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Perspectives from Designated Family Caregivers of Critically Ill Adult Patients During the COVID-19 Pandemic: A Qualitative Interview Study --Manuscript Draft--

Manuscript Number:	PONE-D-21-35872
Article Type:	Research Article
Full Title:	Perspectives from Designated Family Caregivers of Critically Ill Adult Patients During the COVID-19 Pandemic: A Qualitative Interview Study
Short Title:	Perspectives from Designated Family Caregivers of Critically Ill Adult Patients During the COVID-19 Pandemic
Corresponding Author:	Kirsten M. Fiest University of Calgary Calgary, CANADA
Keywords:	Critical Care; Family; Interviews; COVID-19; Restricted Visitation
Abstract:	<p>Background: Family visitation in intensive care units (ICU) has been impacted by the severe acute respiratory syndrome coronavirus 2 (COVID-19) pandemic. While studies report on perceptions of families completely restricted from ICUs, little is known about the burden experienced by designated family caregivers allowed to visit their critically ill loved one. This study sought the perspectives of family caregivers of critically ill patients on the impact of one-person designated visitor policies mandated in ICUs during the COVID-19 pandemic.</p> <p>Methods: Throughout the study period a restricted visitation policy was mandated capturing the first and second wave of the pandemic that allowed one designated family caregiver (i.e., spouses or adult children) per patient to visit the ICU. Designated family caregivers of critically ill patients admitted to ICU September 2020 to November 2020 took part in individual 60-minute, semi-structured interviews at 6-months after discharge from the index ICU admission. Themes from family interviews were summarized with representative quotations.</p> <p>Results: Key themes identified following thematic analysis from six participants included: one visitor rule, patient advocate role, information needs, emotional distress, strategies for coping with challenges, practicing empathy, and appreciation of growth.</p> <p>Conclusion: Designated family caregivers of critically ill patients admitted to ICU during the COVID-19 pandemic perceived a complex and highly stressful experience. Support from ICU family liaisons and psychologists may help ameliorate the impact.</p>
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Additional Information:	
Question	Response
Financial Disclosure	SJM was supported by a Canadian Institutes of Health Research Doctoral Research Award. The funder had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript; no financial relationships with any organizations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could have influenced the submitted work.
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3 **Ill Adult Patients During the COVID-19 Pandemic: A**
4 **Qualitative Interview Study**

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36 **ABSTRACT**

37 **Background:** Family visitation in intensive care units (ICU) has been impacted by the
38 severe acute respiratory syndrome coronavirus 2 (COVID-19) pandemic. While studies report
39 on perceptions of families completely restricted from ICUs, little is known about the burden
40 experienced by designated family caregivers allowed to visit their critically ill loved one. This
41 study sought the perspectives of family caregivers of critically ill patients on the impact of
42 one-person designated visitor policies mandated in ICUs during the COVID-19 pandemic.

43 **Methods:** Throughout the study period a restricted visitation policy was mandated
44 capturing the first and second wave of the pandemic that allowed one designated family
45 caregiver (i.e., spouses or adult children) per patient to visit the ICU. Designated family
46 caregivers of critically ill patients admitted to ICU September 2020 to November 2020 took
47 part in individual 60-minute, semi-structured interviews at 6-months after discharge from the
48 index ICU admission. Themes from family interviews were summarized with representative
49 quotations.

50 **Results:** Key themes identified following thematic analysis from six participants included:

51 one visitor rule, patient advocate role, information needs, emotional distress, strategies for

52 coping with challenges, practicing empathy, and appreciation of growth.

53 **Conclusion:** Designated family caregivers of critically ill patients admitted to ICU during

54 the COVID-19 pandemic perceived a complex and highly stressful experience. Support from

55 ICU family liaisons and psychologists may help ameliorate the impact.

56 **Key Words:** Critical Care; Family; Interviews; COVID-19; Restricted Visitation

57 **INTRODUCTION**

58 Critically ill patients admitted to the intensive care unit (ICU) are among the sickest patients
59 in the healthcare system given their need for urgent treatment with life sustaining
60 technologies [1]. Family caregivers of critically ill patients experience distress, as witnessing
61 critical illness and intense ICU therapies can elicit feelings of helplessness [2]. Family
62 caregivers frequently experience long-lasting, negative psychological consequences, including
63 anxiety, depression, post-traumatic stress disorder, emotional distress, and sleep disturbances
64 [3].

