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Reported impact and protective factors of the care partner role during persistent critical illness: a content analysis

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Abstract

Background Patients with persistent critical illness experience prolonged multi-system morbidity, functional impairments, and chronic conditions. As a result, these patients have prolonged intensive care unit admissions. If discharged, they return home with long-term medical dependencies. Care partners take on a variety of physical, mental health, cognitive, and social roles to support the provision of care for these patients. There is limited evidence, however, of the impact of being a care partner for this patient population during hospitalization.

Methods A qualitative descriptive study was conducted to explore the impact care provision on care partners for patients experiencing persistent critical illness. Patients who have or have had persistent critical illness and care partners were recruited from two inpatient units in a single community academic hospital in Toronto, Canada to participate in semi-structured interviews. Data was analyzed using a team-based inductive content analysis.

Results Seven (43.8%) participants were patient survivors, and nine (56.3%) were care partners. Patients and care partners reported physical, socio-emotional, and social stress as impacts of care provision during persistent critical illness hospitalization. Care partners identified several protective strategies that they used to mitigate the impacts of care provision on them such as seeking external mental health support and boundary setting. Features of formalized and care partner programs were also identified and suggest that these programs can be protective of care partner values, mitigate feelings of helplessness and stress, and may improve relationships between the family members who are in the care partner role and the healthcare team.

Conclusions This study identified physical, socio-emotional, and social stress related impacts of care provision on care partners of patients with persistent critical illness during hospitalization. Additionally, this study identified protective factors initiated by care partners to mitigate the reported stresses of the role, as well as protective features of a care partner program. The results provide a better understanding supportive features of care partner programs that are specific to the experiences and needs of persistent critical illness and add to the growing body of evidence about how to provide equitable access to care during and post hospitalization.

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Keywords Critical care, Care partner, Persistent critical illness, Prolonged mechanical ventilation, Patient engagement, Patient-centered care

Introduction

Improvements in intensive care unit (ICU) medicine and patient care have led to more patients surviving for longer periods of time. As a result, a new conceptually distinct subgroup of patients with persistent critical illness (PCI) [1] have emerged which we know little about, including understanding care needs and relationships of care across their life course [2]. Patients with PCI experience prolonged multi-system morbidity and functional impairments and chronic conditions related to such factors, including but not limited to, organ failure and muscle wasting. PCI has been characterized as a distinct period along the critical illness continuum requiring ongoing interprofessional health care team management for a cascade of critical illnesses beyond their original admitting diagnosis [1, 3].

Patients with PCI receive care in the ICU or are admitted to specialized weaning programs [4, 5]. A related but conceptually distinct grouping of patients with PCI are those experiencing prolonged mechanical ventilation (PMV). Most frequently defined as requiring greater than 21 days of invasive ventilation, patients with PMV are twice as likely to be discharged to rehabilitation, complex continuing care facilities, or home with health care support, suggesting significant ongoing care needs [6]. At least one-third of patients surviving prolonged treatment in the ICU experience significant physical, cognitive, and mental health impairments and/or chronic conditions as an outcome of extended PCI [7]. Family members and informal caregivers of patients with PCI share the prolonged exposure to the ICU, and associated anxiety, depression, and/or post-traumatic stress disorder [7].

Patient- and family centered care philosophies have compelled clinical settings to shift beyond historically rigid visiting policies so that these spaces are more inclusive of patient informal care networks [8]. Family members and/or informal caregivers are individuals who are considered important or 'essential' to the care and/or experience of the patient, beyond the role of a social visitor [8]. These individuals are socially connected to the patient, but they do not attend as visitors for purely social reasons. Thus, they are conceptually distinct from more formalised notions commonly referred to as 'caregivers' or 'carers'. To make this distinction within this study, we adopted the term 'care partner' to illustrate a shared care dyad role between hospital staff and informal carers of PCI patients. This category was developed to reflect the fact that this group of informal carers (i.e., family members, partners/husbands/wives, intimate friends, etc.) have become more involved in acute care

settings and PCI patient recovery over recent years [9]. A recent Canadian study described patient, care partner, and healthcare provider reported roles of care partners in clinical settings providing care to PCI adult patients including physical, mental health, cognitive, social, and spiritual supportive acts [10].

