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BMJ Open Sacrifice and solidarity: a qualitative study of family experiences of death and bereavement in critical care settings during the pandemic

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ABSTRACT

Background Pandemic-related restrictions are expected to continue to shape end-of-life care and impact the experiences of dying hospitalised patients and their families.

Objective To understand families' experiences of loss and bereavement during and after the death of their loved one amidst the SARS-CoV-2 (COVID-19) pandemic.

Design Qualitative descriptive study.

Setting Three acute care units in a Canadian tertiary care hospital.

Participants Family members of 28 hospitalised patients who died from March–July 2020.

Main outcome measures Qualitative semistructured interviews conducted 6–16 months after patient death inquired about family experiences before and beyond the death of their loved one and garnered suggestions to improve end-of-life care.

Results Pandemic restrictions had consequences for families of dying hospitalised patients. Most family members described an attitude of acquiescence, some framing their experience as a sacrifice made for the public good. Families appreciated how clinicians engendered trust in the name of social solidarity while trying to mitigate the negative impact of family separation. However, fears about the patient's experience of isolation and changes to postmortem rituals also created despair and contributed to long-lasting grief.

Conclusion Profound loss and enduring grief were described by family members whose final connections to their loved one were constrained by pandemic circumstances. Families observed solidarity among clinical staff and experienced a sense of unity with staff, which alleviated some distress. Their suggestions to improve end-of-life care given pandemic restrictions included frequent, flexible communication, exceptions for family presence when safe, and targeted efforts to connect patients whose isolation is intensified by functional impairment or limited technological access.

Trial registration number NCT04602520; Results.

INTRODUCTION

As mortality associated with serious SARS-CoV-2 (COVID-19) infection continues,^{1–5} so

Strengths and limitations of this study

- Strengths of this study include a focus on family experiences of loss and bereavement both within and beyond hospital exposure.
- Results from this work garnered suggestions for improving end-of-life care during pandemic times, which included frequent, flexible and transparent communication to help alleviate distressing images of patients dying alone as well as targeted attention for patients with language barriers or physical and/or cognitive impairments, who are especially impacted by the absence of their family.
- This study extends prior work in a larger sample of 28 families in the North American setting, with a higher participation rate and range of relationships.
- Limitations include a predominantly white, English-speaking sample from the first pandemic wave in the context of a publicly funded healthcare system.
- Results may differ for individuals with more videoconferencing access and ability, in communities with a different COVID-19 prevalence and vaccination penetrance and in different healthcare systems.

do public health measures that restrict family presence in hospital.⁶ Minimal personal contact and maximal barrier precautions profoundly affect the experiences of living, visiting and dying in hospital.⁶ While facilitating an intimate environment for compassionate end-of-life (EOL) care can be difficult at the best of times, the COVID-19 pandemic has made providing personalised care for dying patients and their families more challenging.^{7–10}

With ongoing infection rates, pandemic restrictions are expected to impact hospitalised patients, their families and healthcare providers for months to come.¹¹ Research is beginning to emerge directly from family members on the impact of losing a loved one



during the pandemic.^{12–17} In a Veterans Affairs survey, families of dying patients in acute hospital care, nursing home and hospice settings reported poor communication with the healthcare team and fear of patients dying alone as leading contributors to their experiences of distress.¹⁵ Other qualitative work investigating the experiences of grieving family members describe suffering driven by the separation from their loved ones, an inability to establish strong bonds with staff and an interruption of common death rituals.^{12–16} The forced separation of patients from their family has also troubled clinicians worldwide.^{10–18–21}

Given the tension between pandemic public health mandates and the desire of many relatives to visit their hospitalised family member, the objective of this study was to understand experiences of loss and bereavement for families of dying patients during the pandemic and garner suggestions for comforting practices in this context.

METHODS

In this post-positivist qualitative descriptive study,^{22–23} we contacted families of patients who died in hospital during the first wave of the COVID-19 pandemic between 16 March and 1 July 2020 in three acute care units (ICU, medical step down and COVID-19 ward) at a university-affiliated hospital in Canada. Following a study of hospital-based clinicians to understand adaptations to EOL care during the pandemic,¹⁰ family members of those patients were invited by telephone to an interview to understand how their experience of loss and bereavement was influenced by the pandemic. We attempted to recruit one family member or friend as the designated next-of-kin for each patient based on documentation in the medical chart. Family member recruitment was delayed 6–12 months after the patient's death to honour the anticipated grieving process.

