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Patients' Experiences of Recovery: Beyond the Intensive Care Unit and Into the Community

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Abstract

Aims

To understand barriers and facilitators of recovery for critical illness survivors', who are discharged home from the hospital and do not have access to dedicated outpatient care.

Design

Multi-site descriptive study guided by interpretive phenomenology using semi-structured interviews.

Methods

Interviews were conducted between December 2017 -July 2018. Eighteen participants were included. Data were collected from interview recordings, transcripts, field notes, and a retrospective chart review for sample demographics. Analysis was completed using Interpretive Phenomenological Analysis which provided a unique view of recovery through the survivors' personal experiences and perception of those experiences.

Results

Participants encountered several barriers to their recovery; however, they were resilient and initiated ways to overcome these barriers and assist with their recovery. Facilitators of recovery experienced by survivors included seeking support from family and friends, lifestyle adaptations, and creative management of their multiple medical needs. Barriers included unmet needs experienced by survivors such as mental health issues, coordination of care, and spiritual needs. These unmet needs left participants feeling unsupported from healthcare providers during their recovery.

Conclusion

This study highlights important barriers and facilitators experienced by critical illness survivors during recovery that need be addressed by healthcare providers. New ways to support critical illness survivors, that can reach a broader population, must be developed and evaluated to support survivors during their recovery in the community.

Impact

This study addressed ICU survivors' barriers and facilitators to recovery. Participants encountered several barriers to recovery at home, such as physical, cognitive, psychosocial, financial, and transportation barriers, however, these survivors were also resilient and resourceful in the development of strategies to try to manage their recovery at home. These results will help healthcare providers develop interventions to better support ICU survivors in the community.

1 INTRODUCTION

With increasing numbers of intensive care unit (ICU) patients surviving to discharge (Adhikari et al., **2010**), the physical, cognitive, and psychological morbidities encountered during critical illness recovery are a growing clinical (Iwashyna, **2010**) and public health challenge (Davidson et al., **2013**). It is imperative that the health care of ICU patients incorporate an increased focus on long-term health (Elliott et al., **2014**; Needham et al., **2012**). Although there is growing international awareness of the need to support patients throughout recovery (Elliott et al., **2014**; Needham et al., **2012**; Reay et al., **2014**), dedicated outpatient care for critical illness survivors is limited (Elliott et al., **2014**; Needham et al., **2012**). Post-ICU clinics, first started in 1985 in the UK, were designed to evaluate and treat ICU survivors. While 30% of ICU survivors in the UK currently have dedicated outpatient follow-up 2–3 months after ICU discharge (Teixeira & Rosa, **2018**), many other countries have only recently adopted the post-ICU clinical model and have much lower rates of dedicated follow-up (Golbenson, Johnson & Wilson, **2019**). Currently, there are only 16 post-ICU clinics in the USA (Society of Critical Care Medicine, **2020**).

2 BACKGROUND

ICU survivors face a wide range of challenges (Cuthbertson et al., **2010**; Haines et al., **2015**; Herridge et al., **2011**; McPeake et al., **2019**) as they recover from their critical illness. These global challenges are termed post-intensive care syndrome (PICS): a new or worsening impairment in mental, cognitive, or physical health after critical illness. Although the exact prevalence of PICS is unknown, it is estimated to occur in up to half of ICU survivors (Needham et al., **2012**). ICU-acquired neuromuscular weakness is the most common form of physical impairment, occurring in more than 25% of ICU survivors (Fan, Cheek, et al., **2014**; Fan, Dowdy, et al., **2014**; Hermans et al., **2014**). Cognitive impairment has been reported to occur on average in 25% of ICU survivors, but a few studies have shown a significantly higher incidence of up to 75% (Davydow et al., **2013**; Needham et al., **2013**; Pandharipande et al., **2013**). Thirty per cent of survivors will suffer from anxiety, 10%–50% will suffer from PTSD (Davidson et al., **2013**; Harvey, **2012**) and 28% will suffer from depression (Wade et al., **2012**).