65
66 In response to the burden of critical illness for family caregivers of ICU patients, the Society
67 of Critical Care Medicine Guideline for Patient and Family-Centred Care recommends regular
68 visitation between family caregivers and ICU patients to improve outcomes (e.g., distress) [4,
69 5] and experiences (e.g., satisfaction) [6, 7] among ICU patients and their families. Most
70 hospitals, including the intensive care units, enacted restricted visitation policies as part of
71 infection control measures [8] to limit spread of the COVID-19 virus, reduce use of personal
72 protective equipment, and to facilitate organizing care [9, 10]. Well-intentioned, restricted
73 visitation policies may have unintended negative consequences on family caregivers, such as

74 grief over inadequate communication and sparse involvement in the provision of care [11,
75 12]. Designated family caregivers of critically ill patients admitted to ICUs that mandated
76 one-person designated visitor policies faced additional challenges when having to deliver
77 medical information to other family members that were restricted from visiting [13, 14].

78

79 Restricted visitation in the ICU during the COVID-19 pandemic may lead to long-term
80 detriment [15]. Perspectives from designated family caregivers of critically ill patients are
81 unknown. The objective of this study was to describe perspectives of designated family
82 caregivers of critically ill patients on the impact of one-person designated visitor policies
83 mandated in ICUs during the COVID-19 pandemic.

84

85 **METHODS**

86 **Study Design**

87 This qualitative study was conducted at Foothills Medical Centre ICU (Calgary, AB, Canada)
88 between September 2020 to November 2020. A restricted visitation policy was mandated
89 throughout the study period (March 2020 to May 2021); capturing the (entire) first and

90 second waves and (part of the) third wave of the pandemic that allowed one designated
91 family caregiver per patient to visit. We used a qualitative descriptive approach [16] with
92 data collected from semi-structured interviews with designated family caregivers (i.e.,
93 spouses or adult children designated to visit the ICU routinely) of critically ill patients in
94 accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) (S.
95 Table 1) [17]. The Conjoint Health Research Ethics Board at the University of Calgary
96 approved this study (Ethics ID: REB19-1000). Informed consent and oral consent were sought
97 from all participants that agreed to be interviewed.

98

99 **Selection and Description of Participants**

100 We used a convenience sample, of designated family caregivers who participated in another
101 study by our group and indicated interest in being contacted to participate in additional
102 research projects. Family caregivers were adults (≥ 18 years), able to understand and
103 communicate in English, and able to provide informed consent. We invited family caregivers
104 using the contact information they provided (e-mail or telephone).

105

106 **Semi-structured Interview Guide**

107 A multidisciplinary research team (patient partner (B.S.), doctoral student (S.M.), research
108 assistant (I.Y.), research associate (K.K), epidemiologist (K.F.), and qualitative research expert
109 (J.P.L.)) created a draft semi-structured interview guide based on research experience and
110 relevant literature [14, 18, 19]. For feedback and to ensure quality control, draft semi-
111 structured interview guides were presented to a patient partner (M.A., a community member
112 involved with our research team) and their family caregiver (J.A.), as well as a research
113 coordinator (C.G.), all of whom had no prior involvement in the research study. A revised
114 interview guide was then drafted, and pilot tested independently on three occasions in
115 interviews with two critical care nurses (K.W., V.O.), and an intensivist (N.J.). The set interview
116 guide was refined iteratively based on feedback from pilot interviews; no further edits were
117 required after this point (S. Table 2).

118

119 **Data Collection**

How was selected the study population ? How many patients was
asked to participate before reaching 6 people?

120 Demographic data on patients and family caregivers was collected upon enrollment in the
121 larger RCT. Telephone interviews were conducted by S.M. who has experience planning and
122 facilitating semi-structured interviews. Two days prior to each interview, participants (with e-
123 mail access) were sent information about the interview objectives. Participant oral consent

124 was obtained by the research team prior to the start of each interview. All interviews were
125 conducted within 60-minutes, audio recorded, transcribed verbatim, de-identified, and
126 imported to NVivo-12 (QSR International, Melbourne, Australia) for data management.

127

128 **Data Analysis**

129 We analyzed demographic data by using descriptive statistics. All variables were categorical
130 and reported as counts and proportions. Analysis of qualitative data was conducted
131 concurrently and iteratively using a thematic synthesis approach published by Braun and
132 Clarke [20]. We used a data-driven inductive approach to coding [21] that allowed our
133 working knowledge of the topic [22] to guide the structure of interview discussions while
134 permitting themes to emerge directly from the data [23]. The coding process included two
135 coders (S.M., K.K.) who carefully read all transcripts before coding one-third of the data set
136 to generate initial codes. Once the initial set of codes was developed, coders switched
137 transcripts to ensure that all were coded in duplicate. The two coders searched for themes
138 by collating codes across the data set and met biweekly for one month to refine themes and
139 discuss progress. Two participants were provided with a copy of the final list of themes and
140 sub-themes to review and comment on to ensure credibility, accuracy, and validity. We

141 formally compared themes across participants and compared interpretations across

142 researchers in order to ensure analytic rigor.