Employing qualitative description methods,²³ we used a semi-structured interview guide developed and piloted with our interprofessional research team (online supplemental appendix) who have expertise in critical care medicine, nursing, and respiratory therapy, qualitative research, and spiritual care. Domains included: general experiences of loss and bereavement; influences of pandemic-related hospital policies; videoconferencing technology; and memorial rituals. Interviews were conducted by two trained female interviewers (BD and MS), one of whom is a resident physician (BD). Participants were given the choice of being interviewed by telephone or videoconferencing and of having their interview audio-recorded or having notes taken in place of recording. Verbal informed consent was recorded prior to the interview. Demographic data were captured using open-ended questions.

Data analysis

Transcripts were analysed using conventional qualitative content analysis.²⁴ After an initial phase of open coding

to condense and summarise the data, focused codes were developed through discussion with the research team. New data were compared with emerging analytic concepts for refinement using a constant comparative approach²⁵ during serial investigator meetings. Rigour was ensured by triangulating findings between analysts and participants and through the development of memos through the data collection and analysis process to form an audit trail.^{26–27} Descriptive statistics were used to quantitatively summarise family demographic data.

Patient and public involvement

Patient and public involvement were sought during the development of the original 3 Wishes Project protocol.¹⁰ The 3 Wishes Project is an EOL intervention aimed to honour dying patients and support families in grief. It has grown into a programme of research aimed at improving EOL care across critical and acute care settings.^{28–30} Many studies have emerged from the larger multicentre research programme,^{28–30} demonstrating feasibility, scalability, transferability and value. Due to expedited study processes during the COVID-19 pandemic, dying patients, their loved ones and the public were not directly involved in the design of this study.

RESULTS

Participants

Of 45 deceased patients included in the original study,¹⁰ we were unable to locate a surrogate decision maker for seven patients (eg, no family, changed addresses and no telephone). We contacted family members for 38 patients (figure 1). Of these, seven (18.4%) declined to participate, one due to lack of interest and six explaining their difficulty coping with the death of their loved one. Of 31 family members who agreed to participate, three (9.7%) interviews were not completed due to loss to follow-up. Of 28 family members interviewed, 2 were partners, 4 were parents, 14 were children and eight had other relationships with the deceased (table 1). Participants mean age was 55.5 years (SD 12.0); most identified as white (24, 85.7%), with Christian religious affiliations (18, 64.3%).

From February to July 2021, 28 interviews were conducted at a mean of 9.4 (SD 1.8) months after the patient's death. While 27 participants allowed audio-recording, one preferred written notes.

Qualitative analysis

Analysis of interview data yielded insight on the experiences of families whose loved one died in hospital, organised into four categories that emphasise the concepts of sacrifice and solidarity. Participants expressed prevailing acceptance of public health policies, some with an attitude of acquiescence to restrictions for the greater good. These policies keeping loved ones at a distance had a dual effect, both exacerbating and mitigating common EOL care challenges within and beyond the hospital. Families universally appreciated clinician efforts to maintain

