

The Impact of COVID-19 on Family Caregivers of Individuals With End-Stage Heart Failure

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Before the COVID-19 pandemic, family caregivers were providing a tremendous amount of care for family members with heart failure with the prevalence of caregiver reliance in heart failure expected to increase in the United States. Social distancing and other restrictions during the COVID-19 pandemic may have added further challenges to caregiving routines. The purpose of this study was to examine the family caregiver perception of the effect of COVID-19 on caregiving routines. To determine caregiver perception of COVID-19's impact, 1 Likert question and 1 open-ended response were asked. Braun and Clark's method guided open-ended response thematic analysis. The 113 replies to the open-response question yielded themes such as social isolation, added fear, anxiety, or worry, changed appointments, wearing masks, and living status change. Social isolation (41.6%) was the most common theme; the most significant theme was living status change ($P = .003$), and family caregivers reported that the pandemic affected their routines either negatively or somewhat negatively (62.1%). Family caregivers are affected during times of crisis. Research and policies that recognize the residual effects of COVID-19 on caregiving practices and support care transitions for family caregivers in the heart failure population are needed.

KEY WORDS

care transitions, COVID-19, end-stage heart failure, family caregivers

The disruptive impact of the COVID-19 pandemic on health systems globally, and in the United States specifically, has been well documented. Social distancing, delayed appointments, and the use of virtual visits were practices implemented in response to this global health crisis, disrupting many health care systems and the management of chronically ill patients.^{1,2} Home care visits were consolidated, and many supportive services were halted or switched to virtual formats.² Many patients and family caregivers (FCGs) avoided accessing emergency care because of fear of contracting COVID-19 in settings where social distancing was difficult or impossible.^{2,3} Individuals who experienced chronic or acute illnesses and were either unfamiliar with or did not have access to virtual care were not able to keep appointments.^{1,3} Individuals who required medical attention chose to remain at home rather than being isolated in hospitals where family and other visitors were heavily restricted or not allowed.²

Heart disease is the leading cause of death in the United States,⁴ and heart failure (HF), a component of heart disease, affects more than 6 million people.^{5,6} Heart failure is often classified into 4 functional stages by the New York Heart Association to assist in provider understanding of later disease.^{7,8} The stages include stage I with little physical limitations, stage II with mild symptoms and limitations to physical activity, stage III with marked physical limitations due to increased symptoms, and stage IV with severe physical limitations and symptoms.⁸ Frequently, HF is accompanied by other comorbidities, including dementia.^{7,9} Heart failure is responsible for more than 990,000 live hospital discharges annually,⁷ and 70% of those with HF are rehospitalized within 6 months of discharge because of HF exacerbations.^{7,10}

A range of support services and professionals including specialized clinics, palliative care, and support groups contribute to HF management.⁵ Individuals afflicted with HF also rely on FCGs to provide routine and complex care⁵ such as nutrition management, appointment scheduling,

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medication administration, and surgical device care.^{2,5} In addition, FCGs provide emotional and social support to family members^{5,11,12} and navigate health systems to identify services as HF progresses and prognoses change for their family members.^{5,11} With the challenges that FCGs face on behalf of their chronically ill family members, they too require support.¹²⁻¹⁴ Despite the care FCGs provide, frequent hospital readmissions continue because of HF.^{7,9,10}

As with other aspects of medical care, COVID-19 presented new challenges for HF management. Despite health or disaster preparedness policies in place before the COVID-19 pandemic, many health care systems were overwhelmed with caring for patients afflicted with COVID-19.¹⁵ Subsequent problems arose with identifying high-risk individuals with HF and maintaining communication with lower-risk patients and their FCGs.^{1,15} Family caregivers for individuals with HF already faced difficulty and uncertainty in balancing caregiving duties,^{3,12,14} and continuing to provide quality care during enforced isolation was difficult.¹⁵ During the COVID-19 pandemic, hospitalizations related to HF decreased 50% to 60% in the United States,¹ potentially increasing HF mortality. This is indicative of changes in how patients and FCGs managed illness during the pandemic. Heart failure is a leading comorbid risk factor for severe COVID-19 effects and death; this knowledge may have added to FCGs' concerns for HF morbidity and mortality for affected individuals.^{1,14}

