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To cite this article: Whitney A. Nash, Lesley M. Harris, Kimberly E. Heller & Brandon D. Mitchell (2021): “We Are Saving Their Bodies and Destroying Their Souls.”: Family Caregivers’ Experiences of Formal Care Setting Visitation Restrictions during the COVID-19 Pandemic, *Journal of Aging & Social Policy*, DOI: [10.1080/08959420.2021.1962164](https://doi.org/10.1080/08959420.2021.1962164)

To link to this article: <https://doi.org/10.1080/08959420.2021.1962164>



Published online: 09 Aug 2021.



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“We Are Saving Their Bodies and Destroying Their Souls.”: Family Caregivers’ Experiences of Formal Care Setting Visitation Restrictions during the COVID-19 Pandemic

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ABSTRACT

This study aims to explore the experiences of family caregivers during the COVID-19 pandemic-imposed visitation restrictions at formal care settings (FCS) such as assisted living centers and traditional nursing homes. Participants ($N = 512$) were recruited from an international caregiving social media site that was developed at the beginning of the COVID-19 pandemic. Descriptive data was collected on the family caregivers, the care recipient and facility. Respondents also provided a single feeling word describing their experience and an open-ended question allowed for further exploration. Caregivers were predominantly daughters ($n = 375$). The most common reported feeling words were sadness ($n = 200$), trauma ($n = 108$), anger ($n = 65$), frustration ($n = 56$), helplessness ($n = 50$), and anxiety ($n = 36$). Thematic analysis revealed four overarching themes: 1) isolation 2) rapid decline 3) inhumane care and 4) lack of oversight. This study highlights the importance of addressing the mental, emotional and physical needs of *both* care recipient *and* family caregiver during this challenging time. Caregiver visitation policy reform that includes the care recipient and family caregiver is also discussed.

ARTICLE HISTORY

Received 12 April 2021
Accepted 16 July 2021

KEYWORDS

COVID-19; family caregiver; visitation; restriction; formal care setting; isolation; stress

Introduction

Formal care setting (FCS) residents (care recipients) have been one of the most negatively impacted populations by the COVID-19 pandemic. For the purposes of this study FCS care recipients are defined as those individuals residing in any level of long-term care setting where they are receiving some type of nursing care. Their advanced age and the high prevalence of preexisting conditions placed them at an increased risk for severe illness and mortality from the coronavirus. Furthermore, the congregate setting allowed for the rapid spread of the disease. One measure taken to mitigate the virus’s spread

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was visitation restrictions mandated by federal, state, and local officials (Soergel, 2020); this led to many unintended consequences. One of which was the increase in social isolation within FCS facilities. Beyond the established impact of isolation on the FCS care recipient, family caregivers suffered in part due to their lack of access to their care recipient. The focus of this paper explores the experiences of these caregivers during the COVID-19 pandemic-imposed FCS visitation restrictions.

At the beginning of the pandemic, restrictions related to attempts to mitigate the spread of COVID-19 were much harsher and strictly prohibited any visitors or non-essential healthcare personnel from entering facilities. Some exceptions were made for compassionate care, such as end-of-life situations. As of May 2020, FCSs accounted for 42% of COVID-19 deaths despite limiting visitation (Abrams et al., 2020). Beginning in March and updated periodically, the Centers for Medicare and Medicaid Services (CMS) released guidance for visitation restrictions and reopening through a multiphase approach (Quality, Safety and Oversight Group, 2020). Many facilities could not meet the benchmark guidelines outlined by CMS and therefore continued significant restrictions. In September 2020, federal officials revised guidance and encouraged facilities to allow visitation with a preference for outdoor visits (Soergel, 2020). To date, all but two states have lifted their mandates though many FCSs continued to prohibit or excessively restrict visitation. These mandates and their associated isolation continued to add stress to the caregiver role and contribute to negative outcomes for individuals. Anecdotal physicians' experiences within FCSs suggest that individuals may have died prematurely due to the lack of socialization and stimulation (Abbasi, 2020). Indeed, loneliness, which can occur from social isolation, has been shown to increase the likelihood of mortality by 26% (Holt-Lunstad et al., 2015). Loneliness has also been associated with a 29% increase in coronary heart disease incidence and a 32% increase in risk for stroke (National Academies of Sciences, Engineering and Medicine, 2020). In individuals with dementia, loneliness can lead to further cognitive decline (Chu et al., 2020). Family and friends with care recipients experiencing cognitive decline fear that these restrictions will lead to their care recipients no longer recognizing them once restrictions are removed (Simard & Volicer, 2020). This finding is one of very few that acknowledges the family caregiver perspective in this crisis.

