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Modification of Social Determinants of Health by Critical Illness, and Consequences of that Modification for Recovery: A Multinational Qualitative Study

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Title: Modification of Social Determinants of Health by Critical Illness, and Consequences of that Modification for Recovery: A Multinational Qualitative Study

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Abstract

Purpose: Social determinants of health (SDoH) contribute to health outcomes. We identified SDoH that were modified by critical illness, and the effect of such modifications on recovery from critical illness.

Materials and Methods: Patients and caregivers from three continents, took part in qualitative, in-depth semi structured interviews following hospital discharge. Interview transcripts were mapped against a pre-existing social policy framework: money and work; skills and education; housing, transport and neighbourhoods and family, friends and social connections.

Results: 86 interviews were analysed (66 patient and 20 caregiver). SDoH, both financial and non-financial in nature, could be negatively influenced by exposure to critical illness, with a direct impact on health-related outcomes at an individual level. Financial modifications included changes to employment status due to critical illness related disability, alongside changes to income and insurance status. Negative health impacts included the inability to access essential healthcare and an increase in mental health problems.

Conclusions Critical illness appears to modify SDoH for survivors and their family members, potentially impacting recovery and health. Our findings suggest that increased attention to issues such as one's social network, economic security, and access to healthcare are required following discharge from critical care.

Keywords: socio-economic; post intensive care syndrome; qualitative and rehabilitation.

Article Summary

Strengths and Limitations of the study

- This international multi-centre study utilised in-depth semi structured interviews to understand how the social determinants of health were modified by critical illness.
- Utilised replicable, rigorous qualitative methods, it suggests a complex interplay between the social determinants of health and recovery from critical illness.
- Although the sample size is considerable for a qualitative study, we recognize that we have utilised a convenience sample, with a small portion of all critical care survivors in these countries.

Introduction

Social determinants of health (SDoH) include both upstream policy, environmental, and context factors and their manifestations in terms of individual material and social hardship(1). There has been a growing realization of their central role in shaping the capacity of individuals to not only access high quality care, but also to benefit from such care(2). In some discussions, particularly around the role of SDoH impacting outcomes from acute illness and hospitalization, such factors are conceptualized as causally antecedent to medical care and illness.

Illness can itself result in material and social hardship, opening the possibility of a bidirectional relationship(3). Financial toxicity resulting from oncologic care has been documented and is also found after surgery and respiratory failure(4, 5). Adverse employment outcomes are common after acute myocardial infarction, stroke, and critical illness(6-8). While changes in individual economic and social situations may be exacerbated by gaps in the U.S. social safety net, many have been documented throughout the industrialized world(9).

There has been little effort to systematically identify SDoH which can be worsened by specific acute health events(2). Using critical illness as an extreme case where such effects were hypothesized to be most visible if they exist, we sought to identify SDoH that were modified at the individual level by the experience of critical illness, and the effect of such modifications on patients' and families' recovery. We conducted an international qualitative study of the experience of recovery from critical illness with patients and caregivers from 14 different hospitals across Australia, the US, and the UK.

Methods

Study design and protocol were approved by the Western Health Low Risk Human Research Ethics Panel (Australia, Ref: HREC/17/WH/170); Vanderbilt University Institutional Review Board (US coordinating site, Ref: 171299); and the Southwest (Cornwall and Plymouth, Ref: 18/SW/0137) Research Ethics Committee (UK).

Design and Setting

Sites participating in the Society of Critical Care Medicine's (SCCM) THRIVE programme (10) offered Intensive Care Unit (ICU) recovery programmes in the form of post-ICU clinics and peer support programmes. Patients who had not received any specific intervention were also interviewed (**Table 1**).

Patients attending ICU recovery programmes were invited by professionals at each site if they met: i) Inclusion criteria - English-speaking patients older than 18 years admitted to the ICU, or caregiver of a patient who survived critical illness; and not ii) Exclusion criteria - ongoing severe neurological and/or cognitive impairment or continued inpatient care in hospital or rehabilitation. Informed consent was obtained before each interview.

Data collection

Data were collected through in-depth semi-structured scripted interviews via telephone. Separate questions were used for caregivers and patients; these were adapted for those who did not receive a post critical illness intervention (**S1**). Questions were generated from previous literature and through iterative discussion within the research group (JMM, LB, KJH, CS). All researchers, alongside patient representatives, discussed the interview script to ensure consistency. Some interviewers were known to the participants through their role in direct clinical care. Data were audio-recorded and transcribed verbatim.

Data Analyses

We sought to understand how SDoH were potentially modified at the individual level by the experience of critical illness, and the effect of such modifications on recovery. To do so, we systematically mapped our analysis against a set of pre-defined concepts related to SDoH, adapted from a public policy framework(11), including: money and work; education and skills; housing transportation and neighbourhoods; and family, friends and social connections. In this analysis, we defined a 'rural' setting as a located out with a main town or city.

The Framework Analysis technique was used to analyze data across these concepts(12) , through seven stages: 1) Transcription; 2) Familiarization with the interview; 3) Coding; 4) Developing a working analytical framework; 5) Applying the analytical framework; 6) Charting data into the framework matrix; 7) Interpreting the data(11). Three researchers (JMM, LB, JM) independently undertook preliminary sweeps of the data. Key quotes to support the findings were then independently extracted by JMM and JM. The Consolidated Reporting of Qualitative Research (COREQ) checklist was used for this study(13).

Patient and Public Involvement

Patients and caregivers who had previously been admitted to intensive care helped create the interview schedules utilised for this study. The also supported the planning of the study conduct and reviewed all study documentation.

Results

Across 14 sites, interviews were completed with 66 patients and 20 caregivers from Australia, the US, and the UK (**Table 1**). Interviews took place between July 2018 and February 2019. We analysed the data across four main domains of SDoH: money and work; education and skills; housing transportation and neighbourhoods; and family, friends and social connections. Supporting quotes, illustrating these concepts can be found in **Table 2**.

Demographic	Patients (n=66)	Caregivers (n=20)
Age (years), Median (IQR)	52 (40-62.5)	52 (46-67)
Gender, n male (%)	26 (39.4)	3 (15)
Patient Admission Diagnosis n (%)		
Sepsis	28 (42.4)	
Respiratory Failure	15 (22.8)	
Post GI Surgery	5 (7.6)	
Trauma	2 (3)	
Other	16 (24.2)	
Ventilated, n (%)		
Yes	57 (86.4)	
No	9 (13.6)	
Length of time since ICU discharge, n (%)		
<6 months	15 (22.8)	
7-11 months	9 (13.6)	
1-2 years	12 (18.2)	
2-5 years	22 (33.3)	
>5 years	8 (12.1)	
Relationship to the patient, n (%)		
Spouse/Significant other		10 (50)
Parent		5 (25)
Sibling		3 (15)
Child		2 (10)
Nationality, n (%)		
United States	50 (75.7)	16 (80)
UK	13 (19.7)	2 (10)
Australia	3 (4.6)	2 (10)
Participated in recovery programme, n (%)		
Yes	52 (79)	11 (55)
No	14 (21)	9 (45)

Table One: Participant Demographics

Money and work

Loss of both money and work following critical illness was discussed frequently across the interviews. For example, a patient from Australia described how their new critical illness disability had changed their employment status:

'I come home and now you've lost your job and you can't work and then the realisation that you are on oxygen for the rest of your life.'

Job loss and change had a direct negative impact on income, access to care and subsequent recovery from critical illness. For example, one patient of the loss of not only insurance but also savings during critical illness and the recovery period following forced unemployment:

'For the first surgery I had two insurances.. second surgery, my school, they were nice enough to keep me on there, but then I lost it because I wasn't working…. We had a little savings, but that's all gone, because we have had to use it for medical bills and driving to the hospital an hour and a half.'