It is unclear how fully FCGs were impacted by the social distancing guidelines and other changes imposed during the pandemic.^{3,14} Family caregivers previously reported isolation in HF caregiving;^{12,16} however, FCGs may have experienced even greater isolation in response to COVID-19 restrictions. Those who provided care for family members living in structured facilities or residences may have been separated from their family members during affected individuals' illness exacerbations and hospitalizations, causing duress.¹⁴ Fear of inpatient settings and institutional postponement of non-COVID-19 care may have delayed critical medical care and caregiver support options, further affecting individuals with HF and their FCGs.² Family caregivers who experience socioeconomic health disparities also may have been impacted by COVID-19-related changes to HF management.³ This study aimed to examine the impact of the COVID-19 pandemic on FCGs of individuals with end-stage HF by answering the following research question: How did COVID-19 affect family caregivers providing care for individuals with HF?

METHODOLOGY

This study emerged from a larger cross-sectional online survey on FCGs of individuals with end-stage HF.

Participants

Inclusion criteria were participants aged 18 years or older who identified as FCGs of family members with end-stage

HF at the time of the survey. There were 132 responses to this part of the survey. The participant age range was 23 to 78 years (M = 50.58). Family caregivers were predominantly female (88.6%), White (85.6%), and non-Hispanic/Latino (93.9%); many of the respondents were married (68.9%). Many (59.8%) FCGs indicated that they were caring for a family member with stage IV or end-stage HF. Several (59.8%) FCGs were recruited from Facebook groups. Almost one-third (29.5%) of the respondents were from the northeast region of the United States, where the researchers were located, although all regions of the United States were represented (Table 1).

Procedures

Participants were recruited via convenience and snowball sampling from an online national caregiver research registry, an online site for statewide councils of aging, social

Characteristic	M	SD	Range
Age	50.58	12.75	23-78
Characteristic	n	%	
Sex			
Female	117	88.6	
Male	15	11.4	
HF Stage			
Stage IV	79	59.8	
Stage III	18	13.6	
Stage II	8	6	
Stage I	1	0.9	
Other	26	19.7	
Ethnicity			
Non-Hispanic/Latino	124	93.9	
Hispanic/Latino	8	6.1	
Race			
White	113	85.6	
Non-white	19	14.4	
Marital status			
Married	91	68.9	
Non-married	41	31.1	



media sites, faith communities and community health centers in New England, and a large home hospice organization north of Boston. Potential participants were invited to complete an online survey on Qualtrics¹⁷ from February 2021 through May 2021.

Ethical Considerations

Study procedures received institutional review board approval from the University of Massachusetts Lowell before study onset (#21-016-KOR-EXM), and collaborative agreements were followed for all participating agencies. Prospective participants were provided informed consent and indicated consent for participation. Participants were able to withdraw from the survey at any time, as well as to refuse response for specific items. All data were anonymized.

Measures

Demographics

The demographic portion of the larger survey had 19 questions. Study variables were chosen from prior HF literature indicating the need for research examining FCG characteristics^{3,5} and were age in years, sex, HF stage, ethnicity, race, and marital status.

COVID-19 Questions

The survey data included 1 Likert-style COVID-19 question (C19Q), “How has COVID-19 affected your caregiving routines since March 2020?” Participants could respond with *Negatively*, *Somewhat Negatively*, *Neither Negatively nor Positively*, *Somewhat Positively*, and *Positively*. To ensure contextual richness, 1 open-ended COVID-19 question was added, “What are some ways COVID-19 has affected your caregiving routines?”

Data Analysis

Thematic analysis was conducted using the 6-step method of Braun and Clarke¹⁸: familiarize yourself with the data, generate initial codes, search for themes, review potential themes, define and name themes, and produce the report. This flexible approach has been used to identify relevant themes in qualitative literature. Qualitative data analysis (QDA) was performed using 2 methods; data were coded by hand and by using computerized data analysis. Initial data review and coding were conducted in a Microsoft Excel (version 16.53) matrix. Initial themes were determined by highlighting text, reviewing each item separately, and then reviewing as a whole dataset. Data were then exported to the current version of R (version 4.0.5, 2021) for review and confirmation of themes.^{19,20} Use of both methods allowed for visualization of data, researcher collaboration, and methodological triangulation.^{18,20} We performed QDA text mining in R using the *tm*²¹ package to determine the most frequently responded words, identify

word associations, and generate codes and subsequent themes. Text mining themes were compared against the themes in the data matrix for comparison and analysis of common themes, redundant themes, and negative and alternative explanations. Thematic analysis, text mining, and R syntax were conducted by 1 researcher and reviewed by 2 researchers for rigor, trustworthiness, and intercoder agreement by percent agreement.^{18,20} Initial themes were compared in the matrix and in R, and researcher review and discussion confirmed the themes.