Recognition of adverse post-ICU outcomes have prompted critical care providers to extend care beyond the ICU (Lasiter et al., **2016**; McPeake et al., **2019**; Sevin et al., **2018**; Williams & Leslie, **2008**). The Society of Critical Care Medicine's THRIVE initiative has recommended initiation of ICU follow-up clinics (Lasiter et al., **2016**; McPeake et al., **2017**; Sevin et al., **2018**), however, most survivors do not have access to such programs. Little is known about what ICU survivors, without access to dedicated outpatient care, are doing to facilitate their recovery. To improve the long-term outcomes for ICU survivors and design interventions that meet the needs of all survivors, it is imperative we understand critical illness survivors' barriers and facilitators to recovery.

3 THE STUDY

3.1 Aim

To understand barriers and facilitators of recovery for critical illness survivors', who are discharged home from the hospital and do not have access to dedicated outpatient care. To address the study aim, three open-ended questions were used: (a) What have you done to facilitate your recovery since discharge from the hospital? (b) Tell me about barriers you have encountered since you were discharged from the hospital; and (c) What have you done to overcome the barriers that you encountered?

3.2 Design

Interpretive phenomenology guided the larger study that sought to describe critical illness survivors experience of recovery. This study reports on one aspect of the study, the facilitators and barriers of recovery. Interpretive phenomenology seeks to understand the deeper layers of human experience that lay obscured beneath surface awareness and how the individual's lifeworld influences this experience (Bynum & Varpio, **2018**). It goes beyond description to the interpretation of the phenomenon. The researcher must be aware of the influence of the individual's background and account for the how this impacts the individual's experience of being (Neubauer et al., **2019**). Interpretive Phenomenology also recognizes that the researcher, like the research subject, cannot be rid of his/her lifeworld. Instead, the researcher's past experiences and knowledge are valuable guides to the inquiry (Neubauer et al., **2019**) and are therefore included in the process of data collection and analysis through a dynamic process of reflecting and writing which guides data analysis (Bynum &

Varpio, 2018). The researcher believes that survivors of critical illness encounter several barriers to their recovery once they are discharged from the hospital. Since many of these survivors do not have access to resources in the community, survivors must develop ways to overcome these barriers and facilitate their recovery.

3.3 Sample/participants

Participants were recruited from six ICUs in four hospitals, a community, regional, Urban, and level one trauma and academic hospital. To include a diverse sample, inclusion criteria were kept broad; participants were eligible if they were over the age of 18, spoke and understood English, in ICU for 3 or more days, mechanically ventilated for at least 24 hr, and were discharged home. Survivors were excluded if they had a cognitive impairment that made them unable to consent or participate in the interview or were discharged to a post-acute care institution. Purposive sampling was used.

Screening occurred two to three times per week. Once identified participants were approached to discuss the study, questions were answered and understanding of the study was verified. Interested participants were contacted approximately 2 weeks after discharge to discuss the study and schedule an interview for at least 4 weeks after hospital discharge. Consent for study participation was obtained prior to the interview. Eighteen participants were included in the study. Forty-three permission to contact forms were obtained, 19 consented and participated in an interview, 11 did not answer follow-up phone calls or emails, seven changed their minds, three died, two were still hospitalized when recruitment ended, and one was discharged to a rehabilitation facility. One participant was withdrawn from the study by the PI due to a change in mental status during the interview. All data from this patient were deleted. Participants were no longer recruited when data saturation was reached.

4 DATA COLLECTION

To construct a rich understanding of factors that influenced ICU recovery, interpretive phenomenology was used to guide the interview. The interview focused on capturing the lived experience (Van Manen, 1990) and aimed at evoking a comprehensive account of the participant's experience of recovery (Moustakas, 1994). Interviews were semi-structured to allow the participants to direct the conversations and describe their experiences in detail. Field notes were taken and analysed during and after the interviews. Preliminary analysis during data collection revealed emergent themes which allowed for additional data collection and deeper understanding of the recovery experience and the facilitators and barriers encountered.

Interviews were conducted between December 2017 -July 2018. To ensure privacy and comfort, participants chose the interview location. Interviews took place in the survivors' homes (11), over the phone (5), at the hospital (1), and in a church office (1). All interviews were audio recorded and transcribed. After participant consent, a retrospective chart review was completed to provide sample description. Data retrieved included ICU days, ventilator days, sedation, and vasoactive medication use. The Acute Physiology and Chronic Health Evaluation (APACHE) II score was calculated on each participant. The APACHE II score is a severity of disease classification system. It uses a point score (0–71) based on initial values (within first 24 hr of ICU admission) of 12 routine physiological measurements, age, and previous health status to provide a measure of severity of illness. (Knaus et al., 1985).