There were health-related consequences of the changes. For example, participants described how they could no longer afford the treatments necessary for recovery:

Social Determinant of Health Modification	Illustrative Quote
Family, Friends and Social Connections	'I went back to my daughters and I stayed there for a while. I relaxed and um I did relax…I had my grandchildren around me who I think are one of the best healer's um because just being with them makes me feel erm good…' 'God has helped me through the ministry…for 50 years we were pastors. Knowing and seeing how he has worked with other people in their lives, I think has given me the experiences to know that' hey you don't have to do this by yourself'. 'Our friends all disappeared. …I'm not who I was before. I think that, for most people, they couldn't deal with it. And so our community just sort of vanished. "I would feel better and I wouldn't feel so alone with all of this. Because while my family was supportive, they reached a point where they didn't want to talk about it. They didn't want to relive it."
Money and Work	'Financially…for the first surgery I had two insurances, mine and my husband. Second surgery, my school, they were nice enough to keep me on there, but then I lost it, because I wasn't working. Financially, if its less than a year you've got deductibles. There's no plan that helps people that are working…if we were very, very poor, or very, very rich, but there's nothing that helps you in the middle. There isn't…. We had a little bit of savings, but that's all gone, because we've had to use it medical bills, and driving to the hospital an hour and a half.' 'Whether you know when he came home, whether the house had to be reconfigured for a wheelchair or anything like that- that was another challenge not knowing as well, financial circumstances that's another challenge you know- he's out of work he was a breadwinner and now he's not sort of thing and who do we rely, what do we do, and everything like that- that's a big issue I think with everyone who is sick I suppose. ' 'I would say being able to get back into the field of work and build relationships and actually function….I just felt worthless, because without your money…We associate money with the ability to educate or be educated. There's no secret'. 'I think it's changing the paradigm from thinking that ICU is the endpoint…with medicine the way it is, it isn't the next step to the funeral home necessarily…these people are surviving. They're not perishing…. it's affected every aspect of a person's family life. And often it's affecting their money. And things that are big, that are really going to impact them, and I don't think people realize. I think there just needs to be a better support system in place.
Skills and Education	'I was fully able to read small things in neurological journals. My husbands a physician, so I would take whatever passwords he had to things so I could get to the journals that normally lay pay can't get into them.' 'I think that the other thing that's helped us do well is just some of the personal tools we have. We're not ashamed to ask or accept help, or to ask a question, or to be kind of vulnerable… some of that has to do with our education, like we're both very resourceful…. I can see if you've maybe poorly educated, I can see if you lived in a world where people haven't been trustworthy, so you don't trust people, I can see if we had different life experience, it could just look a lot differently.'
Housing, Transportation and Neighbourhoods	'What I did, when I got back home, the only place I could sleep for a while was the recliner. I could not lay down on our bed.' 'Now our hospital in (geographical area name) its good for a band-aid. If you have anything else wrong with you, you do not want to go there.' 'I wanted to give back….. it would be easy for me not to go, because it's a long distance and its kind of a hassle to get up there.'

Table 2: Modification of the SDoH at the individual level and potential effects of such modifications on recovery from critical illness

'my insurance company is messing with me right now… I'm out of my medicine. I'm out of one of them. I called to see how much it was and I can't afford that. They want $55 for seven days. I can't afford that.'

Participants discussed how these changes to money and work were a direct mechanism for mental health problems. One participant from the US spoke about how changes to her health insurance had increased feelings of anxiety:

'There was an issue with the insurance….the first time said they weren't going to cover any of our hospital bills. You can imagine…'We're going to lose our house, oh my God…' The anxiety of it all. ….'

A participant from the UK discussed changes to her employment situation following critical illness and subsequent emotional disruption:

'I've changed jobs, I was a teacher before, but now I've gone into office work and I'm still trying to adjust. My GP wrote a letter saying I wasn't fit to go back to teaching because of the kind of asthma I've got…At the time I was devastated, I was really, really devastated.'

Caregivers suffered similar loss of money and work, albeit via different mechanisms. One participant (patient) spoke about how their partner had lost their job due to new/increased caregiving responsibilities following hospital discharge:

'I was working when I went in, and so was she and she had to take time off from work, and they had let her go from work, after she wasn't making her units, and it made it rough on us.'

Skills and Education

The increased disability caused by critical illness resulted in an inability to return previous roles and activities. One participant, who had a highly skilled role, described the impact of cognitive disability on function:

'*My brain's just not making the connection…I'm retired but I was a judge and for a long time I wouldn't go back to court…. I can tell my brain is not making the connection.'*

Similarly, a participant who had been in a skilled academic role could no longer return to their previous appointment, because of critical illness-caused cognitive decline:

'My identity was a writer and professor had been built around being smart and so those issues manifested themselves as word finding, executive functioning…I couldn't go back to work though. I was having cognitive difficulties…my request to have support for my particular cognitive deficits has been denied.'

Such loss of skills required survivors to re-evaluate future career and employment prospects. One younger participant spoke of having to change educational pathways:

'*it's changed my career path. I'm only 20…I just turned 21. And so I'm still really young. I'm in college. I changed my major because of it.'*

Housing, Transportation, and Neighbourhoods

New critical illness related disability significantly disrupted housing, transportation and residency in those survivors interviewed. Patients needed to move house due to physical inability:

"It took, again, a lot of coordination and a lot of….Everyone pitched in…but it did provide a lot of stress, just in managing food and managing cleaning, and all the little things that you have to do from day to day. One of the reasons we began looking to move…having such a large house was a big struggle for her. Even going up and down stairs."

A participant from Australia spoke about the challenges to find funding for the housing adaptations which were required following critical illness and the financial and emotional stress this caused:

'when he came home whether the house had to be reconfigured for a wheelchair or anything like that…the financial circumstances that's another challenge… he was a breadwinner and now he's not and who de we rely, what do we do?'

The burden of transportation rose for survivors, who now needed to attend more medical appointments. Yet many critical illness survivors could no longer drive, so this ongoing health burden caused disruption for the entire family unit:

'It wasn't necessarily one doctor's appointment that stood out, but it was the fact that there were so many of them, and I think it was so significant because we had to drive an hour each way to get there.'

These changes influenced recovery for many, especially for those living in rural areas, as accessing appropriate and reliable healthcare became harder:

'I mean around here you're not going to find any medical help that's going to be decent. We're just so far removed from everything….quite a disadvantage of being so far away from everything.'

Changes to how participants could access transport also had a direct impact on recovery. For example, one participant spoke about how their inability to drive led to feelings of isolation:

'I couldn't drive for quite a long time, so I felt fairly dependent, I felt pretty trapped in.'

Family, Friends and Social connections

Critical illness changed survivors' social networks and relationships within families. For example, participants spoke about the negative impact of physical and emotional changes on wider social networks:

'and so our community sort of vanished… I still have these huge scars and I'm not who I was before. I think for most people, they couldn't deal with it.'

Critical illness also led to fractures in family networks. In some cases, families struggled to manage the enormity of the situation, which led to challenges during recovery. For example, one survivor from the UK highlighted the impact which it had on the family unit:

'I was doing something in the kitchen, and I couldn't do it and I ended up smashing stuff all over the kitchen and my brother came in and I started shouting at him, saying you know this is my life?'

These changes had consequences during recovery. Participants described isolation, challenges re-engaging with activities of daily living, and mental health problems related to these changes. A participant from the US described how these changes had impacted their mental health and behaviour:

'No one talked to me about how I might be when I get home, like emotionally…I react to things… I feel bad 'cause its like hell for my family. I have these… I can't control them…just absolute fits of anger and rage… and just crying.'