Multiple linear regression was performed in R on the C19Q responses; the predictors were demographic characteristics and the themes that emerged from QDA. The variance inflation factor was assessed to determine if there was multicollinearity with any of the variables, with greater than 2 indicating multicollinearity.²² A χ^2 test was performed on the C19Q to determine if an endorsement of a response had values for caregiving. The responses *Somewhat Negatively* and *Negatively* were clustered together (C19Q-neg), and the responses *Somewhat Positively* and *Positively* were clustered together (C19Q-pos) for χ^2 probabilities. Descriptive statistics were analyzed in R.

RESULTS

Caregiving Effects

There were 167 partial or complete responses to the parent survey, with 132 (79%) replies to the C19Q question. Most of the respondents (62.1%) indicated that COVID-19 had affected their caregiving routines either *Negatively* or *Somewhat Negatively*. Less (3.8%) respondents reported that COVID-19 had affected their routines *Somewhat Positively* or *Positively*. In comparison to both extremes, approximately one-third (34.1%) of the respondents shared that the pandemic had not affected their caregiving routines either *Negatively* or *Positively*. A χ^2 test was performed between the responses C19Q-neg, *Neither Negatively nor Positively* (C19Q-neut), and C19Q-pos; the odds of having a negative effect on caregiving routines were more than one and a half times greater than having a positive or neutral effect on caregiving routines (Table 2).

Thematic Analysis

There were 113 (67.7%) responses to the open-ended question. Five themes resulted from the thematic analysis of the open-response question. The themes were as follows: *social isolation was real*; *changes in everyday routines*; *keeping or making appointments was challenging*; *masks and precautions were necessary*; and *there was added fear, anxiety, or worry* (Table 3).

Social Isolation Was Real

Forty-seven respondents (41.6%) identified that social isolation, either for themselves or the family members they



TABLE 2 Family Caregiver Responses to C19Q (N = 132)

Question	n	%	Response	χ^2	P	Odds
COVID-19 caregiving effect			Cluster			
Negatively	44	33.3	C19Q-neg	7.7576	.005	1.64
Somewhat negatively	38	28.8	C19Q-neut	13.364	<.001	0.52
Neither negatively nor positively	45	34.1	C19Q-pos	112.76	<.001	0.04
Somewhat positively	4	3				
Positively	1	0.8				

were caring for, was an issue. Family caregivers were concerned about the toll that caregiving had on their own time. One FCG reported, “[I] can't get outside and away enough.” A second participant concurred, “No outlet to get away.” There were concerns about missing other

family members, “No interaction with my family.” There was difficulty in self-care as 1 FCG indicated, “[I] am unable to get proper care due to the visitor restrictions...” An additional participant stated, “I can't do my own things...volunteering and the gym, seeing family.” A sixth

TABLE 3 Thematic Results (N = 113)

Themes	Percentage	Word Associations	Sample Responses
Social isolation was real	41.6	Home Socialization	“[I] can't get outside and away enough” “Hospital visitation policies make it hard to care for my wife” “...Not being able to attend church...” “...I had COVID and could not care for him”
Changes in everyday routines	36.3	Family members Unable Work	“Moved mom out of assisted living and in with us” “Harder to ask for outside help, kids are home instead of at school...” “...Have to rely more on myself...” “Used to get a little break going to work”
Keeping or making appointments was challenging	23	Appointments Visitation Hospital	“Hospice didn't come as often” “Adult day care closed for [our] loved one” “Provider care decreased...only concerned with COVID...” “Not allowed in hospital as his advocate”
Masks and precautions were necessary	15.9	Precautions	“...[Masks] reduce the amount of info you can read in one's face” “...Difficulty in getting masks in dressing change kits...” “...Made mask wearing easier and acceptable” “More time disinfecting surfaces, reminding...”
There was added fear, anxiety, or worry	13.3	Emotional feelings COVID-19	“...For fear of COVID I'm in 128 to 168 hrs/wk” “...Always worried that I could bring it home to him...” “Anxiety, stress, precautions, lack of socialization” “I've had to go to the emergency room... unvaccinated and terrified...”
No change	10	None	“The same isolation due to transplant” “Less blood draws” “COVID eased the transition to disability” “It [COVID] has not affected me”



FCG indicated, "...[I] couldn't take a couple hours for me."