Though emerging data continues to focus on the physical and social well-being of those residing in FCSs, there has been limited investigation exploring the impact that restrictions have had on caregivers. A reported one in five adults in the U.S. is involved in the caregiving of a friend or family member with a health problem or disability (National Association of Chronic Disease Directors, 2018). These individuals play a crucial role in their care recipient's well-being; as an advocate, sharing, if not directing, decision-making, and often providing basic care (e.g., feeding, hygiene, and socialization) during

their visits. Despite much of the literature focusing on caregiving stress, research also suggests that caregivers may derive mental health benefits from their role (Beach et al., 2000; Picot, 1994; Wolff et al., 2007). When the caregiving role changes, either by the death of the patient or changes in the ability of the caregiver, there may be alterations in sleep quality (Arber & Venn, 2011; Carter, 2005; Corey & McCurry, 2018) along with further changes in the physical and mental well-being of the caregiver (Aneshensel et al., 2004; Bodnar & Kiecolt-Glaser, 1994; Corey & McCurry, 2018; Tweedy & Guarnaccia, 2008).

What is left unknown is how the COVID-19 visitation restrictions in FCSs have impacted the family caregivers during this interruption in their role. The purpose of this study was to explore the emotions and experiences of family caregivers affected by the visitation restrictions at FCSs during the 2020 COVID-19 pandemic.

Methods

Study sample

This study included 518 adults, who self-identified as a caregiver for a person living in residential care during the time of the COVID-19 pandemic. The study link and description were posted on the Facebook group “Caregivers for Compromise . . . Because Isolation Kills Too.” This group was launched on July 6, 2020 and was created as a space to allow members to share information, garner support and rally for improved access to their care recipient in FCSs during the COVID-19 pandemic. There are currently over 14,000 members of this group.

Sampling strategy and recruitment

Following approval from the Facebook group’s administrators, a description of the study, survey link, and principal investigator’s contact information was shared with the group members. The survey was live for two weeks (September 25 to October 9, 2020). Respondents did not have to be members of the group to participate, and members were encouraged to share the study link. Individuals who were unpaid, usually family caregivers for a care recipient in a FCS during the COVID-19 pandemic were eligible to complete the survey. The care recipient did not have to currently be living for the caregiver to participate. Individuals were eligible to participate even if their care recipient had transitioned to home or other living arrangement. Questions were focused on their experience while their care recipient was in a FCS during the COVID-19 pandemic. No incentives for completing the survey were provided.

All study procedures were approved by the Institutional Review Board at the University of Louisville.

Data collection

Respondents completed a survey that included questions regarding personal demographic characteristics and health status, demographics, and the health status of the care recipients, as well as information about their care recipients' facility. This included questions about whether they had reported concerns to facility leadership or government officials. Also included was a specific question regarding their concern about retaliation should they report a concern. Additionally, respondents provided a one-word response to, "*Please list any feelings that you have had in regard to the reduced visitation of your loved one (care recipient), and please use one word to describe each feeling.*" Following this question, family caregivers were asked to write a response to the prompt, "*Please use this space to communicate anything else about your experience with your loved one (care recipient) who resided in a formal care setting during the COVID-19 pandemic.*" The data from the survey, and the responses to the prompts were exported from Qualtrics into Excel for data analysis.

Data analysis

The open-ended responses were coded for inductive themes using an applied thematic approach (Guest et al., 2012) informed by the constant comparative method of qualitative analysis (Boeije, 2002). First, the research team read all of the feeling words from the open-ended responses in their entirety. Then half of the responses were coded line by line. After the first half was coded, initial codes were clustered together by topic to develop thematic codes.