Little is known about the impacts of care provision on care partners of patients with PCI. A recent literature review identified physical, psychological, and economic implications of care provision in acute care, however, also identified a paucity of evidence from ICUs, specialized weaning programs, or evidence from North American care centres in general [11]. Given the multidimensional support care partners play in the care of patients with PCI, and the negative long-term sequela of prolonged ICU admission, we sought to better understand the experience of care partners providing this supportive role during hospitalization. Specifically, our research questions were: (1) What are the reported impacts of being a care partner during hospitalization with PCI on care partners? And (2) What are protective factors as reported by patients and care partners in this clinical context?

Methods

Design

We conducted a qualitative descriptive study to explore the impact of the care partner on care provision for patients experiencing PCI. Qualitative descriptive methodology lies within the naturalistic approach, and is often used to develop an understanding and describe a phenomenon as described [12]. The qualitative descriptive study design is most appropriate for studying our understanding of experiences because this low inference approach fosters a deeper understanding of the experienced impact of being a care partner through eliciting thick descriptions of participants' experiences allowing for probing on ways to improve program development [12, 13]. Importantly, this study includes patients and care partners individually or as dyads, allowing comparison of perceived impacts from the patient's and care partner's unique experiences in receiving and providing care.

Study setting

Two inpatient units in a single Community Academic Hospital located in Toronto, Canada were the contexts for the study. The two units were selected as study sites because they accept ICU transfers from across Ontario to provide specialized care for patients with PCI. The first unit is an eight-bed adult specialized weaning program set within an acute inpatient respiratory ward. Medical

care of patients on this unit is managed by a Respiriologist and Nurse Practitioner. The second unit is a six-bed adult long stay ICU program set within the medical surgical ICU. Medical care of patients on this unit is managed by an Intensivist, with care coordination by a Clinical Utilization Coordinator. Both units have diverse multiprofessional care team members, including nursing and allied professions. At baseline, both units had access to a hospital-wide care partner program.

Participants

The participants for this study included adult patients experiencing or who have experienced PCI admitted to one of the two clinical settings described above and/or their care partners. Eligibility criteria are described in Table 1.

Sampling

We used a multi-modal and convenience recruitment strategy including posters and identification of discharged patients by members of the patients' circle of care. Recruitment continued until we perceived our recruitment targets were met in terms of variation in participant characteristics and had achieved sufficient information power for our relatively narrowly focused study aim and the specificity of our study participants [14].

Data collection

Between June and October 2023 and following informed consent, three authors conducted interviews using a semi-structured interview guide developed iteratively by the research team and based directly from the research questions [10]. After the first two interviews, questions and responses were reviewed by the research team to ensure they were understood correctly, and

no changes were made. The questions asked were: (1) Can you describe your or your loved one's experiences as a patient care partner/care partner? and (2) Can you describe the impact of being a care partner on you (or on your loved one when asking patient participants). All three interviewers (LI, TM, and SB) identify as women, and all have training and applied experience with qualitative interview methods. The authors all work at the study setting in various roles. LI is a Nurse Practitioner with critical care nursing experience, TM is a Registered Nurse with experience working with ventilated patients, and SB is an Occupational Therapist with critical care experience. Interviews were conducted alone or in pairs. Demographic information was collected at the time of the interview consisting of age, gender, relationship to patient.

Interviews were conducted with patients and care partners either just before or after discharge from the inpatient setting. Interviews were conducted in person (8, 50%), over the phone (7, 44%), or by using a videoconferencing platform (i.e., Zoom) (1, 6%) according to the participants' preference. Interviews were between 23 and 62 min (average 45 min), digitally recorded, and transcribed using NVivo (version 14). No repeat interviews were conducted, two interviews (i.e., four participants) were conducted as a patient/care partner dyad, again per the preference of the participants.

Preliminary discussions prior to interview commencement were used to establish a relationship with each participant and comfort with the subject area. Some participants were previously known to the interviewers. To mitigate the possibility of bias because of this we made efforts to pair interviewers with participants who were not known to them, or who had less interaction with them in advance. Notes were made on participant reactions to questions and reflections not otherwise captured by the digital recording or transcription. The research team has extensive experience with patients experiencing PCI and working with care partners and engaged in reflexive discussions during data collection and analysis. Interviews were recorded and transcribed verbatim.