Restricting home visitors and following inpatient visitor restriction policies for hospitals or other living facilities were concerns. One respondent indicated the hardship in seeing family members who became ill, "My mom fell ill during this terrible time...very difficult to be with my mom." Another participant stated, "Hospital visitation policies make it hard to care for my wife." A third FCG indicated, "My dad was in the hospital and rehab 2x. Not able to visit. I had COVID and could not care for him." One FCG remarked, "I am more vigorous in limiting visitors." Social distancing extended to church services, "...Not having any social interactions with others...not being able to attend church..." Another respondent found that the church was not supportive, "Isolated to stay safe as primary caregivers for his mom, then ostracized by church for staying home."

Lack of socialization for family members concerned FCGs. One respondent stated, "...Unable to bring loved ones out of the home for socialization." An additional FCG agreed, "Can't take him out in public...activities are severely limited." Another FCG indicated, "...Keep loved one home from hair and nail [appointments]." Another FCG found difficulty in bringing family out, "My mom is medically fragile, so getting her out to move has been very limited."

Change in Everyday Routines

Forty-one (36.3%) respondents reported a change to their overall caregiving routines. These were on subthemes of *change in living status*, *change in work or financial status*, *change to supplies*, and *change to availability of help*. Some FCGs found that their family members' locations were changed to provide better care for them, "Moved mom out of assisted living and in with us." Another FCG added, "I moved mother home with me after 8 years in a nursing home because we couldn't see her." A third FCG stated that family member relocation was not optional, "While figuring out home care, my grandmother was placed in a nursing facility and I could not visit." Family caregivers with children reported that they now had children at home while performing caregiving routines, "Harder to ask for outside help, kids are home instead of at school..." Having children at home added to FCG parental duties while caregiving; however, children may have also provided help.

There were changes in work schedules and financial situations. One FCG indicated, "I lost my part time job." Another participant responded, "Working from home full time affects me as a caregiver...reduced salary also affected me." A third FCG stated, "I am working from home since last March. Used to get a little break going to work." A final FCG agreed, "...Financial constraints."

Family caregivers also found difficulty in getting supplies. One FCG stated, "...[I] couldn't get out to see other

people or shop." Another offered, "Everything changed, insurance getting medical supplies or prescriptions." A third FCG added, "I couldn't get out of my house to get groceries and medicine." A final FCG concurred that there were "less trips to the store."

Difficulty getting help was an issue for FCGs. Family caregivers reported that other caregivers were absent, unreliable, or unable to make it because of social distancing requirements. One FCG indicated, "Our paid caregiver is unreliable..." Another FCG stated, "...Have to rely more on myself..." One FCG responded, "Aunt would not come to relieve me due to stay-at-home order." A fourth FCG offered, "Can't get help from anyone else because you can't let them in the house." One respondent indicated, "...Not as much respite as we are limiting visits."

Keeping or Making Appointments Was Challenging

Twenty-six (23%) respondents indicated that medical or other provider appointments for their family members were canceled or affected. The concern of no respite also was observed with limited hospice appointments. "Hospice doesn't have volunteers available to help offer respite." Another respondent reported that "hospice didn't come as often." A third respondent indicated that "Adult daycare closed for [our] loved one."

"Canceled doctor appointments," "...Doing virtual appointments..." and "...Unable to attend most appointments..." were worries by 3 participants. One FCG indicated that "provider care decreased [as they appeared] only concerned with COVID and very concerning for those with serious disease not being able to accompany [family] to procedures." Other FCGs relayed concerns about who would care for and advocate for family members during appointments in their absence. One FCG offered, "Not allowed in hospital as his advocate." Another said, "I am unable to attend medical visits with my ill spouse. He forgets to advocate for his needs..."

Masks and Precautions Were Necessary

Eighteen respondents (15.9%) stated considerations regarding masks and precautions. One respondent indicated that masks changed the way facial expressions could be interpreted, "...Reduce the amount of info you can read in one's face." Three participants addressed the amount of time masks and precautions added, "More time disinfecting surfaces, reminding...about mask and hand hygiene...", "more thorough cleaning...", and "often teaching use of precautions." One participant indicated not liking the extra precautions, "I dislike wearing the mask constantly...", whereas another participant indicated that the mandatory precautions provided ease, "Made mask wearing easier and acceptable." An additional FCG expressed difficulties because imposed precautions and masks were used by everyone during the pandemic,

making it difficult to obtain needed masks for at-home treatments, "...Difficulty in getting masks in dressing change kits...."