Discussion

This international, multi-centre study suggests a complex interplay between SDoH and recovery from critical illness. It is already well-established that upstream policy and contextual factors, as well as individual hardship, are associated with worsened onset of critical illness and outcomes; the early months of the COVID-19 epidemic particularly highlighted this(14). These qualitative results demonstrate how critical illness precipitated adverse changes in the recovery environment. These changes and other behavior changes resulted in lost connections with family and social support, loss of the instrumental, social, and psychological benefits of work, and having numerous other practical difficulties. Together these changes impeded successful access to and benefit from even traditional health services. Our findings provide evidence that the relationship between social determinants and recovery plays out across multiple domains of SDoH and recovery, as well as bi-directionally. Further, they demonstrate that the "social determinants of recovery" are not fixed nor the same as patients' pre-illness statuses, suggesting a need to assess these mechanisms, and their impact, across time.

These findings can be situated in a broader body of work that suggests their generalizability. Inadequacies of the U.S. health and social safety net are well-described, but it is notable that the data for this study also included examples from Australia and the United Kingdom. Loss of employment and/or financial hardship after AMI, acute respiratory distress syndrome, or traumatic injury are not uncommon(6, 15, 16). Studies have likewise found many suffer from significant financial costs and related material hardship due to chronic and ongoing illness, such as cancer(17) and heart disease(18).

Some, but not all, of the difficulties here seem to be a failure of the insurance functions of existing organizational arrangements to buffer patients and their families against purely financial shocks of critical illness. This interpretation is reinforced by findings that specifically financial stress is central after acute respiratory failure(5), as well as work on surprise billing(19) and risk for high bills after surgery(20), or decades-old findings about patients self-management of diabetes in the presence of

cost concerns(21). Additionally, substantial evidence supports our findings that critical illness leads to other financial hardship through job loss, unpaid family caregiving, and new nonmedical expenses due to new disability(4, 7, 22). Moreover, recent data from the UK suggest that patients who have ongoing disability due to critical illness, are more likely to require government funded welfare support in the years following discharge, in comparison to contemporary hospital controls(23); concerns are emerging about COVID-19 patients(24, 25).

Efforts to address these resulting financial hardships through direct payments to patients and caregivers have shown promise; the Medicaid Cash and Counseling program found improved patient and caregiver wellbeing alongside improved health outcomes(26, 27). Similarly, the US Department of Veteran Affairs' Program of Comprehensive Assistance to Family Caregivers suggests financial support provides crucial assistance in varied ways, depending on specific needs(28). In the UK, efforts to include social welfare consultation as part of critical illness recovery programs have also shown promise(29). These issues may become more prominent as moves to telehealth and remote monitoring require patients to bring more of their own technology to fully access services, potentially exacerbating inequities(30, 31).

Other challenges do not appear to be purely financial and would not be remediated by even theoretically complete insurance against total healthcare costs. Particularly prominent are the impacts of critical illness on social isolation. Social isolation is not benign; the influence of social relationships and social isolation on mortality is comparable to smoking, obesity and alcohol(32). initiatives across the UK and the US have successfully introduced innovation to support social isolation. For example, in Chicago, one health system added a social connection question to a pre-existing health screening tool, alongside care pathways such a friendly caller initiative to promote community socialisation during the COVID-19 pandemic(33). Peer support programmes which link individuals who have had similar healthcare experiences may also be advantageous, with evidence suggesting

peer support could be a mechanism for reducing social isolation and improving global mental health(34).

These data in the context of emerging literature have implications for clinicians and health systems seeking to promote full recovery of critically ill and other patients by addressing SDoH(35, 36). First, the data suggest that assessments of risk might include not just current hardship, but the extent to which the patients' reserves (broadly construed) are sufficient to prevent future hardship. It is unclear to what extent currently suggested patient-level risk assessments of SDoH(37, 38) are capable of predicting changes of the type these patients described. Second, given the myriad ways in which SDoH impacted each other following critical illness, understanding the impact of post-illness interventions (or lack thereof) must also be scrutinized across multiple domains, understanding that positive and negative consequences may be different for each patient. Certainly, targeted interventions to assure access to follow-up care, such as transportation support (e.g., Uber or Lyft vouchers) or telehealth support (e.g., device provision and training) can address some impacts. However, the multi-faceted and interactive results of our study also suggest that broader programs of direct assistance after critical illness, which address financial and non-financial resources, should be explored and potentially advocated for.

Limitations

Strengths of this study include its international, multicenter approach to understanding the interplay between SDoH and recovery from critical illness. However, although the sample size is considerable for a qualitative study, we recognize that we have utilised a convenience sample, with a small portion of all critical care survivors in these countries. We acknowledge that the primary aim of these interviews was not to delineate the socio-economic problems which participants faced during recovery from critical illness. As such, important concepts may have been missed in this analysis. For example, we did not find cross-country differences; this is an important construct which could have

been missed. Finally, we have used a broad definition of the term 'rural' in this analysis to ensure that it is applicable internationally. However, there are international variances in rural and urban interfaces, as such we may be under or over reporting this as an issue.

Conclusion

In conclusion, this international, multi-center study has explored how critical illness changes social circumstances, impacting recovery and health. Our findings suggest that increased attention to issues such as one's social network, economic security, education and skills, access to healthcare, and living environment are required following critical care discharge. Targeting interventions toward these domains, could potentially improve outcomes.

Ethics and consent to participate:
The study design and protocol were approved by the Western Health Low Risk Human Research Ethics Panel (Australia, Ref: HREC/17/WH/170); the Vanderbilt University Institutional Review Board (US coordinating site, Ref: 171299); and the Southwest (Cornwall and Plymouth, Ref: 18/SW/0137) Research Ethics Committee (UK). All participants provided informed consent.

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Figure and Table Legends:

Table One: Participant Demographics
Table 2: Modification of SDoH at the individual level and potential effects of such modifications on recovery from critical illness.

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Supplemental File 1: Patient Interview Schedule

1. Can you tell me about the how you have been getting on since you left hospital?
2. Thinking back to what you recall of your time in ICU, and then walking through your recovery from hospital to home to now – what were the most important moments for you? What stands out the most to you?
3. Thinking about this time from ICU to home, what were some of the challenges you encountered along the way?
4. How did you try and solve some of these challenges?
5. Can you describe any successful parts of your recovery?
6. Thinking about your involvement in the ICU recovery programme, how did you feel when you received the invitation to take part?
7. What motivated you to participate? Why do you think you were able to participate at the time you did?
8. How did you feel when you first went to the program? Did that experience change over time?
9. How has the programme influenced your recovery?
10. Has anyone commented on changes which they have seen in you, if so what have they said?
11. What do you think are the most important parts of a support programme?
12. How could we better support patients and their families following discharge from ICU?
13. If another patient was thinking about participating in such a programme, what would you say to them?
14. Is there anything else you would like to add or ask?

Informal Caregiver Interview Schedule

1. Can you tell me about how you have been getting on since your loved one left hospital?

2. Thinking back to what you remember about being in the ICU, and then the recovery period through to now – what were the most important moments for you? What stands out the most to you?

3. Thinking about this time, what were some of the challenges you encountered along the way?

4. How did you try and solve some of these challenges?

5. What were some of your greatest successes as your provided support to your loved one?

6. Thinking about your involvement in the program (quote relevant program), how did you feel when you received the invitation to join this program?

7. What motivated you to participate? What made it possible for you to participate when you did?

8. How did you feel when you first went to the program? How did that experience change over time?

9. How has the program influenced your experience as a caregiver following ICU?

10. What do you think are the most important parts of a support program from ICU discharge to post-hospital?

11. How could we better support patients and their caregivers following discharge from ICU? 12. Can you describe what you think would help people cope better with recovery after being in ICU?