143

144 **RESULTS**

145 **Participants**

146 Ten designated family caregivers participated in another study by our group from September

147 2020 to November 2020, of which eight ($n=8$, 80%) indicated interest in being contacted to

148 participate in additional research projects through a telephone call ($n=2$, 25%) or an e-mail

149 invitation ($n=6$, 75%) (Figure 1). Six (75%) family caregivers agreed to participate in the

150 telephone interview. Interviews were conducted at an average of 6.3 months (standard

151 deviation [SD] 2.3) post-ICU discharge.

To be in methodology. Need reference
from original study.

152

153 Family caregivers were mostly female ($n=4$, 67%), of North American descent ($n=4$, 67%),

154 and had completed some university/college, without receiving a degree ($n=4$, 67%). Half

155 ($n=3$, 50%) of the participants were spouses of critically ill patients (Table 1). Some family

156 caregivers ($n=2$, 33%) self-reported being diagnosed or treated for depression (prior to ICU

157 admission) and half ($n=3$, 50%) self-reported being diagnosed or treated for anxiety (prior to

158 ICU admission). Critically ill patients were mostly male ($n=4$, 67%) with either some high

159 school ($n=2$, 33%) or a Master's degree ($n=2$, 33%). No patient was diagnosed with the

160 COVID-19 virus prior to or during their ICU stay.

These are data describing the patient, not the study population . To clarify

161

162 **Table 1.** Demographics of designated family caregiver participants and their critically ill
 163 loved one admitted to an intensive care unit during the COVID-19 pandemic

164

Demographic	Family Caregivers (N=6)	Critically Ill Patients (N=6)
<i>Sex¹</i>		
Male	2 (33.3%)	4 (66.7%)
Female	4 (66.7%)	2 (33.3%)
<i>Gender²</i>		
Male	2 (33.3%)	4 (66.7%)
Female	4 (66.7%)	2 (33.3%)
<i>Ethnic or cultural group³</i>		
Other North American	4 (66.7%)	3 (50.0%)
First Nations	1 (16.7%)	0 (00.0%)
Eastern European	2 (33.3%)	2 (33.3%)
Western European	2 (33.3%)	1 (16.7%)
British Isles	1 (16.7%)	0 (00.0%)
<i>Education⁴</i>		
Some high school	0 (00.0%)	2 (33.3%)
High school graduate	0 (00.0%)	1 (16.7%)
Some university/college (no degree)	4 (66.7%)	0 (00.0%)
Bachelor's degree	2 (33.3%)	0 (00.0%)
Master's degree	0 (00.0%)	2 (33.3%)
Professional degree	0 (00.0%)	1 (16.7%)
<i>Relationship to patient</i>		
Spouse or Common-Law	3 (50.0%)	--
Adult Child	3 (50.0%)	--
<i>Considered primary caregiver⁵</i>		
Yes	6 (100.0%)	--
No	0 (00.0%)	--
<i>Clinically relevant depression⁶</i>		
Yes	2 (33.3%)	--
No	4 (66.7%)	--
<i>Clinically relevant anxiety⁶</i>		
Yes	3 (50.0%)	--
No	3 (50.0%)	--

165 Numbers are counts with percentages. Dashes indicate that the question was not asked.

166 ¹Recorded at birth

167 ²Reported as gender identity

168 ³Multiple selections per participant were allowed

169 ⁴Highest degree received

170 ⁵During patient stay in the ICU and after discharge from hospital

171 ⁶Relating to direct medical treatment by a healthcare professional prior to ICU admission as self-reported by the participant

172 **Family Caregiver Perceptions**

173 Designated family caregivers of critically ill patients admitted to ICU during the COVID-19

174 pandemic perceived a complex and highly stressful experience. **Support from ICU family**

Comment from the study population or author?

175 **liaisons and psychologists may help ameliorate the impact.** Participants described their

176 experiences with having to process their loved one's prognosis and treatment information,

177 engage in shared decision making, and then relay information to family members who were

178 not allowed to visit.

179

180 Seven themes related to caring for a critically ill patient as the designated family caregiver

Confused, to be explain

181 during the COVID-19 pandemic were identified in the data: (1) **one visitor rule;** (2) **patient**

182 **advocate role;** (3) **information needs;** (4) **emotional distress;** (5) **strategies for coping with**

183 **challenges;** (6) **practicing empathy;** and (7) **appreciation of growth** (Table 2).