There Was Added Fear, Anxiety, or Worry

Fifteen (13.3%) respondents indicated fear, anxiety, or worry for themselves or their family member during the pandemic. These FCGs were concerned about being unvaccinated or contracting COVID-19 and possibly passing it on to their family members. Respondents indicated an inability to bring in other caregivers in fear of transmitting the virus. One FCG stated, "...For fear of COVID, I'm it 128 to 168 hrs/wk." Another said, "...Anxiety for giving my loved one the virus, no break or help with caregiving." One respondent indicated, "I've had to go to the emergency room on several occasions unvaccinated and terrified of COVID." Another respondent summed things up, "...Always worried that I could bring it home to him. Just always worried." Another stated, "Anxiety, stress, precautions, lack of socialization."

No Change

Despite the above themes, 11 respondents (10%) indicated there was no change in their caregiving routines. One person replied that there was "the same isolation due to transplant." Another person stated, "It [COVID] has not affected me." Other participants did not elaborate in their replies. Two respondents addressed the potential ease that COVID-19 had on their situation. One FCG indicated that their family member was post "heart transplant in Feb 2021," and "COVID eased the transition to disability." Another added that there were "less blood draws," suggesting that not having to deal with this procedure was a positive effect.

Regression Analysis

Each of the demographic variables and themes was regressed on the C19Q. When individually regressed, the variables age, sex, marital status, race, and ethnicity did not have associations with C19Q. *Changes in everyday routines* ($R^2 = 0.057, P = .007$) and *keeping or making appointments was challenging* ($R^2 = 0.027, P = .045$) had bivariate associations with C19Q. All 5 themes and the variables age, sex, race, ethnicity, marital status, and HF stage were regressed on C19Q. The HF stage variable restricted the model's variability because of participants indicating either they did not know or could not recall their stage (19.7%), resulting in loss of degrees of freedom. Because of this substantial loss of data, this variable was omitted from the final regression model. With the resulting model ($R^2 = 0.141, P = .004$), *changes in everyday routines* ($P = .003$), *keeping or making appointments was challenging* ($P = .007$), and *social isolation* ($P = .009$) had a significant association with C19Q (Table 4). *Masks and precautions were necessary* and *added fear, anxiety, and worry*

TABLE 4 Multiple Regression COVID-19 Effect on Caregiving Routines (N = 113)^a

Independent Variables ^a	β	SE	t	P
Numerical age in years	0.01	0.01	0.54	.589
Female sex	0.05	0.31	0.16	.875
White race	0.22	0.29	0.77	.445
Non-Hispanic/Latino ethnicity	0.53	0.40	1.33	.188
Married	-0.28	0.20	-1.38	.172
Social isolation**	-0.47	0.18	-2.66	.009
Mask and precautions	0.03	0.23	0.13	.900
Fear, anxiety, and worry	-0.33	0.25	-1.30	.197
Changes every day**	-0.59	0.19	-3.10	.003
Keeping appointments**	-0.57	0.21	-2.77	.007
Dependent Variable	Intercept	SE	t	P
C19Q***	2.18	0.21	-2.77	<.001

$R^2 = 0.141, F(10, 102) = 2.833, P = .004.$
^a19 observations were removed for missing data.
 ** $P < .01.$
 *** $P < .001$

did not have any significant associations with C19Q. Variance inflation factor values (<2) indicated no substantial multicollinearity.²²

DISCUSSION

The aim of this research was to identify the impact of the COVID-19 pandemic on caregiving routines for FCGs who cared for family members with end-stage HF. Family caregivers reported some negative consequences similar to previous caregiving experiences identified in the caregiving literature for HF: social isolation; affected work experiences; change in living experiences; no respite; difficulty getting help; and fear, anxiety, and worry. Findings from this study that were associated with caregiving during the pandemic were precaution-related and appointment-related.