5 ETHICAL CONSIDERATIONS

The study was approved by the institutional review board (IRB) at the main site with other sites relying on the primary review. Because reliving difficult events and experiences can be distressing (Hersen & Turner, **2013**), participants could stop the interview at any time or skip any questions. The crisis hotline number was provided, to which they could self-refer. Pseudonyms were used to ensure privacy and anonymity of participants.

6 DATA ANALYSIS

Interview transcripts were analysed using Interpretive phenomenological analysis (IPA), a blended approach which draws on fundamentals of phenomenology, hermeneutics, and idiography. IPA draws on phenomenology with deep engagement in the data, hermeneutics which influences the understanding of the lived experience and idiography that focuses on in-depth analysis of single cases before producing general statements (Smith & Osborn, **2012**). It aims to provide detailed examination of the lived experience of a phenomenon through participant's personal experiences and perceptions of objects and events (Neubauer et al., **2019**). IPA positions the researcher as an integral part of the research process. It involves a process of rich engagement and interpretation involving both the researcher and research. The researcher seeks to make sense of the participants making sense of their world. IPA offers direction on how to approach the phenomenon of interest with guidance on sampling, data collection, and analysis (Peat et al., **2019**).

The data were first coded by reading through word documents and field notes, identifying preliminary themes. Data were entered into a data management database (NVivo) to facilitate coding and analysis. The PI read and re-read the interviews and listened to the recordings to ensure full immersion in the data and to gain an in-depth, detailed understanding of survivors' responses. Open coding began with highlighting salient statements and adding comments/notes in the margins. Each section of salient statements was then assigned a code. Codes were grouped into themes and subthemes. Reflective field notes captured during and immediately following interviews were also used during analysis which allowed for a deeper understanding of recovery. More than half of the transcripts were independently coded by two other members of the research team. Developed themes were discussed among all three researchers for validation and accuracy.

6.1 Rigour

Lincoln and Guba's (**1985**) criteria for rigor informed the study. To ensure credibility, the PI had prolonged engagement with the data to develop a deep understanding of what it is like to recover from a critical illness. For transferability, the PI included detailed descriptions from the participants to support study findings and themes. Dependability was addressed by completing an inquiry audit with two other researchers. To ensure confirmability, a reflexive journal was used to document the research process, methodological decisions and rationale, logistics of the study, and reflections on the study including values and feelings.

7 FINDINGS

Eighteen participants contributed to the findings of this study. The participants differed by medical diagnosis and background; however, their experiences of recovery were similar.

Participants had a mean age of 57.5 (*SD* 12.1) years old with a high severity of illness (median APACHE II score of 22, range 25), median ICU days of 5.5 days, range 45 days, and median ventilator days of 4 days with range of 13 days (Table 1).

TABLE 1. Sample characteristics (*N* = 18)

Age [Mean (<i>SD</i>)]	57.5 (12.1)
Gender (Male) [<i>N</i> (%)]	11 (62)
Race [<i>N</i> (%)]	
African American	10(56)
Caucasian	8 (44)
Housing [<i>N</i> (%)]	
Lives with family	14 (78)
Lives alone	4 (22)
Education [<i>N</i> (%)]	
High school	8 (44)
Some college	4 (22)
Other ^a	6 (34)
ICU Length of stay (days) [median (range)]	5.5 (45)
Ventilator days [median (range)]	4 (13)
Sedation received [<i>N</i> (%)]	18 (100)
Vasopressors received [<i>N</i> (%)]	13 (72)
APACHE II score [median (range)]	22 (25)
Diagnosis [<i>N</i> (%)]	
Cardiovascular	4 (22)
Respiratory	8 (44)
Sepsis	2 (11)
Surgical	1 (6)
Other ^b	3 (17)

^a Other: Some High School 2 (11), Bachelor's degree 1 (6), Master's degree 2 (11), and Doctorate degree 1 (6).

^b Other: Necrotizing pancreatitis 1 (6), Haemoptysis 1 (6), and Seizures 1(6).