13. Is there anything else you would like to add or ask?

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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BMJ Open

Modification of Social Determinants of Health by Critical Illness, and Consequences of that Modification for Recovery: An International Qualitative Study

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Title: Modification of Social Determinants of Health by Critical Illness, and Consequences of that Modification for Recovery: An International Qualitative Study

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On behalf of the Society of Critical Care Medicine's THRIVE Initiative

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Abstract

Purpose: Social determinants of health (SDoH) contribute to health outcomes. We identified SDoH that were modified by critical illness, and the effect of such modifications on recovery from critical illness.

Materials and Methods: Patients and caregivers from three continents, took part in qualitative, in-depth semi structured interviews following hospital discharge. Interview transcripts were mapped against a pre-existing social policy framework: money and work; skills and education; housing, transport and neighbourhoods and family, friends and social connections.

Results: 86 interviews were analysed (66 patient and 20 caregiver). SDoH, both financial and non-financial in nature, could be negatively influenced by exposure to critical illness, with a direct impact on health-related outcomes at an individual level. Financial modifications included changes to employment status due to critical illness related disability, alongside changes to income and insurance status. Negative health impacts included the inability to access essential healthcare and an increase in mental health problems.

Conclusions Critical illness appears to modify SDoH for survivors and their family members, potentially impacting recovery and health. Our findings suggest that increased attention to issues such as one's social network, economic security, and access to healthcare are required following discharge from critical care.

Keywords: socio-economic; post intensive care syndrome; qualitative and rehabilitation.

Article Summary

Strengths and Limitations of the study

- This international multi-centre study utilised in-depth semi structured interviews to understand how the social determinants of health were modified by critical illness.
- Utilised replicable, rigorous qualitative methods, it suggests a complex interplay between the social determinants of health and recovery from critical illness.
- Although the sample size is considerable for a qualitative study, we recognize that we have utilised a convenience sample, with a small portion of all critical care survivors in these countries.

Introduction

The Social determinants of health (SDoH) are the non-medical factors which influence health outcomes and include both upstream policy, environmental, and context factors and their manifestations in terms of individual material and social hardship(1). There has been a growing realization of their central role in shaping the capacity of individuals to not only access high quality care, but also to benefit from such care(2). In some discussions, particularly around the role of SDoH impacting outcomes from acute illness and hospitalization, such factors are conceptualized as causally antecedent to medical care and illness.

Illness can itself result in material and social hardship, opening the possibility of a bidirectional relationship(3). Financial toxicity resulting from oncologic care has been documented and is also found after surgery and respiratory failure(4, 5). Adverse employment outcomes are common after acute myocardial infarction, stroke, and critical illness(6-8). While changes in individual economic and social situations may be exacerbated by gaps in the U.S. social safety net, many have been documented throughout the industrialized world(9).

Within the critical care context, more detailed evidence is emerging about the potential interaction between SDoH and recovery. For example, a recent multi-centre study from the US revealed that social isolation was a risk factors for poor outcomes (mortality) among older adults surviving critical illness (10). Similarly, in the UK, recent data has shown that almost one third of participants requested a social and welfare consultation during an ICU recovery clinic, in order to alleviate ongoing welfare and social issues (11). However, a full and systematic understanding of the challenges survivors face, alongside how critical illness may worsen SDoH, is lacking.

The objective of this study, therefore, was to identify SDoH that were modified at the individual level by the experience of critical illness, and the effect of such modifications on patients' and families'

recovery. We conducted an international qualitative study of the experience of recovery from critical illness with patients and caregivers from 14 different hospitals across Australia, the US, and the UK.

Methods

Design and Setting

We utilised a qualitative, descriptive design. Sites participating in the Society of Critical Care Medicine's (SCCM) THRIVE programme (12) offered Intensive Care Unit (ICU) recovery programmes in the form of post-ICU clinics and peer support programmes. Patients who had not received any specific intervention were also interviewed (**Table 1**).

The THRIVE programme was a programme of work run via the SCCM for five years. It actively recruited hospitals internationally to work with the Society to support innovation in the field of ICU recovery up until 2019. It ran two collaboratives: peer support and post-ICU clinics. We invited sites to take part in this programme of work from these two collaboratives.

We chose to undertake interviews internationally, in three developed nations, where the social context for support and health needs could be fully understood. The purpose of this, was to understand if different developed healthcare systems supported care in diverse ways.

Patients attending ICU recovery programmes were invited by professionals at each site if they met: i) Inclusion criteria - English-speaking patients older than 18 years admitted to the ICU, or caregiver of a patient who survived critical illness; and not ii) Exclusion criteria - ongoing severe neurological and/or cognitive impairment or continued inpatient care in hospital or rehabilitation. Informed consent was obtained before each interview.

Data collection

Data were collected through in-depth semi-structured scripted interviews via telephone. Separate questions were used for caregivers and patients; these were adapted for those who did not receive a post critical illness intervention (**S1**). Questions were generated from previous literature and through

iterative discussion within the research group (JMM, LB, KJH, CS). All researchers, alongside patient representatives, discussed the interview script to ensure consistency. Some interviewers were known to the participants through their role in direct clinical care. Data were audio-recorded and transcribed verbatim.

Data Analyses

We sought to understand how SDoH were potentially modified at the individual level by the experience of critical illness, and the effect of such modifications on recovery. To do so, we systematically mapped our analysis against a set of pre-defined concepts related to SDoH, adapted from a public policy framework(13), including: money and work; education and skills; housing transportation and neighbourhoods; and family, friends and social connections. In this analysis, we defined a 'rural' setting as a located out with a main town or city.

The Framework Analysis technique was used to analyze data across these concepts(14) , through seven stages: 1) Transcription; 2) Familiarization with the interview; 3) Coding; 4) Developing a working analytical framework; 5) Applying the analytical framework; 6) Charting data into the framework matrix; 7) Interpreting the data(11). This analytical framework is widely used in policy settings and allows structured and systematic analysis of qualitative data. Three researchers (JMM, LB, JM) independently undertook preliminary sweeps of the data. Key quotes to support the findings were then independently extracted by JMM and JM. Member checking with a small number of interview participants was undertaken pre and post analysis to enhance rigour of the reported results. The Consolidated Reporting of Qualitative Research (COREQ) checklist was used for this study(15).

Patient and Public Involvement

Patients and caregivers who had previously been admitted to intensive care helped create the interview schedules utilised for this study. These representatives helped developed question content

and structure. The also supported the planning of the study conduct and reviewed all study documentation.

Permissions

Study design and protocol were approved by the Western Health Low Risk Human Research Ethics Panel (Australia, Ref: HREC/17/WH/170); Vanderbilt University Institutional Review Board (US coordinating site, Ref: 171299); and the Southwest (Cornwall and Plymouth, Ref: 18/SW/0137) Research Ethics Committee (UK).

Results

Across 14 sites, interviews were completed with 66 patients and 20 caregivers from Australia, the US, and the UK (**Table 1**). Interviews took place between July 2018 and February 2019. We analysed the data across four main domains of SDoH: money and work; education and skills; housing transportation and neighbourhoods; and family, friends and social connections. We have presented each SDoH as an individual category, however, how this particular category of SDoH influenced outcomes and indeed other SDoH are also explored. Supporting quotes, illustrating these concepts can be found in **Table 2**.