For the feeling word responses, the research team organized them into seven thematic categories, which represented each emotion. For the responses to the prompt asking about caregiver experiences, the most frequent and significant focused codes were used to construct a codebook of nine codes with definitions.

Next, two research team members used Dedoose software to inductively code one hundred percent of the responses. Themes in the data were discussed and finalized in consensus building discussions with the full study team, including topic and method experts. The number of times the themes were mentioned in the transcripts was tabulated.

Three additional steps were taken to ensure credibility and confirmability of our research findings (Lincoln & Guba, 1985). For triangulation of data, we used two sources of data, both the emotion word and the written narratives of caregivers to understand the phenomenon of separation at a deeper level. Additionally, the research team performed a negative case analysis to search

for data that did not support our main findings. This came in the form of five caregivers who reported full trust and satisfaction with the FCS in which the care recipient was living. Upon closer examination of these data, we learned that the caregivers were not living within the same location as their family member, and therefore had to rely more on a long distance, trusting relationship with the FCS. They were also more likely to already communicate with their family member using phone or technology, so therefore the long-distance caregivers did not experience as drastic of a change in communication. Lastly, as a research team, we used peer debriefing with the two authors who were not involved in the data analysis (WN and KH) as a way to engage analytical probing. This process also led to conversations on taken for granted assumptions and perceptions on behalf of the two members of the analytic team (LH and BM). This support helped refine the analysis in terms of clarifying our emerging findings.

Results

Care recipient

The majority of caregivers' care recipients were still living at the time of survey completion (90.4%). The most frequently cited reason for admission was a diagnosis of Alzheimer's disease or related dementia (ADRD) (33%). This was followed by experiencing a fall (13.4%). When asked if their care recipient was able to make their needs known verbally, 61.2% felt they could, while 28.4% reported their care recipient was unable or needed an assistive device. Of those who were able to communicate their needs, 55% expressed concern regarding their care at their facility. Greater than 92% of caregivers reported that their care recipient had experienced an injury or a decline in their health during the COVID-19 pandemic with 11.4% diagnosed with COVID-19.

Caregivers

The majority of caregivers were female (96.5%) with 77.6% being the daughter of the care recipient (Table 1). Questions regarding the caregivers' health status revealed that although 40.3% of individuals reported "feeling fine" when asked if they had experienced a change in their health status during the COVID-19 pandemic, additional data presented a different picture. Over 38% of caregivers reported a current diagnosis of a mental health diagnosis (anxiety/depression) with 24% reporting a new or worsening mental health condition. Anxiety and depression were the top two health conditions reported (38%) followed by "other" (9.1%) and weight gain of more than 10% (6.4%). Nearly 11% had a significant medical event such as a surgery or

Table 1. Demographic characteristics of caregivers and their loved ones.

Characteristic	Resident (n = 522)	Caregiver (n = 518)
Age (M, SD)	84.3 (10.3)	59.7 (8.9)
Gender (%)		
Male	29.5	2.9
Female	70.3	96.5
Race/Ethnicity (%)		
Caucasian	97.3	96.3
African American	1.2	1.2
Other	1.2	1.2
Facility Type (%)		
Nursing Home	78.4	–
Assisted Living	17.2	–
Other	4.3	–
Relationship to Loved One (%)		
Child	–	77.8
Spouse	–	10.2
Sibling	–	3.1
Other	–	8.6
Employment (%)		
Full-time	–	31.4
Part-time	–	9.5
Self-employed	–	6.9
Retired	–	36.1
Laid off since March 2020	–	2.4
Other	–	13.8

a new serious medical diagnosis, although these were not clearly defined. Fifteen caregivers (2.90%) had been diagnosed with COVID-19.

Experiences with FCSs during the COVID-19 pandemic

Prior to the COVID-19 imposed visitation restrictions, 87% of caregivers visited their care recipient at least once a week with 29.9% of those going daily. As part of those visits 58.1% provided some type of personal care including feeding and hygiene. This all changed in March 2020. Visitation restrictions have evolved repeatedly during the pandemic. [Table 2](#) demonstrates the wide range of strategies that were being implemented at the time of this survey. According to an AARP report (Markowitz, 2020), Indiana was the

Table 2. Visitation strategies implemented for family caregivers.