Participants encountered several barriers to recovery at home, such as physical, cognitive, psychosocial, financial, and transportation barriers. They experienced unmet needs, including issues with mental health, coordination of care, and spiritual needs that had an impact on their recovery. These barriers and unmet needs left many survivors feeling unsupported by healthcare providers after discharge, however, these survivors were also resilient and resourceful in development of strategies to manage their recovery at home. Five major themes emerged during analysis: Self-Managing Recovery, Following Recommendations, Support, Barriers to Recovery, and Unmet Needs (Table 2).

TABLE 2. Themes

Theme	Subtheme	Description
Self-Managing Recovery	Medical management	Frequent appointments, medical procedures, feeding tube, Wound Vac, PICC line, re-hospitalization
	Lifestyle adaptation	Unable to drive, climb stairs, get in the bathtub, return to work, cook, lawn care, basic ADLs

Following Recommendations		Take prescribed medications, wearing my life-vest, going to doctor appointments, following recommended diet and activities
Support	Social	Family, friends, church family, neighbours, co-workers
	Medical	Physical therapy, occupational therapy, and visiting nurses.
	Spiritual	Going to church, talking to God, and praying
	Self-support	Writing notes, keeping a calendar, seeking information, talking to family and friends, watching TV, and reading
Barriers to Recovery	Physical	Weakness, difficulty sleeping, pain, shortness of breath, and difficulty ambulating
	Cognitive	Poor memory and forgetful.
	Psychosocial	Depressed, sad, agitated, feeling isolated, withdrawn, feeling moody, stressed out, and unpredictable
	Financial	No insurance, problems with housing, unable to have recommended cares, and unable to fill medications prescribed
	Transportation	No transportation to appointments or the store
Unmet Needs	Mental health	Need to talk to someone regarding mental health, what they had and were experiencing, and how they were feeling
	Coordination of care	Lack of communication about appointments, illness, and what to expect during recovery
	Spiritual counselling	Need counsel on why they survived

Participants described multiple strategies they initiated to assist in their recovery or overcome barriers within three major themes: Self-Managing Recovery, Following Recommendations, and Support.

7.1 Self-managing recovery

Self-Managing Recovery included activities that participants initiated to facilitate recovery at home. Self-Managing Recovery included Medical Management and Adaptations to Lifestyle.

7.1.1 Managing medical needs

Some participants had medical devices that required management at home. Participants described their efforts to find support in managing them. Doug (56-year-old, 48 days in ICU) who was sent home with a feeding tube summarized:

He [my dad] helped me out a lot with the feeding machine, 'cause I couldn't have done that alone, you had to change the bag, flush the tube that was in me ... and the bags had to be changed every day.

Several participants had frequent doctor appointments after they were discharged home.

Chuck (62-year-old, 6 days in the ICU) stated “we [he and his wife] are seeing someone every week, yup, maybe two or three times a week.” He had appointments with a primary care provider, radiologist

who placed his biliary drain and infectious disease doctor. Sue (57-year-old, 3 days in ICU) had difficulty keeping track of all of her appointments “it's just the other outside appointments they are making for me...I just missed one today, now I got to call them and tell them that I couldn't make it this morning, I overslept.”

Other participants were re-hospitalized. William (51-year-old, 4 days in the ICU) discussed how he had been hospitalized in the ICU three or four times in the last 6 months after open heart surgery. “I got back home here and maybe a week or two, I was back in ICU again for some other sickness.”

7.1.2 Lifestyle adaptations

Participants described lifestyle adaptations they made to manage symptoms including changes they made to their everyday routine such as washing their hair in the sink, sitting down when necessary, not using stairs and using a motorized cart while grocery shopping. For example, Mike (65-year-old, 5 days in ICU) found it difficult to go upstairs and get in the bathtub:

I didn't go upstairs for a while. I washed my hair and kind of washed up in the sink for a while because I didn't want to get in the tub. The daily tasks, you know as far as making the food and things, I just wasn't capable of doing that right away.

7.2 Following recommendations

Participants reported they were following recommendations to assist in their recovery including taking medications, following a specific diet or going to appointments. For some, this was an adjustment from previous lifestyle. Daryl (64-year-old, 5 days in the ICU) described how he was following doctor's recommendations: “I am taking care of my health and going to the doctor and all my appointments. Whatever's wrong with me, [I'm] getting it done.” He further described how previously he did not care about his health but now he stopped drinking brandy, got Chantix to quitting smoking, started taking his medication for high blood pressure, was redirecting his life, and taking care of himself. He stated, “I've come to the realization that I'm not superman and I could die if I don't take care of myself.”