Data analysis

We used a team-based directed inductive content analysis which involved recommended stages of reviewing transcripts to identify meaning units, recontextualize, categorize, and compile main and sub-coding categories [15]. Using paired coding via coding software (NVivo) the entire research team together created working definitions of the main code categories. The team met regularly to discuss the definitions, compared findings, and to develop sub-categories within the main codes that comprehensively described the reported impact of being a care partner and emerging protective factors. Finally,

Table 1 Eligibility criteria for participation

Patient participants	Care partner participants
Inclusion	Inclusion
1. 18 years of age or older	1. 18 years of age or older
2. Currently admitted or recently discharged from the study setting	2. A care partner of a patient who is currently admitted or was recently discharged from the study setting
3. Medically stable according to medical provider	(within 1 year or longer if able to recall experiences)
4. Able to communicate by some means (e.g., gestures, augmentative or alternative communication, phonation)	3. Some English speaking at minimum
5. Some English speaking at minimum	4. Able to provide informed consent (i.e., able to understand and appreciate the consequences of their decision to participate or not participate in the study)
6. Able to provide informed consent (i.e., able to understand and appreciate the consequences of their decision to participate or not participate in the study)	5. The patient they cared for agreed to have them participate in the study

through reflexive group discussion that included reflecting on our own experiences, biases, and potential influence on the research, we consolidated the main and sub-categories to compile and compare results between patient and care partner participants.

Ethical considerations

Ethics approval was obtained from Michael Garron Hospital (883-2211-Mis-391) and Toronto Metropolitan University (REB 2023–357). Informed written consent was obtained prior to interview commencement. Participants were referred to by number on data transcripts (e.g., P001, P002, etc.) to preserve anonymity.

Rigor

In accordance with recommendations for transparent and comprehensive reporting, we used the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines to describe our methods and findings [16]. To enhance the credibility and trustworthiness of the analysis coding was done in pairs, with team-based discussion throughout, and a code book (See Supplementary File A) and audit trail were created [17, 18].

Results

Participant characteristics

Of the participants recruited for this study, seven (43.8%) were patients, and nine (56.3%) were care partners. The overall average age of participants was 60 years old (patients 41–80 years old, care partners 35–75 years old). Most of the patient participants were male, men (71.4%) and most care partner participants were female, women (77.8%). Most participants overall were racially white (85.7% patients, 77.8% care partners), including Greek and Middle Eastern ethnicities. Approximately half

(56.6%) of care partners were spouses of patients who had experienced PCI (Table 2).

Reported overall impact

Patient and care partner reported impacts of care provision during PCI hospitalization are described below. Reported impacts were defined as ways in which being a care partner impacted the individual's experience, health, and/or wellbeing. These impacts included physical, socio-emotional, as well as social stresses including social relationships, maintaining a household outside the hospital, work and finances while being in the care partner role over prolonged periods.

Physical stress

Patients and care partner participants both described physical stresses on care partners including the impacts of staying long hours at the hospital with patients experiencing PCI. Physical stress and impacts on the health and socio-emotional wellbeing of care partners described by participants traversed issues of fatigue, nutrition, food security and poor diet, and compromised ability to engage in health protective behaviours. One care partner participant used the term 'neglect' (P004) to describe how exhaustion from care provision prevented her from participating in self-care activities such as going to the gym. A patient participant who reflected on the physical demands of his ICU extended time on his care partner stated that: "yeah, would find what she's doing extremely difficult because it would be very taxing" (P013).

Another participant described the impact of being a care partner on her ability to live a healthy lifestyle, including eating properly.

Oh well, let's just say eight, ten hours a day sitting around was not the healthiest way to live (P006).