Visitation Strategy	<i>n</i>	%
No visitation allowed	82	8.0
Telephone/video chat	232	22.7
Window visits only	210	20.6
Patio visits only	154	15.1
Scheduled visits in facility with PPE and social distancing	73	7.1
In-person visits with ability to care for loved one with precautions ^a	53	5.2
In-person visits with negative COVID-19 test result	32	3.1
Allowed out for medical appointments	89	8.7
Other	81	7.9

N = 518. Responses reflect family-caregiver reported visitation policies at time of survey completion.

Respondents were able to select multiple responses. PPE = Personal Protective Equipment.

^aPrecautions include PPE and hygiene practices.

first state (June 2020) that authorized an essential caregiver program that allowed individuals that had previously provided some level of care to a care recipient in a FCS to continue in an abbreviated capacity. By the time this survey was conducted four more states had joined this effort.

Most participants (87%) were unaware of any State Board of Nursing, State Board of Health or CMS infractions or citations against the FCS where their care recipient resides/resided. Participants were not asked if they knew how to access that information. Although 58.1% of caregivers reported that they were fearful that if they raised a concern their care recipient may be retaliated upon, 77.6% still brought their concern to the facility's administrator. Beyond the FCS, 33.4% of caregivers brought concerns to the state ombudsman and 54.6% felt compelled enough to reach out to their state representative for assistance.

Feelings regarding reduced visitation

Responses to the question, "*Please list any feelings that you have had in regard to the reduced visitation of your loved one (care recipient), and please use one word to describe each feeling*", were categorized by type of emotion (Table 3). The most common reported emotion was sadness ($n = 200$), which included feeling words such as heartbroken, sorrow and devastation. This was followed by trauma ($n = 108$) which included words such as horrified, panic, and desperate. Other categories of emotion included anger ($n = 65$) (i.e., mad and rage), frustration ($n = 56$) (i.e., unfair and annoyed), helplessness ($n = 50$) (i.e., debilitating and inadequate), and anxiety ($n = 36$) (i.e., stressed and worried).

Thematic analysis of the opened question revealed four overarching themes including: 1) isolation 2) rapid decline 3) inhumane care and 4) lack of oversight.

Table 3. Participants one-word response to describe their feelings with the Covid-19 visitation restrictions.

	N	%
Anger	60	11.83
Sad	58	11.44
Frustration	53	10.45
Helplessness/Hopeless	50	9.86
Devastated	47	9.27
Heartbroken	38	7.50
Despair/Desperation	20	3.94
Abuse/Criminal/Cruel/Neglect	17	3.35
Worried/Stressed	16	3.16
Depressed	14	2.76
Fear/Frightened/Terrified	12	2.37
Anxious	11	2.17
Concerned	7	1.38
Other	104	20.53

Responses accounting for less than 1% of the total were categorized as "Other."

Theme 1 isolation

Isolation was the most commonly applied code ($n = 246$) and the highest rate of code co-occurrence. Participants defined isolation as seeing their care recipient confined to their room, with no activities, visitors, or communal dining for months at a time. Isolation was also conceptualized as mutual, being that many caregivers experienced the detrimental effects of isolation, because they had previously been engaged in socializing and receiving emotional support from their care recipient. Caregivers described isolation as being “inhumane” due to the length of time (over 6 months when these data were collected). Another respondent gave an example of what isolation looks like within her mother’s facility, *“Although her facility has done most everything they can to ensure safety for residents from COVID and almost no effort has been made to ensure their mental health due to the isolation. Staff rarely stay and visit with Mom, no special in-room activities or stimulation has been attempted.”* From the negative effects of isolation came suggestions for policy changes related to the status of family caregivers. One participant stated, *“We should be recognized as essential caregiver and be allowed into our loved one’s facility using the same safety precautions as staff to provide physical, emotional support . . . because isolation kills too.”*

Theme 2 rapid decline

Many participants ($n = 203$) reported a rapid decline in their care recipient’s mental and physical state as soon as lock down began. One caregiver reported, *“The decline due to isolation was dramatic, alarming and devastating.”* Caregivers equated the deterioration to a lack of mental, physical, emotional and social stimulation. Participants stated that they were often the key person who their care recipient turned to provide stimulation, despite being in assisted living or other FCS.