While participants had good intentions to follow recommendations, they also found challenges in following through. One participant, Dale (56-year-old, 16 days in ICU) shared how he was doing the best he could to follow recommendations:

I've done what they told me to do, I'm taking my medications and wearing the [life] vest. I'm just pretty much doing what they told me to do as much as I can. I've goofed up a few times. I've missed a couple times taking my pills.

In contrast, some participants reported that they did not know how to help with their recovery or how to manage barriers they were encountering. Tosha (50-year-old, 10 days in ICU) explained that she was having difficulty with her physical recovery. She was having pain with walking which made it difficult, but she was not taking any action because: “they didn't tell me what to do yet”.

7.3 Support

Participants discussed different types of support that aided their physical, cognitive, and emotional recovery including social, medical, spiritual, and self-support.

7.3.1 Social support

Social support provided by family, friends, neighbours, or church members was an important part of participants' recovery. Bill (64-year-old, 10 days in ICU) spoke of the support from his church family during his recovery:

I live alone, but I am not alone. That's my church family, it's like I have 17,000 mothers. I've gotten a lotta support and like I said, a whole bunch of mothers that I didn't know I had saying "are you taking your meds?" So yes, it's very humbling, to have so many people be concerned about your well-being.

Several participants struggled trying to care for themselves after their loved ones needed to return to work. Mike (65-year-old, 5 days in ICU) stated how he depended on his wife and indicated when she went back to work, he felt he was left alone too soon:

Once I got out of the hospital, they [my family] were here; my wife was here when she wasn't working. My personal opinion, she could have taken a little more time off work because I think I was kind of pushed out of the boat before I was ready to swim.

7.3.2 Medical support

Some participants had access to medical services such as visiting nurses, physical therapy, occupational therapy, and wound nurses. They described how support from these services had an impact on their recovery. Marg (65-year-old, 6 days in ICU) was sent home with a Wound Vacuum-assisted closure (VAC) and Peripheral Inserted Central Catheter line for IV antibiotics:

It was great. I mean, I had visiting nurses as many times a week as they felt I needed them. It was like three times a week. I had that Wound Vac, so they'd change that.

7.3.3 Spiritual support

The role of spiritual support during recovery, including prayer and the survivor's relationship with God, was a common theme. Barbara (62-years-old, 4 days in ICU) wanted to ask her doctor for a referral to a psychiatrist but in the meantime described how prayer and reading her bible was helping with her depression:

My primary doctor may have a psychiatrist that I can talk to, but right now prayer is helping me a lot and reading my Bible. Yup, that's what I'm doing right now.

7.3.4 Self-support

Almost every participant mentioned self-support which incorporated skills they employed to assist in their recovery, such as writing notes, keeping a calendar, and seeking information about their illness. Self-support also included coping strategies such as taking naps, talking to family and friends, watching TV, and reading. Deb (64-years-old, 8 days in ICU) had several self-support strategies she incorporated in her recovery:

I sit on my deck and watch the birds; I just love to watch the birds. My solitude, it's being outside, it's sitting with my husband and talking with him. Just sitting down to watch TV is a good coping mechanism for me.

Participants liked to talk to others about what they had been through. Mike (65-years-old, 5 days in ICU) described that sharing his critical illness experience with others was not so they knew what happened but more his need to talk about the experience: “Just to verbalize some of that [his critical care experience] so that other people, you know ... uh, I mean, that was more not them wanting to know, it was more me wanting to talk about it.”

7.4 Barriers to recovery

Participants experienced numerous barriers to their recovery once they were discharged home including physical barriers, cognitive barriers, psychosocial barriers, financial barriers, and transportation barriers.

7.4.1 *Physical barriers*

Physical barriers reported by the participants were related to symptoms they experienced such as weakness, pain, and lack of energy. Jennifer (19-year-old, 6 days in ICU) mentioned how weakness affected her ability to work: “After I got out of the hospital, I was so weak. Oh, I couldn't do anything. I couldn't go back to work ‘til April because I was so weak.” Patricia (76-year-old, 4 days in ICU) suffered from lack of energy and was dependent on continuous oxygen which had an impact on her ability to complete activities of daily living:

I need a person to come in a couple times a week to try to help me with doing laundry...go grocery shopping. I don't really have the energy to walk around the store, I won't go to the store unless they have one of those carts you can ride around in.