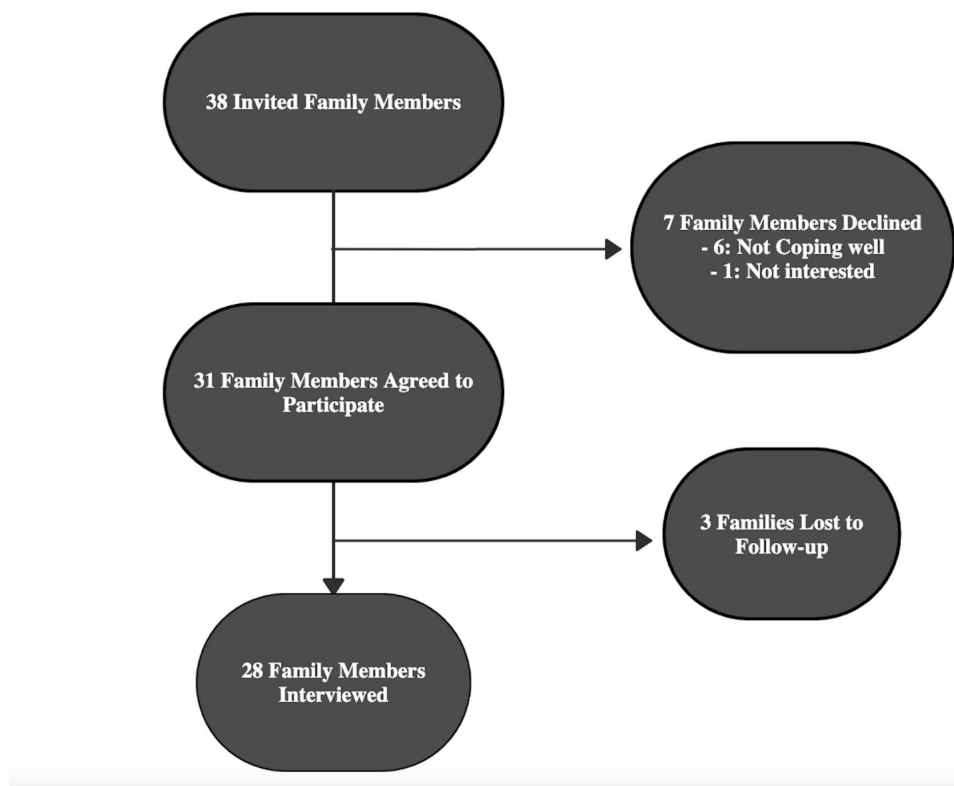


Figure 1 Family participant flow diagram. Summary of recruitment flow for eligible families.

compassionate care, sometimes casting their own sacrifice in solidarity with efforts that clinicians made in service to the community. They also shared adaptations to traditional postmortem practices and rituals that influenced their grieving.

Acquiescence to pandemic-related restrictions

Despite the suffering and loss endured by families during the pandemic, acquiescence to the pandemic-related restrictions was acknowledged as a civic duty. Families explained how being away from their loved one during their final days reflected their recognition of the rationale for jurisdictional rules. In surrendering their hospital visits to minimise transmission risk, many participants invoked the concept of social solidarity and safeguarding the community.

I never abused the procedures that we had to follow. We try and understand because it was for the greater good... it was for the best... they had to take some precautions. (Partner)

In a poignant example of accepting the risk of missing her husband's final moments, one participant described her decision of a delayed hospital visit in terms of protecting others from possible viral transmission:

I told [the doctor] I had been dealing with the public so I would need to go home anyhow and shower and change my clothing before I came up to the hospital and when I was enroute home, the Charge Nurse called and she said, 'You know, if you do what you

say you're going to do, he may not be here.' And I said, 'Well, you know, [patient's name] would have it no other way.' He wouldn't want me coming up and contaminating the hospital. (Partner)

Some family members assented to the necessary restrictions but considered the perceived changes in care as a casualty of the pandemic:

She was in hospital there and I couldn't visit her there and with the hearing impairment and sight impairment [it was] even harder for her because now she's in a strange place. Everyone's wearing PPE, which I don't blame, and I'm sure the people couldn't spend as much time as they may have wanted to with her because of the situation...I guess she was just collateral damage from whole COVID situation. (Son)

Loving and grieving from afar

The experiences of being separated from a loved one during periods of critical illness and up to the moment of death were universally described as agonising. Being kept apart led many family members to experience decisional dilemmas regarding safety for themselves and others. Participants wondered if their visits could introduce the virus, including to their dying loved one who was not infected. One participant asked himself if he should 'take the risk of where I get my mother sick' (son). Another family member remarked on a possible conflicting sense of duty for people who would otherwise visit hospitalised patients,

Table 1 Characteristics of family members and their deceased loved ones

Characteristics	n=28
Age, years, mean (SD)	55.5 (12.0)
Female n, (%)	22 (78.6)
Ethnicity, n (%)	
White	24 (85.7)
Indigenous	2 (7.1)
Arabic	1 (3.6)
East Asian	1 (3.6)
Religion, n (%)	
Christian	18 (64.3)
Atheist	5 (17.9)
Agnostic	4 (14.3)
Indigenous	1 (3.6)
Relationship to deceased, n (%)	
Child	12 (42.9)
Parent	4 (14.3)
Friend	4 (14.3)
Sibling	3 (10.7)
Partner/spouse	2 (7.1)
Relative by marriage (in-law)	2 (7.1)
Grandchild	1 (3.6)
Ward at patient's time of death, n (%)	
Intensive care unit	23 (82.1)
COVID-19 ward	2 (7.1)
Acute medical stepdown unit	1 (3.6)
Palliative care suite	1 (3.6)
Hospital medical ward	1 (3.6)

In this table, we report characteristics of interviewed family members and location of the patient's death. The COVID-19 ward cared for acutely ill COVID-19 patients; those requiring high-flow nasal cannula or $\text{FiO}_2 > 0.70$ were transferred to the intensive care unit.

FiO_2 , fractional inspired oxygen.

such as a case worker from a group home, because '*she wouldn't want to bring it back there*' (son).