One participant reflected, *“To think in her final year(s) when she is most vulnerable and most in need of love and support from her children & was denied this for 6 months is in my opinion is devastating. I would rather my Mom died of COVID with me by her side than deteriorating and suffering emotionally with no family advocate holding her hand.”*

In situations where family members were able to visit via online platforms, they noticed decline in their care recipient’s physical and mental condition. One caregiver reflected, *“We watched her decline before our eyes at the video visits. She didn’t understand what was happening. She thought she did something wrong. The anxiety and worry cause horrible depression.”*

Theme 3 inhumane care

The third most frequently applied code was the inhumane environment their care recipient was being subjected to during the COVID-19 pandemic ($n = 150$). One participant stated, *“We are saving their bodies and destroying*

their souls.” Another participant said, *“They are being treated like caged animals.”* Caregivers expressed heartbreak over seeing relatives, who often had diagnosis of Alzheimer’s or dementia, experience isolation without being able to comprehend why their family members could not enter the facility or their room. Caregivers were sometimes allowed visits through an online platform or a glass window, which for many triggered feelings of being in prison, and often led to an increase in agitation behaviors and emotional outbursts. One caregiver explained that her mother, *“doesn’t understand why we can’t come in. She has lost over 41 lbs since COVID and now has stopped eating and drinking. Starting Monday, she will be in Hospice. Why do we have to wait until they are almost dying before we can see them! It is inhumane! Everyone needs love!”*

Theme 4 lack of oversight

Participants ($n = 126$) reported a lack of oversight in terms of the facility in which their care recipient was residing. The lack of oversight created an environment of neglect due to short staffing as one caregiver explained, *“Facility never has sufficient staffing leaving the residents laying in their own waste all night. Numerous large bruises neglect. Mom has lost 11lbs in 3 months. She has mentally and physically declined making her dementia worse.”* Family members would witness the neglect through their window visits. A daughter visiting her mother from outside of the facility described the scene, *“Dementia patients need consistent routines in order to stay stimulated. This is the most heartbreaking thing that has been agonizing to see in the 90-degree temperatures outside a window.”*

The impact of the COVID-19 pandemic caused many CNAs to quit their job due to the high rates of the illness within their facilities. The short staffing and lack of oversight from management led to emotional distress and infections. One daughter describes the panic experienced by her father’s phone call, *“He called crying he has been calling nurse and CNA and they would not come to take him to bathroom. He was discharged (dc) with urinary tract infections (UTIs) 6x in 7 months. I cannot even imagine what he went through.”*

As a final resort, 30 participants reported that they decided to provide care outside of the FCS and bring their care recipient home. One caregiver reported on how these events unfolded, *“It became very clear that I was providing at least 20% of my mother’s care in the facility prior to quarantine. She did not get that personal care during quarantine. She failed to thrive, so I brought her to my home.”* At times, family members were too late to nurse their care recipient back to health, as demonstrated by the following caregiver, *“We could tell she was failing to thrive. We watched helplessly through her window. Finally, we took her home and she died 5 hours later with no mention she was at end of life.”* One concerning aspect about caregivers providing care in this manner is geography. One husband spoke about taking his wife out of her facility, *“I*

filed a lawsuit after I was evicted from our assisted living for being a nonessential spouse. It went nowhere. After 10 weeks of separation, I brought my wife to our mountain cabin to live with me, with no caregiving help.”