Each point needs a small definition and how the classification was made

184

185 **Table 2.** Perspectives of designated family caregivers on caring for critically ill loved ones
 186 admitted to an intensive care unit during the COVID-19 pandemic

187

Themes	Quotes
One Visitor Rule	<p><i>At that time, one visitor was allowed that had to be the same visitor. So, our children were not allowed to visit, which was really hard on them all. Okay, we thought, we have to deal with this. (Spouse)</i></p> <p><i>I just couldn't imagine him being there all by himself—I just had to be there, it was very important to me. (Son)</i></p> <p><i>It was absolutely harder because of COVID. I felt like I had to be there all of the time because only one person was allowed, and I didn't ever want him to feel like he was alone. He didn't understand why the kids couldn't be there—that made it very hard, not being able to have that support. (Spouse)</i></p>
Patient Advocate Role	<p><i>I was there and I saw the lung exercises, so then I could quiz him later on. I asked, did you do it, do you remember how long you're supposed to do it? You're supposed to do it every hour. Are you doing it? Those people out there really care, and I want you to do your lung exercise. But what I know is that is that was just a phone call [if no visitors were allowed in the ICU], I wouldn't know those specifics and I wouldn't be able to watch and be an advocate. (Spouse)</i></p> <p><i>Even though I was the only one in there I was never asked to pipe up, to tell them about what he is really like, to advocate—I didn't know how you know, being alone. (Spouse)</i></p> <p><i>The lessons learned is I wish I would have been more involved in rounding. I wish I would've been more invited. I know it's hard right now, given [COVID-19] restrictions, but if I was even just listening, I would have felt included. (Daughter)</i></p>
Information Needs	<p><i>I'm a very curious person and I like to know what's going on. So, I spent a long time asking questions whenever they were there. The staff was very good at giving us answers, but yet a lot of the time we were waiting—sitting and waiting or going back and forth and waiting for them to come to your patient. (Daughter)</i></p> <p><i>I was afraid to ask questions. I felt isolated. Not a lot of information was given. I felt intimidated. (Spouse)</i></p> <p><i>I had to give daily updates to everybody. I would wait for a report and then I would go out to call everybody, let them know how he was doing. So many calls—I had to make myself a pretty decent schedule. The only things I had time for were to come in [to the ICU], make all my calls, go back to the hotel, turn on TV for a few minutes and then go to bed. (Spouse)</i></p>
Emotional Distress	<p><i>It was an emotional and very difficult experience. I felt scared, left out, kind of anxious. (Daughter)</i></p> <p><i>I spent many hours just sitting there wondering, you know, listening to machines, beeping, very loudly. I was on an emotional rollercoaster—I couldn't find solitude. (Spouse)</i></p> <p><i>I think that you fool yourself into thinking that you're okay. I'm okay. I'm okay. I'm okay, I kept saying. You just are running on adrenaline, right. I didn't relax until he left ICU and I know it's the times, right. I had to tell myself that it was fine...initially anyway. (Spouse)</i></p>
Strategies for Coping with Challenges	<p><i>I knew my lifestyle. I had to eat better, you know, as far as getting some sleep at night. And so, sometimes I wouldn't come back a second time, and there was one time I remember I actually felt really guilty. (Son)</i></p> <p><i>I'm very scheduled. So, I made myself a daily schedule. Mostly for my own mental health. (Son)</i></p> <p><i>I made myself a decent schedule... day in and day out. That helped for all of us. (Spouse)</i></p> <p><i>I wrote everything down. I would write it down, what the care team said for the entire day, and then at end of each day I would write everything in a second book that I left for my husband so that he could look back and find what he needed to know, even when I wasn't there. (Spouse)</i></p>
Practicing Empathy	<p><i>Being able to talk to them [the ICU care team] provided a feeling of solidarity. They were going through a hard time. You know, you do take an interest in other people who are always there. The talking helped, like teamwork. (Son)</i></p> <p><i>I would suggest a [virtual] peer group of people that have to deal with these issues, so we can exchange coping mechanisms and ideas, and show empathy for others, you know, that would be helpful. (Spouse)</i></p>
Appreciation of Growth	<p><i>I mean, once you've been through these stressful, traumatic, draining situations, you look back and reflect and think, great, I can do tough things because I've dealt with a lot. (Spouse)</i></p>

I'm very happy that it's over. It gets better and I've learned a lot—I've grown and hey, that's not what I was expecting to say. (Son)

189 **One Visitor Rule**

190 Participants from all interviews provided their perspectives on the challenge of adhering to
191 the one designated visitor policy. Difficult for all, this policy was especially burdensome to
192 families with young children: "At that time, one visitor was allowed that had to be the same
193 visitor. So, our children were not allowed to visit, which was really hard on them all."
194 (Spouse). Most designated family caregivers agreed about the guilt when absent from the
195 unit: "I just couldn't imagine him being there all by himself—I just had to be there, it was
196 very important to me" (Adult Child). One family caregiver remarked that not having external
197 support (present with them in the ICU) was challenging:

198 *It was absolutely harder because of COVID. I felt like I had to be there all of the time*
199 *because only one person was allowed, and I didn't ever want him to feel like he was*
200 *alone. He didn't understand why the kids couldn't be there—that made it very hard, not*
201 *being able to have that support.* (Spouse)

202

203 **Patient Advocate Role**

204 All designated family caregivers shared their perspectives on the importance of being
205 present that provided an opportunity for the family caregiver (who knows the patient best)

206 to weigh in on subtleties they may notice in the patient's overall demeanor. Family

207 caregivers took opportunities to be actively involved in care of their loved one:

208 *I was there and I saw the breathing exercises, so then I could quiz him later on. I asked,*
209 *did you do it, do you remember how long you're supposed to do it? You're supposed to*
210 *do it every hour. Are you doing it? Those people out there really care, and I want you to*
211 *do your breathing exercise. But what I know is that if that was just a phone call [if no*
212 *visitors were allowed in the ICU], I wouldn't know those specifics and I wouldn't be able*
213 *to watch and be an advocate. (Spouse)*

214 In contrast, some family caregivers described feeling distress about being involved in patient
215 care and were waiting to be asked to weigh in. One family caregiver remarked: "Even though
216 I was the only one there I was never asked to pipe up, to tell them about what he is really
217 like, to advocate—I didn't know how you know, being alone" (Spouse). The lack of invitation
218 evoked feelings of isolation in one family caregiver: "The lesson learned is I wish I would
219 have been more involved in rounding. I wish I would've been more invited. I know it's hard
220 right now, given [COVID-19] restrictions, but if I was even just listening, I would have felt
221 included" (Adult Child).

222

223 **Information Needs**

224 Participants shared their need to receive regular and clear information from the healthcare
225 team regarding their loved one. One family caregiver began to ask questions in order to feel
226 more involved: "I'm a very curious person and I like to know what's going on. So, I spent a
227 long time asking questions whenever they were there. The staff was very good at giving us
228 answers, but yet a lot of the time we were waiting—sitting and waiting or going back and
229 forth and waiting for them to come to your patient" (Adult Child). However, despite being
230 present, designated family caregivers felt absent without the support of their family in the
231 ICU. A spouse pronounced: "I was afraid to ask questions. I felt isolated. Not a lot of
232 information was given. I felt intimidated" (Spouse). In addition, participants unanimously
233 described the burden of having to relay medical information to remaining family members
234 who were not allowed to visit in the ICU. The significance of other family members in the
235 ICU was conspicuous by their absence:

236 *I had to give daily updates to everybody. I would wait for a report and then I would go*
237 *out to call everybody, let them know how he was doing. So many calls—I had to make*
238 *myself a pretty decent schedule. The only things I had time for were to come in [to the*

239 *ICU], make all my calls, go back to the hotel, turn on TV for a few minutes and then go to*

240 *bed. (Spouse)*

241

242 **Emotional Distress**

243 Designated family caregivers described feeling emotionally distressed for their critically ill

244 loved one. One family caregiver recalled: "It was an emotional and very difficult experience. I

245 felt scared, left out, kind of anxious" (Adult Child). Families were mindful of the unnatural

246 and lonely feeling of being in the ICU without other family members: "I spent many hours

247 just sitting there wondering, you know, listening to machines, beeping, very loudly. I was on

248 an emotional rollercoaster—I couldn't find solitude" (Spouse). Caring for a critically ill patient

249 without support of other family, during a pandemic, sometimes involved self-affirmations:

250 *I think that you fool yourself into thinking that you're okay. I'm okay. I'm okay. I'm okay, I*

251 *kept saying. You just are running on adrenaline. Right? I didn't relax until he left ICU and I*

252 *know it's the times, right. I had to tell myself that it was fine...initially anyway. (Spouse)*

253

254 **Strategies for Coping with Challenges**

255 “Mostly for my own mental health” (Adult Child), while others echoed: “I made myself a
256 decent schedule... day in and day out. That helped for all of us” (Spouse). When hospitalized,
257 separated, and isolated at night, one spouse recounted their strategy to cope with the
258 challenge of restricted visitation:

259 *I wrote everything down. I would write it down, what the care team said for the entire*
260 *day, and then at end of each day I would write everything in a second book that I left for*
261 *my husband so that he could look back and find what he needed to know, even when I*
262 *wasn't there.* (Spouse)

263

264 **Practicing Empathy**

265 Participants described practicing empathy with members of the ICU care team, rather than
266 other family caregivers, as waiting rooms were closed and caregivers from different families
267 were not allowed to interact in the ICU. Bearing witness to the challenges faced by other
268 family caregivers, one adult child shared: “Being able to talk to them [the ICU care team]
269 provided a feeling of solidarity. They were going through a hard time. The talking helped,
270 like teamwork” (Adult Child). Families recommended potential avenues for designated family
271 caregivers to provide support to each other throughout restricted visitation: “I would suggest

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272 a [virtual] peer group of people that have to deal with these issues, so we can exchange
273 coping mechanisms and ideas, and show empathy for others, you know, that would be
274 helpful" (Spouse).