Demographic	Patients (n=66)	Caregivers (n=20)
Age (years), Median (IQR)	52 (40-62.5)	52 (46-67)
Gender, n male (%)	26 (39.4)	3 (15)
Patient Admission Diagnosis n (%)		
Sepsis	28 (42.4)	
Respiratory Failure	15 (22.8)	
Post GI Surgery	5 (7.6)	
Trauma	2 (3)	
Other	16 (24.2)	
Ventilated, n (%)		
Yes	57 (86.4)	
No	9 (13.6)	
Length of time since ICU discharge, n (%)		
<6 months	15 (22.8)	
7-11 months	9 (13.6)	
1-2 years	12 (18.2)	
2-5 years	22 (33.3)	
>5 years	8 (12.1)	
Relationship to the patient, n (%)		
Spouse/Significant other		10 (50)
Parent		5 (25)
Sibling		3 (15)
Child		2 (10)
Nationality, n (%)		
United States	50 (75.7)	16 (80)
UK	13 (19.7)	2 (10)
Australia	3 (4.6)	2 (10)
Participated in recovery programme, n (%)		
Yes	52 (79)	11 (55)
No	14 (21)	9 (45)

Table One: Participant Demographics

Money and work

Loss of both money and work following critical illness was discussed frequently across the interviews. For example, a patient from Australia described how their new critical illness disability had changed their employment status:

'I come home and now you've lost your job and you can't work and then the realisation that you are on oxygen for the rest of your life.'

Job loss and change had a direct negative impact on income, access to care and subsequent recovery from critical illness. For example, one patient of the loss of not only insurance but also savings during critical illness and the recovery period following forced unemployment:

'For the first surgery I had two insurances.. second surgery, my school, they were nice enough to keep me on there, but then I lost it because I wasn't working…. We had a little savings, but that's all gone, because we have had to use it for medical bills and driving to the hospital an hour and a half.'

There were health-related consequences of the changes. For example, participants described how they could no longer afford the treatments necessary for recovery:

Social Determinant of Health Modification	Illustrative Quote
Family, Friends and Social Connections	'I went back to my daughters and I stayed there for a while. I relaxed and um I did relax…I had my grandchildren around me who I think are one of the best healer's um because just being with them makes me feel erm good…' 'God has helped me through the ministry…for 50 years we were pastors. Knowing and seeing how he has worked with other people in their lives, I think has given me the experiences to know that' hey you don't have to do this by yourself'. 'Our friends all disappeared. …I'm not who I was before. I think that, for most people, they couldn't deal with it. And so our community just sort of vanished. "I would feel better and I wouldn't feel so alone with all of this. Because while my family was supportive, they reached a point where they didn't want to talk about it. They didn't want to relive it."
Money and Work	'Financially…for the first surgery I had two insurances, mine and my husband. Second surgery, my school, they were nice enough to keep me on there, but then I lost it, because I wasn't working. Financially, if its less than a year you've got deductibles. There's no plan that helps people that are working…if we were very, very poor, or very, very rich, but there's nothing that helps you in the middle. There isn't…. We had a little bit of savings, but that's all gone, because we've had to use it medical bills, and driving to the hospital an hour and a half.' 'Whether you know when he came home, whether the house had to be reconfigured for a wheelchair or anything like that- that was another challenge not knowing as well, financial circumstances that's another challenge you know- he's out of work he was a breadwinner and now he's not sort of thing and who do we rely, what do we do, and everything like that- that's a big issue I think with everyone who is sick I suppose. ' 'I would say being able to get back into the field of work and build relationships and actually function….I just felt worthless, because without your money…We associate money with the ability to educate or be educated. There's no secret'. 'I think it's changing the paradigm from thinking that ICU is the endpoint…with medicine the way it is, it isn't the next step to the funeral home necessarily…these people are surviving. They're not perishing…. it's affected every aspect of a person's family life. And often it's affecting their money. And things that are big, that are really going to impact them, and I don't think people realize. I think there just needs to be a better support system in place.
Skills and Education	'I was fully able to read small things in neurological journals. My husbands a physician, so I would take whatever passwords he had to things so I could get to the journals that normally lay pay can't get into them.' 'I think that the other thing that's helped us do well is just some of the personal tools we have. We're not ashamed to ask or accept help, or to ask a question, or to be kind of vulnerable… some of that has to do with our education, like we're both very resourceful…. I can see if you've maybe poorly educated, I can see if you lived in a world where people haven't been trustworthy, so you don't trust people, I can see if we had different life experience, it could just look a lot differently.'
Housing, Transportation and Neighbourhoods	'What I did, when I got back home, the only place I could sleep for a while was the recliner. I could not lay down on our bed.' 'Now our hospital in (geographical area name) its good for a band-aid. If you have anything else wrong with you, you do not want to go there.' 'I wanted to give back….. it would be easy for me not to go, because it's a long distance and its kind of a hassle to get up there.'

Table 2: Modification of the SDoH at the individual level and potential effects of such modifications on recovery from critical illness

'my insurance company is messing with me right now… I'm out of my medicine. I'm out of one of them. I called to see how much it was and I can't afford that. They want $55 for seven days. I can't afford that.'

Participants discussed how these changes to money and work were a direct mechanism for mental health problems. One participant from the US spoke about how changes to her health insurance had increased feelings of anxiety:

'There was an issue with the insurance….the first time said they weren't going to cover any of our hospital bills. You can imagine…'We're going to lose our house, oh my God…' The anxiety of it all. ….'

A participant from the UK discussed changes to her employment situation following critical illness and subsequent emotional disruption:

'I've changed jobs, I was a teacher before, but now I've gone into office work and I'm still trying to adjust. My GP wrote a letter saying I wasn't fit to go back to teaching because of the kind of asthma I've got…At the time I was devastated, I was really, really devastated.'

Caregivers suffered similar loss of money and work, albeit via different mechanisms. One participant (patient) spoke about how their partner had lost their job due to new/increased caregiving responsibilities following hospital discharge:

'I was working when I went in, and so was she and she had to take time off from work, and they had let her go from work, after she wasn't making her units, and it made it rough on us.'

Skills and Education

The increased disability caused by critical illness resulted in an inability to return previous roles and activities. One participant, who had a highly skilled role, described the impact of cognitive disability on function:

'*My brain's just not making the connection…I'm retired but I was a judge and for a long time I wouldn't go back to court…. I can tell my brain is not making the connection.'*

Similarly, a participant who had been in a skilled academic role could no longer return to their previous appointment, because of critical illness-caused cognitive decline:

'My identity was a writer and professor had been built around being smart and so those issues manifested themselves as word finding, executive functioning…I couldn't go back to work though. I was having cognitive difficulties…my request to have support for my particular cognitive deficits has been denied.'

Such loss of skills required survivors to re-evaluate future career and employment prospects. One younger participant spoke of having to change educational pathways:

'*it's changed my career path. I'm only 20…I just turned 21. And so I'm still really young. I'm in college. I changed my major because of it.'*

Housing, Transportation, and Neighbourhoods

New critical illness related disability significantly disrupted housing, transportation and residency in those survivors interviewed. Patients needed to move house due to physical inability:

"It took, again, a lot of coordination and a lot of….Everyone pitched in…but it did provide a lot of stress, just in managing food and managing cleaning, and all the little things that you have to do from day to day. One of the reasons we began looking to move…having such a large house was a big struggle for her. Even going up and down stairs."

A participant from Australia spoke about the challenges to find funding for the housing adaptations which were required following critical illness and the financial and emotional stress this caused:

'when he came home whether the house had to be reconfigured for a wheelchair or anything like that…the financial circumstances that's another challenge… he was a breadwinner and now he's not and who de we rely, what do we do?'

The burden of transportation rose for survivors, who now needed to attend more medical appointments. Yet many critical illness survivors could no longer drive, so this ongoing health burden caused disruption for the entire family unit:

'It wasn't necessarily one doctor's appointment that stood out, but it was the fact that there were so many of them, and I think it was so significant because we had to drive an hour each way to get there.'