Some families were equipped to administer care to their care recipient, but experienced training delays due to short staffing, which delayed their ability to bring their family member home. However, not all home caregiving situations have proven to be successful. One caregiver reported how she struggled to care for her father within her home, *“I removed my dad from his memory care facility mid-March, cared for him in my home alone, until August. It has ONLY been a month back at the facility, but he has ended up in the hospital once, he lost weight and his clothes are covered in fecal matter regularly. He is fading from a lack of my care and advocacy.”* Situations such as this could create more stress for care recipients and family due to the inability to successfully provide care at home, while re-exposing the care recipient to a failing system of care.

Discussion

Based on this study's findings, the interruption of the family caregiving role due to the COVID-19 FCS visitation restrictions has significantly impacted both the care recipient and the caregiver. This study further validates Holt-Lunstad et al. (2015) work demonstrating the impact that social isolation has on an individual's well-being. In the current study, this includes both the caregiver and care recipient. Each group has members that have experienced a decline in mental and physical health. This decline was self-reported in the caregiver's case, but in many cases, the decline of the care recipient was directly observed by the caregiver or reported to them by facility staff.

Prior to the imposed visitation restrictions, 87% of caregivers visited their care recipient weekly, with nearly 30% going daily. Caregiver responses indicate that part of this time was spent giving personal care, advocating for their care recipient, and monitoring care delivery. Due to the visitor restrictions during the COVID-19 pandemic, informal caregiving support disappeared, which exacerbated the existing challenges related to staff shortages in nursing homes (McGilton et al., 2020).

The wide range of revised visitation procedures changed how the caregiving role was implemented. Caregivers expressed high levels of frustration with their limited access to their care recipient. Many expanded the advocate domain of the caregiving role by reaching out beyond the facility to state authorities. Crossing the Quality Chasm (Institute of Medicine (IOM), 2001) emphasizes patient-centered care as a critical element in quality health care delivery. This approach includes the family as well as the patient. It is apparent from the personal accounts of caregivers in this study that planning for limiting COVID-19 facility spread did not fully take into account the physical and mental health needs of the care recipient. Other sources, including the

Institute for Patient- and Family-Centered Care and The National Quality Forum's National Priorities Partnership support the need for including family and patients in key decision-making. This should extend to how care can be continued even during a pandemic.

Implications

Policy/practice

Much has been learned regarding the crucial role family caregivers play in helping ensure the needs of their care recipients are met during a time of crisis. These results support the previously established impact that can occur when family caregivers are excluded from the process. Older adults are at risk when patient- (or person-) centered care is not continued in FCSs even during challenging times. It is important to note that FCSs were under federal mandate to impose restrictions to visitation early on in the pandemic and many struggled to obtain clear guidance in interpreting and implementing these restrictions.

The results revealed that caregivers deemed that isolation was just as deadly as the pandemic for their care recipients. They reported that the severed ties with their care recipient led to a rapid decline in health. They viewed the social and physical health provided through their caregiving as critical, even when faced with risk factors associated with spreading the virus. As caregivers diminish in presence, this may have led to cascading and deteriorating health status of individuals residing in the facility. Research has already established the link between the psychological impacts of isolation and neglect and the rapid deterioration of health, including mortality (Dong et al., 2009; Pantell et al., 2013), which has been compounded by COVID-19 risk factors.

Our results indicate many caregivers perceived that many deaths were not COVID-related from a medical standpoint but were related to care changes in light of COVID-19. In order to rebuild trust, their concerns should be recognized as a failure of the formal care system to respond and quickly implement policies that enabled safer visitation. This crisis has given way to recommendations grounded in our participants' experiences and by reviewing literature from the Centers for Medicare and Medicaid Services (2020) and the Centers for Disease Control and Prevention (2020). We recommend that a) FCS administrators onboard their residents and staff to technology that facilitates frequent communication between caregivers and care-recipients (e.g., video calls, text messages, e-mail, and phone calls), b) protocols established during compassionate care visits be evaluated and potentially expanded to include ways to include essential caregivers, and c) frequent and scheduled visits which include parades of cars, high-quality visits through glass windows, and

outdoor visits which make accommodations for the weather (e.g., umbrellas, heat lamps, etc.) be implemented to ensure greater comfort for all parties.