7.4.2 *Cognitive barriers*

Participants experienced issues with their memory post critical illness including loss of short-term and long-term memory, struggling to recall information and difficulty managing daily tasks. Barbara (62-year-old, 4 days in ICU) spoke of her memory problems during her recovery which had an impact on her daily activities:

Memory...is not all that good. No, some things I remember and somethings I don't, and that's kind of scary. Just remembering daily things, remembering life, remembering my telephone number, remembering what I need to do that day or get the phone or how to work the phone, just little bitty things.

Jim (63-year-old, 3 days in ICU) also discussed his forgetfulness. He relied on notes to help with his memory: “I have to write my medications down, when I have to go for a blood test, just to make sure I don't forget.” Jim was struggling, even with the notes. His wife planned to quit her job so she could be home to help with his medications and make sure he followed his diet and fluid restriction.

7.4.3 *Psychosocial barriers*

Participants described psychosocial barriers in relation to their emotional health during recovery that had an impact on social interactions and hindered recovery. Participants felt depressed, agitated, sad, and withdrawn. Jennifer (19-year-old, 6 days ICU) resorted to staying in her room and listening to music as she explained: “I just stay to myself. I just go to my room, not talk to nobody, listen to music.”

7.4.4 Financial barriers

Many participants were frustrated because of inability to afford recommended medical care. Bill (61-year-old, 10 days in ICU) talked about how he was not able to have a recommended test for a “spot” they found on his pancreas because he did not have insurance and could not afford to pay out of pocket:

The frustrating thing is not having insurance to do as much of the follow ups ... our father died of pancreatic cancer and she's [my sister] concerned that because of that, whatever this spot they found on the tip of my pancreas could be the start of that.

William (50-year-old, 3 days in ICU) was recommended physical therapy, but he could not afford it:

They wanted me to go to therapy and I told them I couldn't afford it, so I didn't go to it anymore. I told them I could get on the treadmill here at home...just keep myself active because I don't have the money right now to do nothing.

7.4.5 Transportation barriers

Having difficulty with transportation to the grocery store and appointments were barriers. Barbara (62-year-old, 4 days in ICU) used a scooter but it would not fit on the transportation van which prevented her from being able to get out and go grocery shopping:

Barriers were being able to get on that van and go to the store. I can't take my chair because they don't have a van big enough or the lift on there for this, so they were not equipped for a person like me to do that.

Participants faced barriers with finding transportation to needed medical appointments. For instance, William (50-year-old, 3 days in ICU) who was staying with his aunt reported struggling to get to his appointments:

She's [the nurse] trying to help me get a ride back and forth to the doctor. I don't have any other way to get there because she [my aunt] works a lot. I don't know the area, I know nothin' about the buses, I don't know nothin' about how to get nowhere but stay right here where I am at.

7.5 Unmet needs

Participants identified unmet needs including mental health issues, coordination of care, and spiritual counselling. There was a lack of resources and information received by critical illness survivors about their recovery.

7.5.1 Mental health

A few participants spoke of needing to talk to someone regarding what they were experiencing mentally during recovery. They felt that the healthcare providers failed to address what they needed most:

I would have traded both of those [occupational therapy and the dietician] for maybe an hour with somebody that talked to me about my mental condition. I maybe would have appreciated talking to somebody about the other stuff that was going on in my head more than anything else (Mike, 65-year-old, 5 days in ICU).

7.5.2 Coordination of care

Several participants needed better communication with healthcare providers about what happened to them during their illness and follow-up care:

It was frustrating that they had all these appointments made for me that I knew nothing about. They give you a printout, say now you have some appointments coming up, but that's it. I had one appointment that I cancelled because when I called I didn't know who it was with, what it was about and they said, "well you're scheduled for surgery because you have gallstones", I said, I don't remember him telling me I had gallstones, so I cancelled it (Deb, 64-year-old, 8 days in ICU).