These changes influenced recovery for many, especially for those living in rural areas, as accessing appropriate and reliable healthcare became harder:

'I mean around here you're not going to find any medical help that's going to be decent. We're just so far removed from everything….quite a disadvantage of being so far away from everything.'

Changes to how participants could access transport also had a direct impact on recovery. For example, one participant spoke about how their inability to drive led to feelings of isolation:

'I couldn't drive for quite a long time, so I felt fairly dependent, I felt pretty trapped in.'

Family, Friends and Social connections

Critical illness changed survivors' social networks and relationships within families. For example, participants spoke about the negative impact of physical and emotional changes on wider social networks:

'and so our community sort of vanished… I still have these huge scars and I'm not who I was before. I think for most people, they couldn't deal with it.'

Critical illness also led to fractures in family networks. In some cases, families struggled to manage the enormity of the situation, which led to challenges during recovery. For example, one survivor from the UK highlighted the impact which it had on the family unit:

'I was doing something in the kitchen, and I couldn't do it and I ended up smashing stuff all over the kitchen and my brother came in and I started shouting at him, saying you know this is my life?'

These changes had consequences during recovery. Participants described isolation, challenges re-engaging with activities of daily living, and mental health problems related to these changes. A participant from the US described how these changes had impacted their mental health and behaviour:

'No one talked to me about how I might be when I get home, like emotionally…I react to things… I feel bad 'cause its like hell for my family. I have these… I can't control them…just absolute fits of anger and rage… and just crying.'

Discussion

This international, multi-centre study suggests a complex interplay between SDoH and recovery from critical illness. It is already well-established that upstream policy and contextual factors, as well as individual hardship, are associated with worsened onset of critical illness and outcomes; the early months of the COVID-19 epidemic particularly highlighted this(16). These qualitative results demonstrate how critical illness precipitated adverse changes in the recovery environment. These changes and other behavior changes resulted in lost connections with family and social support, loss of the instrumental, social, and psychological benefits of work, and having numerous other practical difficulties. Together these changes impeded successful access to and benefit from even traditional health services. Our findings provide evidence that the relationship between social determinants and recovery plays out across multiple domains of SDoH and recovery, as well as bi-directionally. Further, they demonstrate that the "social determinants of recovery" are not fixed nor the same as patients' pre-illness statuses, suggesting a need to assess these mechanisms, and their impact, across time.

These findings can be situated in a broader body of work that suggests their generalizability. Inadequacies of the U.S. health and social safety net are well-described, but it is notable that the data for this study also included examples from Australia and the United Kingdom. Loss of employment and/or financial hardship after AMI, acute respiratory distress syndrome, or traumatic injury are not uncommon(6, 17, 18). Studies have likewise found many suffer from significant financial costs and related material hardship due to chronic and ongoing illness, such as cancer(19) and heart disease(20).

Some, but not all, of the difficulties here seem to be a failure of the insurance functions of existing organizational arrangements to buffer patients and their families against purely financial shocks of critical illness. This interpretation is reinforced by findings that specifically financial stress is central after acute respiratory failure(5), as well as work on surprise billing(21) and risk for high bills after surgery(22), or decades-old findings about patients self-management of diabetes in the presence of

cost concerns(23). Additionally, substantial evidence supports our findings that critical illness leads to other financial hardship through job loss, unpaid family caregiving, and new nonmedical expenses due to new disability(4, 7, 24). Moreover, recent data from the UK suggest that patients who have ongoing disability due to critical illness, are more likely to require government funded welfare support in the years following discharge, in comparison to contemporary hospital controls(25); concerns are emerging about COVID-19 patients(26, 27).

Efforts to address these resulting financial hardships through direct payments to patients and caregivers have shown promise; the Medicaid Cash and Counseling program found improved patient and caregiver wellbeing alongside improved health outcomes(28, 29). Similarly, the US Department of Veteran Affairs' Program of Comprehensive Assistance to Family Caregivers suggests financial support provides crucial assistance in varied ways, depending on specific needs(30). In the UK, efforts to include social welfare consultation as part of critical illness recovery programs have also shown promise(11). These issues may become more prominent as moves to telehealth and remote monitoring require patients to bring more of their own technology to fully access services, potentially exacerbating inequities(31, 32).

Other challenges do not appear to be purely financial and would not be remediated by even theoretically complete insurance against total healthcare costs. Particularly prominent are the impacts of critical illness on social isolation. Social isolation is not benign; the influence of social relationships and social isolation on mortality is comparable to smoking, obesity and alcohol(33). initiatives across the UK and the US have successfully introduced innovation to support social isolation. For example, in Chicago, one health system added a social connection question to a pre-existing health screening tool, alongside care pathways such a friendly caller initiative to promote community socialisation during the COVID-19 pandemic(34). Peer support programmes which link individuals who have had similar healthcare experiences may also be advantageous, with evidence suggesting

peer support could be a mechanism for reducing social isolation and improving global mental health(35).

These data in the context of emerging literature have implications for clinicians and health systems seeking to promote full recovery of critically ill and other patients by addressing SDoH(36, 37). First, the data suggest that assessments of risk might include not just current hardship, but the extent to which the patients' reserves (broadly construed) are sufficient to prevent future hardship. It is unclear to what extent currently suggested patient-level risk assessments of SDoH(38, 39) are capable of predicting changes of the type these patients described. Second, given the myriad ways in which SDoH impacted each other following critical illness, understanding the impact of post-illness interventions (or lack thereof) must also be scrutinized across multiple domains, understanding that positive and negative consequences may be different for each patient. Certainly, targeted interventions to assure access to follow-up care, such as transportation support (e.g., Uber or Lyft vouchers) or telehealth support (e.g., device provision and training) can address some impacts. However, the multi-faceted and interactive results of our study also suggest that broader programs of direct assistance after critical illness, which address financial and non-financial resources, should be explored and potentially advocated for.

Limitations

Strengths of this study include its international, multicenter approach to understanding the interplay between SDoH and recovery from critical illness. However, although the sample size is considerable for a qualitative study, we recognize that we have utilised a convenience sample, with a small portion of all critical care survivors in these countries. The sample size was not uniform across the three countries involved, which may have also influenced the reported results. We also do not have detailed in-hospital information for each patient.

We acknowledge that the primary aim of these interviews was not to delineate the socio-economic problems which participants faced during recovery from critical illness. As such, important concepts may have been missed in this analysis. For example, we did not find cross-country differences; this is an important construct which could have been missed. Finally, we have used a broad definition of the term 'rural' in this analysis to ensure that it is applicable internationally. However, there are international variances in rural and urban interfaces, as such we may be under or over reporting this as an issue.

Conclusion

In conclusion, this international, multi-center study has explored how critical illness changes social circumstances, impacting recovery and health. Our findings suggest that increased attention to issues such as one's social network, economic security, education and skills, access to healthcare, and living environment are required following critical care discharge. Targeting interventions toward these domains, including specific emphasis on social support and education, could potentially improve outcomes.

Ethics and consent to participate:
The study design and protocol were approved by the Western Health Low Risk Human Research Ethics Panel (Australia, Ref: HREC/17/WH/170); the Vanderbilt University Institutional Review Board (US coordinating site, Ref: 171299); and the Southwest (Cornwall and Plymouth, Ref: 18/SW/0137) Research Ethics Committee (UK). All participants provided informed consent.

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N/A
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Conception and design: JM, CS, KH, TJI, MM
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Analysis and interpretation: LB, JM, TJI
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Figure and Table Legends:

Table One: Participant Demographics
Table 2: Modification of SDoH at the individual level and potential effects of such modifications on recovery from critical illness.