Deprived of the chance to be physically present before and during the dying process haunted most families. Some referenced their absence at the bedside to be detrimental to a patient's recovery. While technology provided opportunities for continued connections, a few families found the virtual visits distressing, and occasionally shocking, especially witnessing the trajectory of their loved one's progressive decline. Others described difficulty understanding how much their loved one had decompensated in hospital without seeing it first-hand.

And then, we had that two week window where we couldn't go in and then, when I pushed again to get

in there, [my mother] was a completely different person...You couldn't get a reaction. (Daughter)

Some described this lack of in-person contact as impairing their ability to make informed end-of-life decisions, especially related to resuscitation directives.

You know, whatever protocol is necessary, I will follow that. I need to physically see her to make that decision. I can't make that decision over the phone. (Daughter)

Families were concerned that the hardship that patients underwent were worse than theirs during the pandemic. The anguish of separation was particularly difficult for families with loved ones with physical disabilities including visual and auditory impairment. The most frequently expressed worry was about patients' ability to communicate with the care team due to sensory and/or cognitive impairments or language barriers.

With the hearing impairments and sign impairments... [it's] even harder for her because now she's in a strange place. (Son)

While all participants grieved the loss of the chance to be physically present at the time of death, one family member acknowledged how this lack of physical presence also averted the anticipated trauma of witnessing the final moments.

I know it sounds awful, I really wanted to be there for her, but that's a really big burden to carry with you for the rest of your life. (Sister)

Imagining their loved one dying alone many months after the death during interviews, all participants expressed heartache.

I'll never know what those three weeks were like. I don't know what an eternity it was. My worst thing was, does he feel forsaken by us? (Partner)

Respect and appreciation for clinicians

Families expressed gratitude for the social workers and chaplains who spent countless hours supporting them when their '*world is falling apart*' (artner). Many participants derived comfort from frequent, open communication:

They always called me back. Even if it was my third call of the day, it was okay. And they gave me an update, whether it was 'no change' or whatever change it was, if there was a change. I didn't feel like I was bugging them. (Daughter-in-law)

Being able to rely on clinicians to deliver supportive messages to their loved one was greatly appreciated.

I said, please make sure that he knows that I'm calling...that I love him very much. I care [pause] and that, you know, due to COVID, we can't be with him. (Partner)

This family-centred contact with clinicians was greatly valued, creating connections and intimate moments whenever possible, particularly at the end:

They did call me and ask me what I wanted to say to him before he went, if he went through the night. That was the biggest thing for me. (Son)

During both in-person and virtual visits, family members observed acts of compassion performed collaboratively by nurses, often with other clinicians, such as humanising the environment and recognising the dignity of the patient through personal care.

Somebody took the care to shave him properly. And, and it just put a smile on my face, you know, that, there was some dignity. You know that even though he was so sick, that somebody cared enough. I'll always remember that. Always. (Partner)

Postmortem impacts of COVID-19

Many adaptations to postmortem practices were described by those unable to visit the hospital, including identification of the body. Contrasted with typical practices of confirming a loved one's identity guided in-person by funeral home staff, one participant described a request to identify her deceased sister on a digital photo over email.

I think of what she looked like when she was dying and I think about the picture she sent me for confirmation, the funeral home - the picture they sent from the morgue... I haven't looked at it again but it's there because I don't know whether I should delete it or not. Like, it feels wrong to delete it but I don't want to look at it. (Sister)

After being barred from hospital, and in some cases from long-term care residences before a patient's hospitalisation, funeral service limitations added another layer of loss for families who had to defer or forgo celebrations of their loved one's life.

It feels like, if you don't have a funeral, you're not honouring her. It's just like she didn't matter. You know? She's just, like, in a box on the mantle and we didn't come together and talk about her and show our love for her. It just feels like [pause] she was just like a blip. (Sister)

Many families described missing out on the comfort of community gatherings associated with the usual post-mortem rituals.

When you go to funeral home and you have those two days or whatever, people come and they express their feelings and they comfort you, which wasn't part of this. We only had two hours at the funeral home and that was it. (Partner)

By contrast, exemption from social obligations during bereavement was also referred to as '*blessings in disguise*' (mother, daughter). Pandemic restrictions led to changes

in conventional ceremonies, which some participants welcomed. Strict lockdown orders necessitated many individuals to work from home and keep services small. Some families found relief in the permission for privacy granted by the pandemic.