Table 2 Demographic characteristics of participants

ID	Type of Participant	Gender	Sex	Race	Age Range	Relation to Patient
P001	Patient	Man	Male	White	71–80	
P002	Care Partner	Woman	Female	White	71–80	Partner/spouse
P003	Patient	Man	Male	White/Greek	71–80	
P004	Care Partner	Woman	Female	White/Greek	41–50	Child
P005	Patient	Man	Male	White/Greek	41–50	
P006	Care Partner	Woman	Female	White	51–60	Parent
P007	Care Partner	Woman	Female	Asian/Philipino	71–80	Partner/spouse
P008	Patient	Woman	Female	White	41–50	
P009	Care Partner	Woman	Female	White	51–60	Parent
P010	Care Partner	Woman	Female	Asian	51–60	
P011	Patient	Man	Male	Asian	51–60	Partner/spouse
P012	Care Partner	Woman	Female	White	51–60	Partner/spouse
P013	Patient	Man	Male	White	51–60	
P014	Care Partner	Man	Male	White	31–40	Child
P015	Patient	Woman	Female	White/Middle Eastern	61–70	
P016	Care Partner	Woman	Female	White	71–80	Partner/spouse

Similarly, a patient participant described his stress watching the physical strain of care provision on his care partner who was his elderly mother.

And if your family skipping meals because they are taking care of you or just snacking on the run, it's like and you see the bags under their eyes, you're just like F.U.C.K, and you don't want to, and I apologize, but you know what I mean (P005).

The reported physical stressors impacted care partners throughout the lifecycle of ICU acute care from admission through to hospital discharge, contributing to new or exacerbating existing health conditions.

Socio-emotional stress

Participants described both acute and prolonged socio-emotional impacts of PCI on care partners. Care partners reported a deep emotional impact of experiencing PCI with patient loved ones. One care partner used the term “abrupt tragedy” (P009) to describe their grief in the unanticipated loss of her daughter’s previous functions including loss of sight, voice, and independent mobilization; functions that were inextricably linked to important parts of the patient’s identity as a teacher, singer, and a runner. She stated, “almost every day, it makes me cry just to think about that” (P009). Another patient participant described the emotional impact on his spouse who was his care partner during PCI.

She broke down on a number of occasions. Just, the stress of dealing with all the things she had to deal with the house, the home, the cottage. I mean, you know, the doctors and nurses. It was not easy (P001).

Another patient participant witnessed the emotional impacts on care partners during a dyad interview and responded, “I wish there was some outlet for you to de-stress” (P010). Her spouse aptly described his emotional experiences as a care partner like being on an “emotional roller coaster” (P011).

The prolonged nature of the emotional stress experienced by care partners of patients experiencing PCI was emphasized by participants. One patient explained that he was protected from some of the emotional trauma because he was unconscious in the days that he was being acutely resuscitated from critical illness, stating, “But it’s my family that went through it, and they’re still traumatized” (P007). A care partner similarly described the feeling as being “stretched very thin” (P009), attributing this feeling to the prolonged and severe nature of her daughter’s PCI.

Social stress

Several social stresses were described by participants as impacts of being in a prolonged care partner role of patients during PCI. These social stresses included shifted relationship roles, loss of external socialization opportunities, financial implications (e.g., costs associated with travel to hospital, loss of wages and employment), and difficulty managing external household responsibilities including home keeping and care provision of other members of the extended family.

A care partner participant described the social changes as a shift in her relationship with her husband who was experiencing PCI.

So, I've had to step in and do more of that kind of thing than I've ever done before because, you know, he was a fully functioning, independent person who did, you know, we were equal partners and stuff. That role has had to shift, and I am trying to honor his desires (P002).

Another care partner described the extended social impact of how she and her husband (also a care partner) alternated shifts at the bedside of their son, who was experiencing PCI.

And I mean, the way we [my husband and I] chose to do it in terms of, you know, coming in the evenings and taking turns had a big impact, obviously on our time together and it probably had a bigger impact on our ability to socialize with other people. Yeah. Just because one of us is always in the hospital (P006).

Patient participants focussed on the social impacts of care partner’s ability to manage the care partner role and concurrently their external household responsibilities. One patient stated, about his spouse who was his care partner and part of a dyad interview:

Put it this way, she's sweating right now. We're looking out the window here. Look at the possibility of rain. And she's worried about my stuff hanging on the line outside (P013).

The financial impacts of being a care partner during PCI was described by participants. One care partner described having to cut down to part time work first, and then had to request a leave of absence (P009). Another reported that he had more time to spend as a care partner because he lost his job while his spouse was experiencing PCI (P011). A care partner of her spouse, both in their seventh decade of life, and caregiver to adult children living with disabilities at home, described her need

to keep working during her husband's PCI to support her family and the impact on her this way:

It adds up because that is how I earned my living. Yeah, that is my, my source of income. Yeah. So, um, but really, the dedication of the time and the work that exhaust me. And I feel like how long I can do this? I'm already 72 years old. How long? How many more years? You think I could stand up and get up and do my responsibilities (P007)?