7.5.3 Spiritual counselling

Some participants prioritized the need for spiritual counselling after the trauma of surviving a critical illness. Bill (61-year-old, 10 days in ICU) described struggling to understand why he was still here and wanted to find a spiritual director to help him understand why he survived:

That's part of the reason why I'm kind of sad, 'cause I don't know why and I need to find a spiritual director...I've asked God that every day, it's like "why am I still here" 'cause I don't know.

8 DISCUSSION

This study took a unique look at ICU survivors' experiences of barriers and facilitators to recovery. New insight into the recovery process emerged from examining post-ICU recovery through the lens of survivorship using interpretive phenomenology analysis. This resulted in a greater understanding of the survivors face and allowed for increased perspective of survivors' management of barriers to their recovery.

Critical illness survivors are resilient and resourceful in the development of strategies to manage their recovery at home. In this study many of the physical, cognitive, and psychosocial barriers experienced by participants after discharge were related to critical illness or treatment. Obstacles to healing included poorly organized care coordination after discharge and spiritual distress related to surviving a critical illness. Lack of mental health resources and healthcare providers' inadequate attention to post-ICU psychological recovery were also described as major barriers by participants.

Similar to findings from this study, a study by Maley et al. (2016) identified ongoing physical impairments, mental health issues, and difficulties in scheduling and coordinating follow-up appointments as major barriers faced by survivors. While other studies have addressed financial barriers to establishing post-ICU clinics (Haines et al., 2019), the current study identified personal financial barriers, including participants not being able to have the necessary follow-up procedures and care post-hospital discharge due to lack of insurance and money. Healthcare providers need to be aware of barriers that survivors experience after they are discharged to assist in overcoming these barriers. Potential interventions include providing transportation to follow-up appointments and community support to help with the financial barriers that may prevent survivors from adhering to the recommended follow-up.

Participants in this study found support to be an important facilitator to recovery including medical, spiritual, social, and self-support. Similar findings have been reported in other studies where spiritual and family support were facilitators to recovery (Maley et al., **2016**). The role of social support described by participants in this study highlights the potential value of formal peer support, a proposed intervention to help support recovery following a critical illness (McPeake & Quasim, **2016**; Mikkelsen et al., **2016**). Support from others, whether it is family, friends, or healthcare providers, is a potentially valuable intervention that could compliment an ICU aftercare model that aims to improve outcomes for ICU survivors.

This study found that survivors struggled to understand why they survived and wanted spiritual guidance to help them cope with their new reality. Similarly, several studies have reported patients' views about having near death experiences and the need to believe in a higher entity (Abdallah & Seilani, **2014**; Magarey & McCutcheon, **2005**; McKinney & Deeny, **2002**). Facing their own mortality may cause patients to revisit the meaning of their lives and focus on making each day count (McKinney & Deeny, **2002**).

Participants in this study also reported unmet needs of coordination of care and knowing what to expect during recovery. Survivors often do not feel supported by healthcare providers with unmet mental, psychological, and care coordination needs at discharge and during recovery.

In the study by Prinjha et al. (**2009**), a lack of contact from healthcare providers resulted in some patients feeling abandoned after hospital discharge. Patients indicate a sense of wanting more information, but not knowing where to obtain it (Czerwonka et al., **2015**; Lee et al., **2009**). Models of survivorship, such as those from oncology or stroke management, which emphasize long-term health management and transitioning survivors from the acute care environment to the community, could help inform ICU survivorship efforts (Herridge, **2009**; Iwashyna, **2010**; Miller, **2008**). We need to design, implement, and test aftercare models that ensure all ICU survivors will have access to resources and services.

9 LIMITATIONS

This was a cross-sectional study that employed purposive sampling with participants recruited from only a few hospitals in one region impacting generalizability. The study focused on early recovery, therefore lacked participants' perceptions of long-term recovery and cannot account for changes in facilitators and barriers to recovery over time. Although data saturation was reached and common themes emerged among the participants, more participants may have provided additional findings.

10 CONCLUSION

This study identified that participants were able to implement strategies to assist in recovery, yet they were unable to overcome all barriers. These unmet needs and barriers left participants feeling unsupported from healthcare providers during their recovery. Nurses are in a unique position to support survivors before, during, and after discharge. They should be involved in critical care discharge planning, care coordination, and follow-up care.

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CONFLICT OF INTEREST

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