Family caregivers found that they were socially isolated, could not perform their own routines, or had no interaction with other family members. Social isolation of FCGs has been discussed in other HF literature.^{5,7,16,23} Family caregivers have been concerned with finding an "escape" and how "to be a good caregiver."¹⁶ A result of social isolation could be poorer quality of life or the possibility that FCGs could not continue to care for their family members.²³ Not experiencing a break in caregiving could lead to a loss



of resilience in FCGs.⁷ Often, palliative care, spiritual care, or respite care can offer needed support for caregiving,^{5,7,23} however, the nature of many services changed during the pandemic.^{1,3,14} Not having a spiritual respite during the pandemic was a difficulty identified by 2 respondents; this may have contributed to lack of emotional and spiritual well-being during this time.²³ Social isolation was the most common, but not the most significant, theme. This may be due to FCGs previously reporting isolation before the COVID-19 pandemic.²³

Family caregivers also found that there were changes to their overall routines. New changes included added difficulties in accessing or purchasing supplies and the added burden of caring for school-aged children at home. Some FCGs reported altering their living circumstances to be more convenient in response to imposed visiting restrictions (ie, moving the family member into the FCGs' home). A previous study indicated that FCGs had to change their living situations to be closer to family members because of strenuous HF caregiving routines.¹² Financial difficulties and job loss have been associated with caring for individuals with HF as well.²³ Findings associated with changes to living status were significantly associated with the response to how COVID-19 impacted caregiving. A more in-depth examination of FCGs' living situations and changes during the progression of HF caregiving is an area for future research.

In a recent study,¹² FCGs also spoke of the importance of being engaged in care and helping family members cope with their illness. In this study, FCGs stated concerns over having appointments canceled, missed, changed from in-person, and not being able to accompany their family members to appointments where they advocate on behalf of their family members. Past FCGs were concerned with caregiving responsibilities, including "being there" for their family members.¹⁶ Family caregivers needed to perform these activities and attend appointments to assist family members with care decisions.^{5,12} Although appointment challenges and cancellations were a newer finding related to the pandemic, it has previously been found that insufficient time with health care providers has been a dissatisfaction for FCGs caring for family members with HF.²³ Family members want to be included in the care for their ill family members and should be involved.

Some FCGs reported that enforced pandemic precautions added new burdens such as increased time necessary to perform caregiving activities, difficulty obtaining needed masks, and compliance with COVID-19 precautions by family members. There were feelings of fear, anxiety, or worry reported with caregiving routines during the pandemic; however, they were not significantly correlated. These feelings have been similarly associated with caregiving routines in times other than the COVID-19 pandemic, suggesting that just caring for an individual with HF may

elicit these feelings. Literature has found that the unknown course of HF can cause FCG anxiety.^{12,16}

Some FCGs (10%) reported that there was no change in their caregiving routines. Several factors may have contributed to this finding: care duration, prior caregiving knowledge, care relationship, and availability of help.^{12,16} Coping ability differs from person to person; hence, each FCG's ability to perceive the pandemic as stressful and its impact on daily routines may vary. Another factor contributing to unequal impact may have been the area of the country the FCG was from. Each state interpreted and mandated precautions differently; thus, the caregiving experiences may have been perceived differently in 1 region of the country than in another.

Strengths and Limitations

This study added to the expanding literature on the impact of COVID-19, specifically on FCGs who care for family members with end-stage HF. COVID-19 presented an overwhelming response nationally and globally with restrictions and social distancing, and this study revealed how those factors impacted the FCG experience. The cross-sectional design allowed for interpretation of non-causal associations during 1 period, which coincided with the pandemic. The open-ended responses offered opportunity for rich, contextual reports on the additional challenges that COVID-19 presented to FCGs. Thematic analysis offered a flexible and credible approach to analysis¹⁸ and was conducted using 2 approaches to QDA: manual thematic analysis for generation of themes and computerized QDA using text mining for confirmation of the themes. Manual QDA and QDA in R contributed to methodological triangulation; logistical coding of data; ease of retrieval, documentation, and storage; and intercoding for rigor, credibility, and trustworthiness.^{18,24} Researcher comparison and agreement of themes for thematic analysis was performed; however, a formal assessment rating for intercoder reliability was not used.²⁵ Future studies may use a formal assessment for enhanced rigor.

The sample was representative of the 4 regions of the United States, providing new information on the collective experience of FCGs during a time when social distancing guidelines may not have been uniform across the United States. Much of the recruitment was limited to social media groups because of social distancing; however, this provided opportunity to reach FCGs who may not have been reached otherwise as many FCGs were at home during the pandemic. The online survey administration allowed for ease in survey completion. Parent survey length may have led to completion burden. Respondents were allowed to stop or skip questions, and this also may have contributed to incomplete data.