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Supplemental File 1: Patient Interview Schedule

1. Can you tell me about the how you have been getting on since you left hospital?
2. Thinking back to what you recall of your time in ICU, and then walking through your recovery from hospital to home to now – what were the most important moments for you? What stands out the most to you?
3. Thinking about this time from ICU to home, what were some of the challenges you encountered along the way?
4. How did you try and solve some of these challenges?
5. Can you describe any successful parts of your recovery?
6. Thinking about your involvement in the ICU recovery programme, how did you feel when you received the invitation to take part?
7. What motivated you to participate? Why do you think you were able to participate at the time you did?
8. How did you feel when you first went to the program? Did that experience change over time?
9. How has the programme influenced your recovery?
10. Has anyone commented on changes which they have seen in you, if so what have they said?
11. What do you think are the most important parts of a support programme?
12. How could we better support patients and their families following discharge from ICU?
13. If another patient was thinking about participating in such a programme, what would you say to them?
14. Is there anything else you would like to add or ask?

Informal Caregiver Interview Schedule

1. Can you tell me about how you have been getting on since your loved one left hospital?

2. Thinking back to what you remember about being in the ICU, and then the recovery period through to now – what were the most important moments for you? What stands out the most to you?

3. Thinking about this time, what were some of the challenges you encountered along the way?

4. How did you try and solve some of these challenges?

5. What were some of your greatest successes as your provided support to your loved one?

6. Thinking about your involvement in the program (quote relevant program), how did you feel when you received the invitation to join this program?

7. What motivated you to participate? What made it possible for you to participate when you did?

8. How did you feel when you first went to the program? How did that experience change over time?

9. How has the program influenced your experience as a caregiver following ICU?

10. What do you think are the most important parts of a support program from ICU discharge to post-hospital?

11. How could we better support patients and their caregivers following discharge from ICU? 12. Can you describe what you think would help people cope better with recovery after being in ICU?

13. Is there anything else you would like to add or ask?

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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Modification of Social Determinants of Health by Critical Illness, and Consequences of that Modification for Recovery: An International Qualitative Study

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Title: Modification of Social Determinants of Health by Critical Illness, and Consequences of that Modification for Recovery: An International Qualitative Study

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On behalf of the Society of Critical Care Medicine's THRIVE Initiative

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Abstract

Objectives: Social determinants of health (SDoH) contribute to health outcomes. We identified SDoH that were modified by critical illness, and the effect of such modifications on recovery from critical illness.

Design: In-depth semi structured interviews following hospital discharge. Interview transcripts were mapped against a pre-existing social policy framework: money and work; skills and education; housing, transport and neighbourhoods and family, friends and social connections.

Setting: 14 hospital sites in the US, UK and Australia.

Participants: Patients and caregivers, who had been admitted to critical care from three continents.

Results: 86 interviews were analysed (66 patient and 20 caregiver). SDoH, both financial and non-financial in nature, could be negatively influenced by exposure to critical illness, with a direct impact on health-related outcomes at an individual level. Financial modifications included changes to employment status due to critical illness related disability, alongside changes to income and insurance status. Negative health impacts included the inability to access essential healthcare and an increase in mental health problems.

Conclusions Critical illness appears to modify SDoH for survivors and their family members, potentially impacting recovery and health. Our findings suggest that increased attention to issues such as one's social network, economic security, and access to healthcare are required following discharge from critical care.

Keywords: socio-economic; post intensive care syndrome; qualitative and rehabilitation.

Article Summary

Strengths and Limitations of the study

- This international multi-centre study utilised in-depth semi structured interviews to understand how the social determinants of health were modified by critical illness.
- Utilised replicable, rigorous qualitative methods, it suggests a complex interplay between the social determinants of health and recovery from critical illness.
- Although the sample size is considerable for a qualitative study, we recognize that we have utilised a convenience sample, with a small portion of all critical care survivors in these countries.

Introduction

The Social determinants of health (SDoH) are the non-medical factors which influence health outcomes and include both upstream policy, environmental, and context factors and their manifestations in terms of individual material and social hardship(1). There has been a growing realization of their central role in shaping the capacity of individuals to not only access high quality care, but also to benefit from such care(2). In some discussions, particularly around the role of SDoH impacting outcomes from acute illness and hospitalization, such factors are conceptualized as causally antecedent to medical care and illness.

Illness can itself result in material and social hardship, opening the possibility of a bidirectional relationship(3). Financial toxicity resulting from oncologic care has been documented and is also found after surgery and respiratory failure(4, 5). Adverse employment outcomes are common after acute myocardial infarction, stroke, and critical illness(6-8). While changes in individual economic and social situations may be exacerbated by gaps in the U.S. social safety net, many have been documented throughout the industrialized world(9).

Within the critical care context, more detailed evidence is emerging about the potential interaction between SDoH and recovery. For example, a recent multi-centre study from the US revealed that social isolation was a risk factors for poor outcomes (mortality) among older adults surviving critical illness (10). Similarly, in the UK, recent data has shown that almost one third of participants requested a social and welfare consultation during an ICU recovery clinic, in order to alleviate ongoing welfare and social issues (11). However, a full and systematic understanding of the challenges survivors face, alongside how critical illness may worsen SDoH, is lacking.

The objective of this study, therefore, was to identify SDoH that were modified at the individual level by the experience of critical illness, and the effect of such modifications on patients' and families'

recovery. We conducted an international qualitative study of the experience of recovery from critical illness with patients and caregivers from 14 different hospitals across Australia, the US, and the UK. We deliberately recruited patients from three different countries to ensure that any international differences in social contexts and recovery could be delineated. The social context in each country and indeed the healthcare systems are different. The US, for example, has an insurance-based healthcare system, whereas the UK has a National Healthcare system and Australia a mixture of both. By including these diverse approaches to healthcare delivery, we could understand the international context better.

Methods

Design and Setting

We utilised a qualitative, descriptive design. Sites participating in the Society of Critical Care Medicine's (SCCM) THRIVE programme (12) offered Intensive Care Unit (ICU) recovery programmes in the form of post-ICU clinics and peer support programmes. Patients who had not received any specific intervention were also interviewed (**Table 1**).

The THRIVE programme was a programme of work run via the SCCM for five years (2015-2019). It actively recruited hospitals internationally to work with the Society to support innovation in the field of ICU recovery up until 2019. It ran two collaboratives: peer support and post-ICU clinics. We invited sites to take part in this programme of work from these two collaboratives. All sites in the initial recruitment waves (2015, 2016) were from Australia, US and the UK, with the majority of sites from the US.

We chose to undertake interviews internationally, in three developed nations, where the social context for support and health needs could be fully understood. The purpose of this, was to understand if different developed healthcare systems supported care in diverse ways. The sample size was decided upon through analysing previous research in the field and through iterative discussions with the research team. This approach was taken across the entire sample and not a site level. The numbers of patients included in the final sample was based on the number of THRIVE sites in each country. Not all THRIVE sites were able to be involved in the research process due to staffing limitations and access to research support at these institutions.

All Patients attending ICU recovery programmes were invited by professionals at each site if they met: i) Inclusion criteria - English-speaking patients older than 18 years admitted to the ICU, or caregiver of a patient who survived critical illness; and not ii) Exclusion criteria - ongoing severe neurological

and/or cognitive impairment or continued inpatient care in hospital or rehabilitation. Informed consent was obtained before each interview.

Data collection

Data were collected through in-depth semi-structured scripted interviews via telephone. Separate questions were used for caregivers and patients; these were adapted for those who did not receive a post critical illness intervention (**S1**). Questions were generated from previous literature and through iterative discussion within the research group (JMcP, LB, KJH, CMS). All researchers, alongside patient representatives, discussed the interview script to ensure consistency. Some interviewers were known to the participants through their role in direct clinical care. Data were audio-recorded and transcribed verbatim.

