facility (*n* = 58)			No Dementia Diagnosis/Residential Facility (*n* = 65)			Dementia Diagnosis/Community (*n* = 49)			No Dementia Diagnosis/Community (*n* = 124)		
	%	*M*	*SD*	*%*	*M*	*SD*	*%*	*M*	*SD*	*%*	*M*	*SD*
Frequency of reported challenges related to FCPs[¥]		.43	.55		.48	.56		.22	.49		.11	.34

Note. CG = caregiver. CR = care-recipient. FCPs = formal care providers.

[¥] transformed variable

Table 2.

LDC Quotes Expressing Challenges Related to Formal Care Providers

Challenge Subtype	Quote
Related to dealing with inadequate care	"…very disappointed with the medical help and the care and treatment…there were a couple of good people but in general, I felt this place was dirty, she was dirty for hours and it was hard to reach people. The social worker was terrible…I was surprised because usually social workers want to help and she just didn't care…there were a few okay doctors but most of them were not caring at all and that was very disappointing…it's to the point I have no trust in doctors…. you kind of have to really take responsibility for your healthcare because a lot of them don't care at all… it was very bad care and very delayed care. She always had to wait for her medicine even when she was in pain, she always had to wait for the doctor for hours and hours…. We never had a good experience with, you know, being cared for properly."
Related to communicating and receiving information from FCP	"It's like pulling teeth trying to get information… it's very difficult to find, like there's no email status… you go into the abyss of voicemails, no one ever picks up the phone… it's challenging." "I am not contacted about her physical or mental well-being or anything like that. I spoke to the social worker and I get some information, but it's quite limited. My understanding of her situation right now is that she has a finite time to live…it would be nice to know at least from a medical standpoint whether there are markers that show whether her decline is or isn't happening. I know they can't make definite prognoses, but I would like some kind of regular update on how she is progressing or is not progressing, it would be really helpful and comforting to me."