275

276 **Appreciation of Growth**

277 All designated family caregivers who participated shared their perspectives of the negative
278 impact of the pandemic and shared lessons learned from providing care:

279 *I mean, once you've been through these stressful, traumatic, draining situations, you look*
280 *back and reflect and think, great, I can do tough things because I've dealt with a lot.*

281 (Spouse)

282 In the end, designated family caregivers, tired and isolated, described the influence of being
283 resilient on their own, personal growth: "I'm very happy that it's over. It gets better and I've
284 learned a lot—I've grown and hey, that's not what I was expecting to say" (Adult Child).

285

286 **DISCUSSION**

287 We conducted a semi-structured interview study to explore perspectives of family caregivers
288 of critically ill patients on the impact of one-person designated visitor policies mandated in

289 ICUs during the COVID-19 pandemic. Our findings indicated that practices to control spread
290 of the SARS-CoV-2 virus changed visitation in the ICU, which transformed the way family
291 caregivers cared for their critically ill loved one. In the context of one-person designated
292 visitor policies in the ICU, these changes led to complex situations that had communication
293 and emotional consequences for family caregivers. The unintended repercussions
294 experienced by designated family caregivers largely hinged on the notion that despite being
295 physically present, designated family caregivers felt helpless and isolated from the ICU care
296 team, and guilt related to being the only family member allowed to visit.

297

298 Supporting family caregivers is fundamental to the practice of critical care medicine [6] that
299 is rarely easy [24] and has been more challenging in the COVID-19 pandemic [25]. Even with
300 uninterrupted bedside access and idyllic support, family caregivers have high risk of long-
301 term physical and mental health problems [26]. A one designated visitor policy at our
302 institution that was similar to mandated policies at other Canadian [27, 28] and American
303 [29, 30] institutions meant that if two family members were present when their loved one
304 was admitted, they were forced to choose: who will sit alone, vigil, at the bedside, and who
305 will walk away, leaving their critically ill family member and grieving partner behind?

306

307 The COVID-19 pandemic resulted in limitations on family caregiver engagement in the ICU
308 and participation in care that completely reengineered their methods to cope and had
309 potential implications on their well-being [31-33]. The issue is that public health, without an
310 understanding of ICU care, broadly directed hospital restrictions usually without an
311 understanding of potential adverse impact and without input and/or feedback from
312 healthcare providers [34]. The evidence that these interventions mitigated spread of the virus
313 (their benefit) was never measured compared to the negative impact to patients and families
314 against which they were applied (the harm) [35-37]. The data suggests that there was harm,
315 and that this should be considered for future pandemic planning which needs to include
316 perspectives from family caregivers on how to best mitigate the negative effects of restricted
317 visitation [38]. Most research has reported on short-term impacts of restricted visitation
318 policies, few including perspectives from family caregivers themselves, and longer-term
319 consequences of restricted visitation policies are unknown [39-41]. Added care for ICU family
320 caregivers that emphasizes respect, dignity, and humanization, might come in the form of
321 long-term support plans delivered by ICU family liaison teams [42-44] and psychologists [45-

322 47] that may help to ameliorate the impact of the COVID-19 pandemic on designated family
323 caregivers of critically ill patients.

324
325 Prior to mandated restricted visitation policies, studies report families being offered an
326 increasingly active role in the ICU in the participation in patient care (e.g., hygiene,
327 orientation, mobility) [48, 49]. This is related to a growing awareness that family caregivers of
328 ICU patients have specific needs including information to understand the diagnosis,
329 prognosis, and treatment in the patient [50], and support in dealing with psychological
330 distress [51]. Participation in care helps to provide families with a feeling of closeness to the
331 patient [52] that may facilitate their sensemaking about the critical illness [53], thus
332 alleviating their stress [54]. Performing some patient care usually left to healthcare
333 professionals may help families to understand the caring nature of ICU treatments, which
334 may otherwise seem highly invasive [55]. Family participation in care can also play a role in
335 decreasing feelings of powerlessness [56] and contribute to a sense of usefulness that may
336 help to alleviate negative mental health consequences such as guilt, grief, or burden [57].
337 Furthermore, a role in patient care for families may help the care team to emphasize that
338 families are not just visitors but welcome and appreciated members in the ICU [58].