The social stress impacts described by participants were varied, but changed significantly from the pre-PCI, with potential for lasting effects beyond discharge from hospital.

Protective strategies and factors

Protective strategies

Reported protective strategies that some care partners used to mitigate the impacts of care provision are described below, and include cognitive and mental health strategies, as well as boundary setting. One participant described how important it was for her to gain medical knowledge about what her husband was experiencing, and the treatments being offered, particularly because of the multiple transitions in care settings and with care teams during PCI.

I've found that I've really had to become knowledgeable about the conditions and the treatments because the case is complex and it involved multiple hospitals, multiple doctors, and particularly the continuity of care and keeping that link going has been something that I've had to do because I'm the one constant throughout the journey (P002).

An emotional strategy described by multiple participants was proactively accessing external mental health services. Connection to a mental health provider through primary care was considered "a gift from God" (P002) during care provision during PCI. Similarly, participants described the need to set boundaries in time spent as a care partner, particularly as patients had longer admissions and/or as they recovered more functional independence. One participant described the way she developed this strategy, through the suggestion from a friend.

If you go at the rate you're going right now, you're going to burn yourself out and you'll be absolutely no good to him at all. So put boundaries up for yourself, no matter how hard it is. So that's what I do (P012).

Additional self-care strategies care partners described as mitigating strategies for the stresses of the role during

PCI included socializing, exercising, and other ways to "take care of myself in the interim" (P011). Interestingly, none of the strategies described by participants were suggested by healthcare providers from the team caring for the patient with PCI, signalling an opportunity to improve this aspect of the care partner program in the future.

Protective features

Protective features of a supported role within a care partner program also emerged from the transcripts and these included that care partner programs can be protective of care partner values, can mitigate feelings of helplessness and stress, and may improve relationships with the healthcare team. A care partner program existed in the study setting at baseline, though not specific for patients experiencing PCI. There were, therefore, some program elements in place and reported by participants as mitigating or protective features to the challenging impacts of PCI. For example, when supported, the care partner role protected care partner values. One participant explained that the care partner role permitted her to do what she valued most, caring for her family.

But I like to be always on the positive side. Be strong and do the best thing I could do. But the most important for me is the well-being of my family (P007).

For some participants the care partner role also combated feelings of helplessness and stress, particularly with the prolonged and uncertain course of PCI. Acknowledging the needs of and welcoming care partners was also noticed by patient participants, who found this protective of some of the physical stresses of the care partner role.

She came out a couple times and ask my mom, are you ok? Can I get you a juice, a sandwich? And she goes no no. I go, actually, could you grab her a sandwich she hasn't eaten since the morning. She comes back, I got two sandwiches and three juices and like, ... if you're close to your family the way I am you have this not intentional but yet still omnipresent stress of what you're putting your family through. It's very low key but it's there (P005).

A supported care partner program also has the potential to support positive relationships between health care teams and family members who are in the care partner role. This protective element is suggested in the descriptions of care partners and patient participants who explained that they felt welcomed, comfortable, and involved.

Nobody ever made me feel bad that I was wanting to be involved and wanting to know [information about her care]. So that was very welcoming. Yeah. And in general, I felt like the tone was very welcoming for me to be there (P009).

And another care partner participant described the increased comfort felt on the unit when in a formal care partner role with a visual symbol of the role such as a lanyard and badge identifying him as a care partner.

Yeah. Yeah, I definitely feel like. Yeah, [as a care partner] I just feel much more comfortable walking around [the unit] (P014).

Beyond passive comfort, some care partners described that they felt like active participants in the patients' care and "very included" (P011) in care planning, which mitigated some of the stresses of being a care partner during PCI. Noted acts of inclusion were proactive communication, inclusion in rounds when available, and listening to care partner concerns.