Research has established that addressing complex grief will be needed among healthcare workers during the COVID-19 pandemic (Greenberg et al., 2020). Recent studies have suggested that nursing home workers will face additional guilt and distress related to their role in transmitting the virus under enormously stressful working conditions, including understaffing (McGilton et al., 2020). Less is known about how grief is experienced by family caregivers who lost their ability to deliver care. Although a care recipient's death in FCSs is typically a normative expectation, the COVID-19 pandemic has altered the meaning-making experiences surrounding death. Grief may be further complicated with trauma and feelings of betrayal. In their article addressing bereavement during the COVID-19 pandemic, Carr et al. (2020) suggest that COVID-19 related deaths exemplify "bad deaths" and support expanded, active advanced care planning that includes respect for the older adults' wishes. We recommend that efforts be made to rebuild trust between family members and nursing homes and that hospice services join the efforts to deliver tailored bereavement services that address families who have lost a care recipient under these circumstances.

Unfortunately, this will most likely not be the last public health crisis that will impact the care recipients' in FCSs. The COVID-19 pandemic, not unlike the aftermath of Hurricane Katrina in 2005, has brought to light the lack of preparedness to deal with the safety and health of our elderly during a crisis (Adams et al., 2011). The authors propose a significant post-pandemic assessment of the physical and emotional health of the individuals in FCSs as well as their informal caregivers. Evidence-based decision-making regarding how best to adapt must be evaluated prior to the next crisis.

Future direction

Although person-centered care has been well established as a critical framework for positive care outcomes, further research is needed to evaluate the balance between providing person-centered care and the need to provide for the safety of all residents, staff, visitors, and the general public when a crisis such as the COVID-19 pandemic occurs. This future research should include input from care recipients, family caregivers as well as formal/paid caregivers and administrators of FCSs. Although some families in this study were able to pivot to administer home health in times of crisis quickly, they experienced delays in being trained on how to administer home health care by staff. Families who transitioned to caring for their care recipient at home successfully during the COVID-19 pandemic may provide valuable insight for disaster preparedness planning. Lastly, much focus has been placed on the role of residential staff in spreading COVID-19. Less attention has been

given to how family members have contributed to the spread of COVID-19 during the pandemic. Future studies can look at how visitation policies have been implemented across various regions to determine how family members may have contributed to the virus's spread. This research might serve as a mechanism for repairing relationships between families and residential care through delivering evidence as to why some "lockdown" procedures were necessary.

Limitations

The current study is limited in part due to the potential for selection bias. Although participants did not have to be a member of the caregiver advocacy group to participate in the survey and respond to the prompts, we recognize that many of the participants were previously engaged in caregiver activism around issues of isolation. It is certainly possible that individuals who were not members of the Facebook page used for recruitment may have had different experiences than those who participated in the study. Additionally, the prompt of asking for a one-word feeling about the reduced visitation experience may have limited the participants' sharing of how and why they expressed the identified sentiment. Finally, 9.6% of the respondents' care recipients had died prior to the completion of the survey. Potential negative feelings toward the FCS regarding the circumstances of the death may have influenced the responses. Future research will explore the connection between experiences and emotional responses of caregivers during the COVID-19 pandemic.

Conclusion

In these unprecedented times, there is a need to ensure that trust remains between FCSs and families. Leadership in the field must acknowledge the harm created by implementing policies that severed family ties while communicating that restrictions were designed to minimize the virus's impact on all parties (i.e., residents, staff, and families). This pandemic has amplified existing problems within FCSs and offered opportunities to rethink the future of long-term care, such as enhanced disaster preparedness, integration of technology for communication, and inclusive planning.

Key points

- Older adults residing in FCSs are at increased risk for decline in health status related to isolation.
- COVID-19 related visitation restrictions increase social isolation for both the care recipient and family caregiver.

- Family caregivers have role disruption and experience stress due to imposed restrictions
- Policy development regarding the needs of *both* the care recipient and family caregiver is critical

Acknowledgments

The authors of this paper would like to thank the members and administrators of the Caregiver for CompromiseBecause Isolation Kills Too FB group for their willingness to share their stories with the authors and facilitate recruitment of others.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

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