339 Participation in care is associated with better satisfaction among family caregivers [59]; thus,
340 it is suggested that healthcare professionals should consider encouraging family caregivers
341 (who wish to do so) to participate in patient care with the support of the ICU care team [52,
342 60, 61].

343

344 The strengths of this study include that the interview guide was informed by narratives
345 reported in the COVID-19 pandemic [62-65], co-designed with researchers, patients, and
346 clinicians, and tested in a pilot study with critical care nurses and intensivists. Interviews were
347 conducted individually and at length, which allowed caregiver's time and space to share
348 perspectives to offer important insights on the psychological burden that afflicts designated
349 family caregivers. There are limitations to consider when interpreting the findings of our
350 study. First, the number of participants included in this study was dependent on the interest
351 of family caregivers in being contacted to participate in additional research projects; other
352 studies were paused many times to conserve resources (i.e., personal protective equipment,
353 staff) to combat the COVID-19 pandemic, which limited recruitment. We did not assess non-
354 designated family members and it is possible that important perspectives were missed.

355 Second, we chose a 6-month follow-up as we were cautious about grief experienced by

356 family caregivers who lost loved ones to critical illness [66, 67]. Third, this is a single-centre
357 qualitative study including six family caregivers that may not be transportable to other ICU
358 settings. Additional interviews to collect data past code saturation in order to assess
359 meaning saturation are required for transferability of our results [68]. Finally, our small
360 sampling frame did not achieve adequate representation of sex, gender, education, and
361 socioeconomic status and we were not able to explore sociocultural factors, including
362 cognitive and linguistic barriers, which might impact communication [69, 70].

363 *It will important to discuss the fear of caregivers of having COVID vs going in Hospital, particularly before
the Understanding of COVID and introduction of vaccination. Risk vs benefits*

364

365 **CONCLUSIONS**

366 Designated family caregivers of critically ill patients in the ICU perceived that restricted
367 visitation policies mandated to control COVID-19 had unintended negative repercussions.

368 The one-person designated visitor policy meant that the designated family caregiver had to
369 process their loved one's prognosis and treatment, make life-changing decisions, and then
370 relay this information to remaining family in addition to coping with their own concerns.

371 Long-term support plans for family caregivers of critically ill patients delivered by ICU family

372 liaison teams and psychologists may help to ameliorate the impact of the COVID-19

373 pandemic on designated family caregivers of critically ill patients. Further research with larger
During COVID or all the time? Need to
be address in discussion.

374 and more diverse sample sizes are required to validate our findings from this hypothesis-

375 generating work.

376

377 **DECLARATIONS**

378

379 **Ethics approval and consent to participate:** The Conjoint Health Research Ethics Board at
380 the University of Calgary approved this study (Ethics ID: REB19-1000).

381 **Consent for publication:** Not applicable.

382 **Competing interests:** The authors declare that they have no competing interests.

383 **Availability of data and materials:** Data cannot be shared publicly because of patient
384 confidentiality. Data may be available upon reasonable request from the University of
385 Calgary research ethics board and Alberta Health Services research and innovation
386 administration (contact via chreb@ucalgary.ca and research.administration@ahs.ca) for
387 researchers who meet the criteria for access to confidential data.

388 **Funding:** SJM was supported by a Canadian Institutes of Health Research Doctoral Research
389 Award. The funder had no role in study design, data collection and analysis, decision to
390 publish, or preparation of the manuscript; no financial relationships with any organizations
391 that might have an interest in the submitted work in the previous three years; no other
392 relationships or activities that could have influenced the submitted work.

393 **Authors' contributions:** All designated as authors have met ICMJE criteria for authorship.

394 1. Substantial contributions to the conception or design of the work; or the acquisition,
395 analysis, or interpretation of data for the work; AND

396 2. Drafting the work or revising it critically for important intellectual content; AND

397 3. Final approval of the version to be published; AND

398 4. Agreement to be accountable for all aspects of the work in ensuring that questions
399 related to the accuracy or integrity of any part of the work are appropriately investigated
400 and resolved.

401 All authors participated in the design and development of the protocol. SJM, KDK and KMF
402 drafted the manuscript, and all authors read and approved the final manuscript.

403 **Acknowledgements:** The authors are grateful for the privilege of speaking with families
404 during the ongoing pandemic. The authors would like to acknowledge the individuals who
405 participated in developing (Bonnie Sept, Israt Yasmeen), reviewing (Melanie C. & Jillian
406 Anglin, Chloe M. de Groot), and piloting the interview guide (Krista Wollny, Victoria Owen,
407 Natalia Jaworska).