Discussion

This qualitative study identified physical, socio-emotional, and social stress related impacts of care provision on care partners of patients with PCI during hospitalization. This study also identified protective factors initiated by some care partners to mitigate the reported stresses of the role, including gaining knowledge, seeking mental health support, setting boundaries, and self-care behaviours. Protective features of care partner programs described by participants, included supporting values, combating feelings of helplessness and stress, and having the potential to support positive relationships between care health care teams and care partners; features that may improve health outcomes for patients and their carers during and post PCI.

Participants in this study reported physical stresses such as fatigue and poor diet. Participants also reported socio-emotional stresses, such as emotional lability, grief, and sustained traumatization from the sudden, severe, and prolonged critical illness. The results from this current study add to existing extant evidence describing the negative impacts on care partners during PCI. For example, a multi-center, prospective, parallel cohort study of patients who had received mechanical ventilation for a minimum of seven days in the ICU and had survived to discharge and their caregivers demonstrated that at one-year caregivers experienced high levels of depressive symptoms [19]. Furthermore, an increase in psychological symptoms including anxiety and depression are reported almost a quarter of family members of patients admitted to ICU in a recent Dutch study, even 3 months

after discharge [20], and in other studies up to two years post discharge from ICU [21]. The results from our study also include patient and care partner reported factors that may mitigate negative impacts of care provision in during PCI. For example, coaching care partners to set boundaries for themselves, early access to mental health support, encouraging and supporting the provision of food, water, and a place to rest were seen as welcoming elements that protected against some of the negative impacts of PCI. Reported factors that worsen anxiety in family, who are of the care partners, of ICU patients include being female, lower educational status, poor sleep pattern, fatigue, lack of regular meetings with medical staff, and failing to meet family needs [21]. Facilitating mental health supports and caring for care givers may be a proactive intervention of care partner program that can be further evaluated for impacts during hospitalization and post discharge from ICU.

In this study, participants also reported that active engagement of care partners in the care planning of patients through the provision of information was seen as a protective component of the care partner role during PCI. Proactive engagement of care partners during PCI can, in this way, potentially mitigate discordance between health care teams and family. Relationships with care teams can impact care partner experience, particularly with extended admissions, uncertain outcomes, and importantly, the unique role care partners play sharing care with formal caregivers. A recent scoping review reporting the experiences and needs of the families of adult ICU patients suggest interactions with the health care team, particularly meeting information needs and providing assurance can have a meaningful impact on family satisfaction and mental health [21]. Similarly, a study of surrogate decision makers and medical treatment orders in older adults with serious illness found that discordance was common and suggested that communication quality between surrogates and care teams is a modifiable factor of negative family experiences during critical illness [22]. The results from our study, therefore, add to potential upstream interventions (i.e., during hospitalization) that may positively impact the experience, health, and well-being of care partners during PCI and post discharge.

Results from this study also suggested a protective role of health literacy and the ability to access and cognitively process medical information to mitigate stress and uncertainty accompanying conditions of PCI (i.e., multiple transitions, shifting care teams, etc.). Although this was described as a protective strategy this was also perceived as an unanticipated new responsibility and stressor. For care partners with limited literacy and/or access to health information this might not be an easy to access protective feature and therefore support of

comprehension is required. A randomized controlled trial described the impact of providing an information leaflet to family as a supplement to family meetings on family satisfaction, with positive results only in those family members with good comprehension [23]. Other described interventions to improve family satisfaction with care through improved comprehension include having a dedicated ICU nurse support staff tasked with helping family understand information provided by the medical team [24]. Facilitating comprehension of medical events through a variety of means can improve satisfaction with care, and, thus, is reasonable protective factor that can be supported in the development of carefully planned care partner programs.