But COVID, in a weird way, was a bit of a blessing in terms of that because I have been working from home since March so I did take a little bit of time off of work. But then, you know, obviously, it's not like the week that I took off fixed everything. I was still kind of hurting from it, it was nice to be able to work and just be by myself and if I needed to, cry, you know. I'd have to like, run to the bathroom at work [pause] I could just kind of do it in my own space. (Daughter)

Other families described domestic adaptations, having: '*a celebration of life in the backyard*' (father). Some religious and secular services used video platforms. Streaming live ceremonies provided relatives opportunities to offer condolences from a distance.

With regards to the church ceremony and also the gravesite ceremony, they broadcasted it live on FaceTime. My brother and our other family in the U.S. and back in Poland and Australia were able to watch at that time. (Son)

Some communities came together in solidarity for hurting families. Local demonstrations of support were recounted, including an instance when a hearse carried a patient's remains to the gravesite.

We called one of the neighbours to come [pause] they all wanted to come but they couldn't [pause] and we told them that we were going to pass by the house for his last time before going to the cemetery. And then they all stood by the front lawn saying good-bye. (Partner)

DISCUSSION

Findings from this study highlight the impact that the COVID-19 pandemic has had on family members who have lost a loved one in hospital. Families expressed acquiescence to pandemic-related restrictions, underscoring a sense of unity for the public good. Nevertheless, the inability to be physically present in hospital had myriad consequences for relatives and friends of dying patients. Participants described multiple distinct losses beyond the death itself, in terms of bedside vigils foregone and rushed rituals afforded by usual mourning practices. Families observed solidarity among clinical staff and sense of unity with staff while entrusting their loved one's care to the clinical team. Although families valued clinicians' efforts to mitigate the negative impact of infection control restrictions, these efforts did not prevent their profound and enduring grief.



Family perspectives about hospitalised dying relatives during the pandemic have been reported in self-administered public surveys^{13 15} and two other qualitative studies.^{12 16} One study of 19 families of patients who died in hospital or another setting in the UK¹² and a report of 19 relatives of patients who died in an intensive care units in France¹⁶ also underscored the impact of physical separation on relatives' experiences of bereavement. Our findings confirm these reports of profound loss described by family members whose final connections and post-mortem rituals to honour their loved one were subverted by pandemic-related infection control measures. Delaying family contact postmortem longer than prior research,^{12 16} the interviews we conducted 6–16 months postmortem indicate vivid recall and suggest enduring grief. Our findings also differ from previous reports describing tension and diminished trust between families and critical care staff,¹⁶ instead highlighting how connections and open communication cultivated with clinicians was a comforting aspect of their experience, perhaps facilitating bonding between families and clinicians, ultimately fostering confidence in the healthcare team.³¹

Contrary to the social division that can result from imposed public health restrictions,³² our study differs from other research in that it revealed a general collective attitude of acceptance. Although public health policies often employ a utilitarian approach, requiring individuals to make personal sacrifices for the greater good, this tension between personal and collective interests can be further exacerbated in states of emergency.³³

Reflections on what stayed with families postmortem illuminate some suggestions for future end-of-life practice under continuing pandemic restrictions. The angst of perceiving their loved one as dying alone¹⁵ calls for frequent, flexible and transparent communication. Additional attention is needed for patients with language barriers or physical and/or cognitive impairments, who are especially impacted by the absence of family members. Ensuring that visual aids, hearing devices or language translation assistance is available may aid communication for the most vulnerable and help to alleviate family distress. Digital solutions to augment phone and in-person connections can help to share details of patients' status, trajectory and care but need technical and emotional preparation and support. Dedicated efforts to humanise the clinical space with personal affects, in conjunction with patient-centred acts of compassion, were small yet impactful ways to comfort families from afar. Additional strategies to promote individualised patient and family-centred EOL care in hospital and create personalised adaptations to memorial services and life celebrations could assist in easing family grief.

Strengths of this study include a focus on family experiences both within and beyond hospital exposure. Interview data reflect a range of relationships; the participation rate was 74%. Limitations include a predominantly white, English-speaking sample from the first pandemic wave in the context of a publicly funded healthcare system.³⁴

Results may differ for individuals with more videoconferencing access and ability, in communities with a different COVID-19 prevalence and vaccination penetrance and in different healthcare systems.

Conclusion

This study highlights the impact of public health measures on family member experiences of the death of a hospitalised loved one. Profound loss and enduring grief were described by those whose final connections were constrained by pandemic restrictions. Despite the overwhelming sacrifices made, families reported acquiescence in the name of population health and solidarity with clinical staff caring for their loved one. Clinicians and public health officials should consider these family-informed perspectives when generating crisis guidelines and future administrative policies to improve EOL care for hospitalised patients.

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Patient consent for publication Not applicable.

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Provenance and peer review Not commissioned; externally peer reviewed.

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