Study data supported the previous literature that is known on FCGs for individuals with end-stage HF, adding

findings that FCGs responded to crisis differently. Some FCGs reportedly did not feel a change to caregiving duties, whereas others relayed negative or positive effects. Consistent with previous HF literature, there was little diversity in FCG race or sex;^{11,12,16} however, new information added the importance of FCGs seeing providers, being engaged in care, and advocating for family members. The findings also identified associations with FCG living status changes, and these effects were accompanied by social isolation and appointment changes (Table 4). It is unknown if the small sample size contributed to the nonsignificant associations for other caregiving themes. Odds for experiencing a negative effect to caregiving during the COVID-19 pandemic were 1.64 (Table 2), confirming the added burden during the pandemic.

The views from this study were from a sample representing FCGs who care for family members with HF; many responses (73.4%) were from family members who identified as caring for family members with stage III or stage IV HF, adding to the literature gap of FCGs caring for family members with later stage HF.⁵ Furthermore, 19.7% of the respondents replied that they did not know, cannot recall, or had not been told the HF stage of their family, introducing the possibility that these FCGs were caring for family members with advanced stage illness; however, this is not clear. This highlights a previously identified gap in care transitions for this population; family members need to be included in conversations when caring for their family members for understanding and successful outcomes to be realized.⁵

CONCLUSION

COVID-19 affected caregiving routines for FCGs of individuals with end-stage HF. Past FCG research for HF has indicated that more interventions are needed to facilitate caregiving services and needs, as well as recognition of FCG skills and coping.⁵ Family caregivers have indicated that they want to be included in their family members' care decisions. The social isolation and restrictions imposed during the COVID-19 pandemic halted many in-person programs, making access to caregiving services more difficult. There were restrictions to hospitals and health care resources during the pandemic; determination of current program availability and access to services that offered patients with HF and their FCGs continuity of care was needed.¹⁵

This research found that FCGs continued to be isolated and experienced lifestyle changes during the pandemic, negatively impacting their already difficult caregiving experience. There were FCGs who stated that their caregiving routines were not affected by the pandemic. It is possible for them that the pandemic's impact has not been experienced yet, or they have experienced similar caregiving routine experiences reported by other FCGs and have already learned to cope with these changes. How FCGs cope

during crisis may prepare them for the uncertain trajectory of caregiving in HF and is a future research indication.

RECOMMENDATIONS

With the ongoing restrictions and effects of COVID-19, recognizing how FCG cope during difficult situations or crises that cause significant duress may help health care professionals design and implement long-standing strategies that mitigate the negative consequences of caregiving. Future nursing research efforts identifying how FCGs cope with care transitions, particularly those who reported being unaffected by COVID-19 in their routines, may assist with long-term FCG interventions and policy decisions. Using specialty nurses to follow up on missed visits and track availability and use of supportive services may assist in continued program access and in keeping options attainable.²⁶ Ongoing referrals for respite, palliative care, and other services are needed, as well as education initiatives for staff and FCGs. As the COVID-19 pandemic continues, assessment for appropriate visit options that include FCGs can assist with advocacy for individuals with HF. Provider virtual visits, implemented during the pandemic, can include patients and their FCGs; assessment and education for available options may help FCGs and their family members feel less worry in seeking inpatient care when indicated. Funding supporting policies for new FCG programs and continued research in FCG assessment, monitoring, and care transitions should be supported.

References

1. Italia L, Tomasoni D, Bisegna S, et al. COVID-19 and heart failure: from epidemiology during the pandemic to myocardial injury, myocarditis, and heart failure sequelae. *Front Cardiovasc Med.* 2021;8:713560.
2. Reza N, DeFilippis EM, Jessup M. Secondary impact of the COVID-19 pandemic on patients with heart failure. *Circ Heart Fail.* 2020;13(5):e007219.
3. Haynes N, Cooper LA, Albert MA, Association of Black Cardiologists. At the heart of the matter: unmasking and addressing COVID-19's toll on diverse populations. *Circulation.* 2020;142(2):105-107.
4. Centers for Disease Control and Prevention. Leading causes of death. <https://www.cdc.gov/nchs/fastats/leading-causes-of-death.htm>. Published 2021. Accessed November 7, 2021.
5. Kitko L, McIlvennan CK, Bidwell JT, et al. Family caregiving for individuals with heart failure: a scientific statement from the American Heart Association. *Circulation.* 2020;141(22):e864-e878.
6. Dionne-Odom JN, Hooker SA, Bekelman D, et al. Family caregiving for persons with heart failure at the intersection of heart failure and palliative care: a state-of-the-science review. *Heart Fail Rev.* 2017;22(5):543-557.
7. Fasolino T. Get to the HEART of palliative care for patients with heart failure. *Am Nurse J.* 2020;15(8):38-42.
8. American Heart Association. Classes of heart failure. <https://www.heart.org/en/health-topics/heart-failure/what-is-heart-failure/classes-of-heart-failure>. Published 2020. Accessed July 1, 2020.
9. Dunbar SB, Khavjou OA, Bakas T, et al. Projected costs of informal caregiving for cardiovascular disease: 2015 to 2035: a