This study described social impacts of being in a care partner role during PCI, including impacts on relationships (i.e., to the patient, to social networks) and financial security (i.e., through reduction of income or loss of employment). In this setting, both patients and their care partners are subjected to loneliness and social isolation. Hospitalization due to PCI renders the patient isolated from their social networks as they are often confined to their bed. In the case of the care partners, they are also isolated from their social networks as they spend most of their time in the hospital providing care to the patient. Survivors of critical illness face new and challenging impacts of their critical illness, with higher mortality and increased risk for readmission to hospital and ICU [6]. Health disparities experienced by survivors of critical illness can be exacerbated by social and structural determinants of health including factors that prevent or limit access to primary care post discharge [25]. A recent international multicentre qualitative study of social determinants of health modification post critical illness for patients reported results like our study including social stresses experienced by care partners starting even during admission with PCI including negative financial and social impacts [26] suggesting the need to create and support care partner programs that might have protective functions against some of these negative impacts. A focus on improved understanding of the impact of care partnering roles during PCI add to the growing body of evidence about how to provide equitable access to care during and post PCI. With this in mind, it is important to note that providing equitable care requires that we assess and understand the bidirectional impact of PCI on the social determinants of health and their intersections. While this study focused on the provision of care in the context of hospitalization, further research is needed to determine the utility of having a care partner post-discharge. This information would be of great use as clinicians can encourage and support the identification of a care partner in preparation for discharge from the hospital.

Important clinical practice implications arise from this research include the need to recognize and address the multifactorial impacts of adopting the aide of informal care providers. Highlighting the need to formally acknowledge the importance of such roles during extended hospitalizations, care partner programs can be further developed, integrating interprofessional training and attending to relevant hospital policies impacting some of the experiences described in this study. The results of this study extend beyond the PCI population, and can be considered for other populations experiencing prolonged and complex hospitalizations with uncertainty in outcomes such as patients who have had a cerebrovascular incident and their care partners. Research implications from this study include the need to further elucidate appropriate outcomes associated with evaluating care partner programs. For example, gaining a clearer understanding of the improvements in health that can be made through addressing some of the reported impacts in this study. Future research stemming from this study includes a community co-design study aiming at creating recommendations for designing, implementing, and evaluating a care partner program for PCI settings.

Limitations

This study had several limitations including a self-selected sample and despite including a diverse sample across two units, the results of this single hospital study may not be generalizable to other organizations. Participants were also self-selected for this study, introducing the potential for bias, which might limit reported experiences to include those of people with either very positive or very negative experiences. Also, as many of the participants were known to the members of the research team conducting interviews, we acknowledge that a limitation of this study might also include social desirability bias of participant responses. Finally, we also permitted participants to choose the method and location of the interview so that it was most convenient and suitable to their availability and physical abilities. This flexibility in approach, though an important ethical consideration, introduced some methodological limitations including not seeing facial expressions during telephone interviews which may have provided additional insights in the impacts of care provision during PCI.

Conclusions

This study reports on the negative physical, socio-emotional, and social impacts experienced by care partners providing care to patients hospitalized with PCI in the ICU or a specialized weaning centre. Apart from the obvious effect on their overall wellbeing, these impacts may also affect the care partners' ability to provide care, suggesting a bidirectional relationship. In response to

these impacts, care partners implement strategies that are self-protective in nature. Furthermore, there are protective features that can be incorporated into a hospital's care partner program to support the provision of care for both the patients and their care partners. Insights gained from this study improve our overall understanding of the PCI population and their care partners, who are often incorporated into care pathways informally. The reported impacts are integral to understand so that the design and evaluation of formalized care partner programs address end-user needs and so that programs are designed with the overall aim to positively impact the short and long-term health impacts and sequela of prolonged hospitalization with PCI.

Abbreviations

COREQ	Consolidated criteria for reporting qualitative research
ICU	Intensive care unit
PCI	Persistent critical illness
PMV	Prolonged mechanical ventilation

Supplementary Information

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Supplementary Material 1

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Author contributions

L.I. conceptualized the project, led data acquisition, performed formal analysis, and wrote the manuscript. A.J.G. data curated, performed formal analysis, and assisted with writing the manuscript. L.H. conceptualized the project and performed formal analysis. T.M. assisted with data acquisition and analysis. S.B. assisted with data acquisition and analysis. K.S. conceptualized the project, performed formal analysis, and assisted with writing the manuscript. K.M.S. conceptualized the project, performed formal analysis, and assisted with writing the manuscript. All authors edited and reviewed the final manuscript.

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Data availability

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

Ethics approval was obtained from Michael Garron Hospital (883-2211-Mis-391) and Toronto Metropolitan University (REB 2023 – 357). Informed written consent to participate was obtained ahead of interviews from all participants.

Consent for publication

Informed written consent for publication was obtained ahead of interviews from all participants.

Competing interests

The authors declare no competing interests.

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