408

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- 604

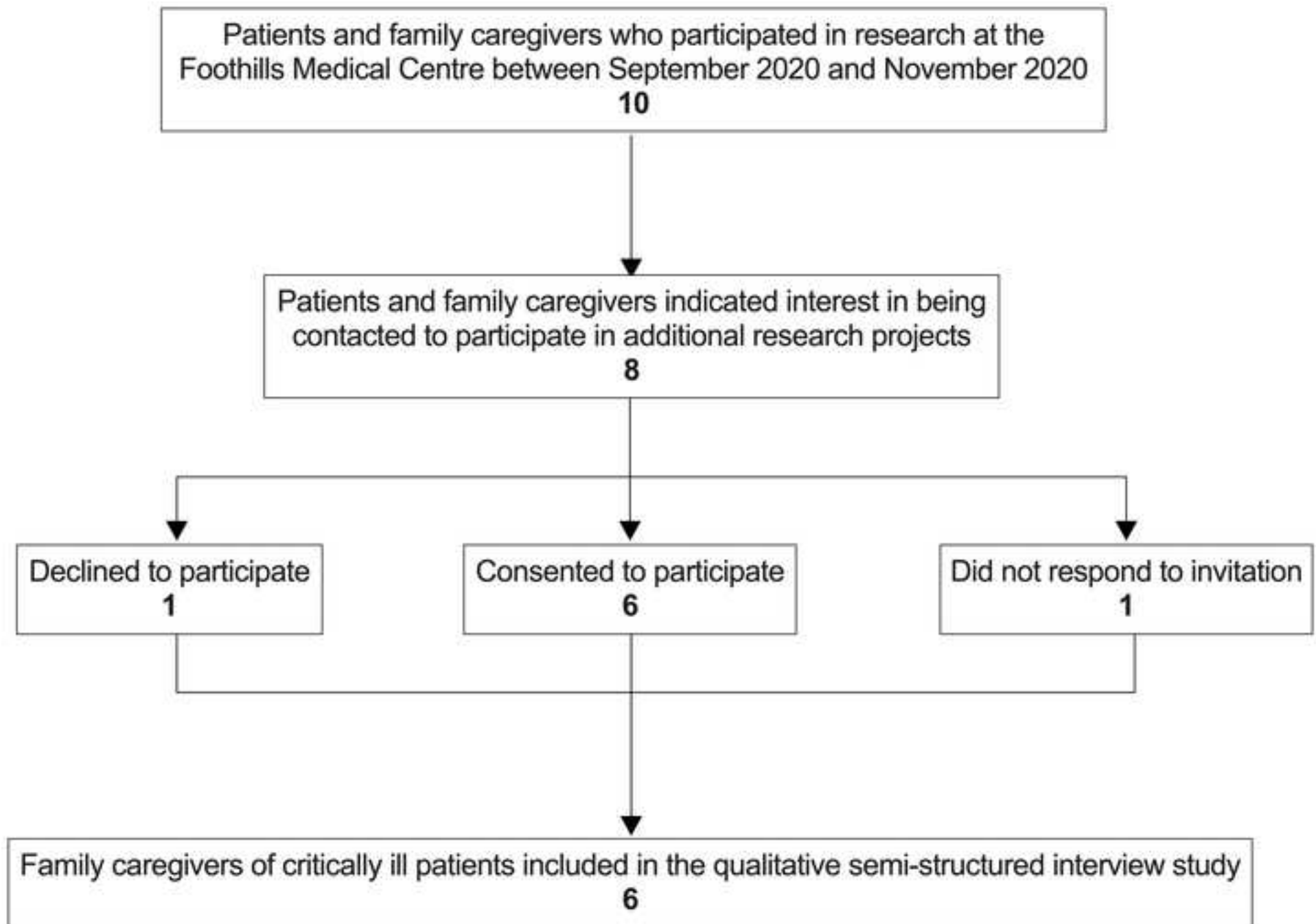
605 **FIGURE CAPTIONS**

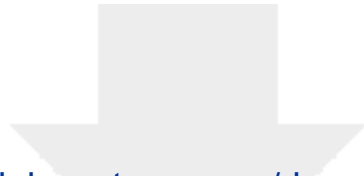
606 **Figure 1.** Flow diagram of selection of family caregivers for interviews

607 **SUPPORTING INFORMATION**

608 **S Table 1.** Consolidated criteria for reporting qualitative studies (COREQ)

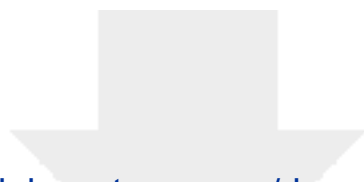
609 **S Table 2.** Interview guide





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Supporting Information
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