- policy statement from the American Heart Association. *Circulation*. 2018;137(19):e558-e577.
10. Bergethon KE, Ju C, DeVore AD, et al. Trends in 30-day readmission rates for patients hospitalized with heart failure: findings from the get with the guidelines-heart failure registry. *Circ Heart Fail*. 2016;9(6):e002594.
 11. Wingham J, Frost J, Britten N, et al. Caregiver outcomes of the REACH-HF multicentre randomized controlled trial of home-based rehabilitation for heart failure with reduced ejection fraction. *Eur J Cardiovasc Nurs*. 2019;18(7):611-620.
 12. Petruzzo A, Paturzo M, Naletto M, Cohen MZ, Alvaro R, Vellone E. The lived experience of caregivers of persons with heart failure: a phenomenological study. *Eur J Cardiovasc Nurs*. 2017;16(7):638-645.
 13. Wingham J, Frost J, Britten N, et al. Needs of caregivers in heart failure management: a qualitative study. *Chronic Illn*. 2015; 11(4):304-319.
 14. Gorodeski EZ, Goyal P, Cox ZL, et al. Virtual visits for care of patients with heart failure in the era of COVID-19: a statement from the Heart Failure Society of America. *J Card Fail*. 2020; 26(6):448-456.
 15. Bansal A, Goldstein D, Schettle S, et al. Institutional preparedness strategies for heart failure, durable left ventricular assist device, and heart transplant patients during the Coronavirus Disease 2019 (COVID-19) pandemic. *J Thorac Cardiovasc Surg*. 2020; 162(1):131-135.
 16. Sullivan BJ, Marcuccilli L, Sloan R, et al. Competence, compassion, and care of the self: family caregiving needs and concerns in heart failure. *J Cardiovasc Nurs*. 2016;31(3):209-214.
 17. Qualtrics. Survey software: the best tool and platform. <https://www.qualtrics.com/core-xm/survey-software/>. Published 2021. Accessed October 20, 2021.
 18. Creswell JW, Poth CN. *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*. 4th ed. Thousand Oaks, CA: Sage Publications; 2020.
 19. R Core Team. R: a language and environment for statistical computing. <https://www.R-project.org/>. Published 2021. Accessed June 1, 2021.
 20. Estrada S. Qualitative analysis using R: a free analytic tool. *Qual Rep*. 2017;22(4):956-968.
 21. Feinerer I. Introduction to the tm package: text mining in R. <https://cran.r-project.org/web/packages/tm/vignettes/tm.pdf>. Published 2020. Accessed June 1, 2021.
 22. Fox J, Weisberg S. *An R Companion to Applied Regression*. 3rd ed. Thousand Oaks, CA: SAGE Publications; 2019.
 23. Doherty LC, Fitzsimons D, McIlfratrick SJ. Carers' needs in advanced heart failure: a systematic narrative review. *Eur J Cardiovasc Nurs*. 2016;15(4):203-212.
 24. Polit DF, Beck CT. *Nursing Research: Generating and Assessing Evidence for Nursing Practice*. 10th ed. Philadelphia, PA: Wolters Kluwer; 2017.
 25. O'Connor C, Joffe H. Intercoder reliability in qualitative research: debates and practical guidelines. *Int J Qual Methods*. 2020;19: 1-13.
 26. Reinhard SC, Feinberg LF, Houser H, Choula R, Evans M. Valuing the invaluable: 2019 update: Charting a path forward. <http://www.aarp.org/homealone>. Published 2019. Accessed October 20, 2021.