Data Analyses

We sought to understand how SDoH were potentially modified at the individual level by the experience of critical illness, and the effect of such modifications on recovery. To do so, we systematically mapped our analysis against a set of pre-defined concepts related to SDoH, adapted from a public policy framework(13), including: money and work; education and skills; housing transportation and neighbourhoods; and family, friends and social connections. In this analysis, we defined a 'rural' setting as a located out with a main town or city.

The Framework Analysis technique was used to analyze data across these concepts(14) , through seven stages: 1) Transcription; 2) Familiarization with the interview; 3) Coding; 4) Developing a working analytical framework; 5) Applying the analytical framework; 6) Charting data into the framework matrix; 7) Interpreting the data(11). This analytical framework is widely used in critical care research and allows structured and systematic analysis of qualitative data(15, 16). Three researchers (JMcP, LB, JMcC) independently undertook preliminary sweeps of the data. Key quotes to support the

findings were then independently extracted by JMcP and JMcC. Member checking with a small number of interview participants was undertaken pre and post analysis to enhance rigour of the reported results. Member checking, also known as participant or respondent validation, is a technique for exploring the credibility of results. Data or results are returned to participants to check for accuracy and resonance with their experiences(17). Participants who had agreed to ongoing contact with the research team were involved in the member checking process. The Consolidated Reporting of Qualitative Research (COREQ) checklist was used for this study(18).

Patient and Public Involvement

Patients and caregivers who had previously been admitted to intensive care helped create the interview schedules utilised for this study. These representatives helped developed question content and structure via iterative discussion with the research team. These individuals had been part of ICU follow-up services previously; they were known to staff involved in the research and had given permission to be contacted about involvement such as this. They also supported the planning of the study conduct and reviewed all study documentation.

Permissions

Study design and protocol were approved by the Western Health Low Risk Human Research Ethics Panel (Australia, Ref: HREC/17/WH/170); Vanderbilt University Institutional Review Board (US coordinating site, Ref: 171299); and the Southwest (Cornwall and Plymouth, Ref: 18/SW/0137) Research Ethics Committee (UK). Written consent was obtained from participants.

Results

Across 14 sites, interviews were completed with 66 patients and 20 caregivers from Australia, the US, and the UK (**Table 1**). Interviews took place between July 2018 and February 2019. We analysed the data across four main domains of SDoH: money and work; education and skills; housing transportation and neighbourhoods; and family, friends and social connections. We have presented each SDoH as an individual category, however, how this particular category of SDoH influenced outcomes and indeed other SDoH are also explored. Supporting quotes, illustrating these concepts can be found in **Table 2**.

Demographic	Patients (n=66)	Caregivers (n=20)
Age (years), Median (IQR)	52 (40-62.5)	52 (46-67)
Gender, n male (%)	26 (39.4)	3 (15)
Patient Admission Diagnosis n (%)		
Sepsis	28 (42.4)	
Respiratory Failure	15 (22.8)	
Post GI Surgery	5 (7.6)	
Trauma	2 (3)	
Other	16 (24.2)	
Ventilated, n (%)		
Yes	57 (86.4)	
No	9 (13.6)	
Length of time since ICU discharge, n (%)		
<6 months	15 (22.8)	
7-11 months	9 (13.6)	
1-2 years	12 (18.2)	
2-5 years	22 (33.3)	
>5 years	8 (12.1)	
Relationship to the patient, n (%)		
Spouse/Significant other		10 (50)
Parent		5 (25)
Sibling		3 (15)
Child		2 (10)
Nationality, n (%)		
United States	50 (75.7)	16 (80)
UK	13 (19.7)	2 (10)
Australia	3 (4.6)	2 (10)
Participated in recovery programme, n (%)		
Yes	52 (79)	11 (55)
No	14 (21)	9 (45)

Table One: Participant Demographics

Money and work

Loss of both money and work following critical illness was discussed frequently across the interviews. For example, a patient from Australia described how their new critical illness disability had changed their employment status:

'I come home and now you've lost your job and you can't work and then the realisation that you are on oxygen for the rest of your life.'

Job loss and change had a direct negative impact on income, access to care and subsequent recovery from critical illness. For example, one patient of the loss of not only insurance but also savings during critical illness and the recovery period following forced unemployment:

'For the first surgery I had two insurances.. second surgery, my school, they were nice enough to keep me on there, but then I lost it because I wasn't working…. We had a little savings, but that's all gone, because we have had to use it for medical bills and driving to the hospital an hour and a half.'

There were health-related consequences of the changes. For example, participants described how they could no longer afford the treatments necessary for recovery:

Social Determinant of Health Modification	Illustrative Quote
Family, Friends and Social Connections	'I went back to my daughters and I stayed there for a while. I relaxed and um I did relax…I had my grandchildren around me who I think are one of the best healer's um because just being with them makes me feel erm good…' 'God has helped me through the ministry…for 50 years we were pastors. Knowing and seeing how he has worked with other people in their lives, I think has given me the experiences to know that' hey you don't have to do this by yourself'. 'Our friends all disappeared. …I'm not who I was before. I think that, for most people, they couldn't deal with it. And so our community just sort of vanished. "I would feel better and I wouldn't feel so alone with all of this. Because while my family was supportive, they reached a point where they didn't want to talk about it. They didn't want to relive it."
Money and Work	'Financially…for the first surgery I had two insurances, mine and my husband. Second surgery, my school, they were nice enough to keep me on there, but then I lost it, because I wasn't working. Financially, if its less than a year you've got deductibles. There's no plan that helps people that are working…if we were very, very poor, or very, very rich, but there's nothing that helps you in the middle. There isn't…. We had a little bit of savings, but that's all gone, because we've had to use it medical bills, and driving to the hospital an hour and a half.' 'Whether you know when he came home, whether the house had to be reconfigured for a wheelchair or anything like that- that was another challenge not knowing as well, financial circumstances that's another challenge you know- he's out of work he was a breadwinner and now he's not sort of thing and who do we rely, what do we do, and everything like that- that's a big issue I think with everyone who is sick I suppose. ' 'I would say being able to get back into the field of work and build relationships and actually function….I just felt worthless, because without your money…We associate money with the ability to educate or be educated. There's no secret'. 'I think it's changing the paradigm from thinking that ICU is the endpoint…with medicine the way it is, it isn't the next step to the funeral home necessarily…these people are surviving. They're not perishing…. it's affected every aspect of a person's family life. And often it's affecting their money. And things that are big, that are really going to impact them, and I don't think people realize. I think there just needs to be a better support system in place.
Skills and Education	'I was fully able to read small things in neurological journals. My husbands a physician, so I would take whatever passwords he had to things so I could get to the journals that normally lay pay can't get into them.' 'I think that the other thing that's helped us do well is just some of the personal tools we have. We're not ashamed to ask or accept help, or to ask a question, or to be kind of vulnerable… some of that has to do with our education, like we're both very resourceful…. I can see if you've maybe poorly educated, I can see if you lived in a world where people haven't been trustworthy, so you don't trust people, I can see if we had different life experience, it could just look a lot differently.'
Housing, Transportation and Neighbourhoods	'What I did, when I got back home, the only place I could sleep for a while was the recliner. I could not lay down on our bed.' 'Now our hospital in (geographical area name) its good for a band-aid. If you have anything else wrong with you, you do not want to go there.' 'I wanted to give back….. it would be easy for me not to go, because it's a long distance and its kind of a hassle to get up there.'

Table 2: Modification of the SDoH at the individual level and potential effects of such modifications on recovery from critical illness

'my insurance company is messing with me right now… I'm out of my medicine. I'm out of one of them. I called to see how much it was and I can't afford that. They want $55 for seven days. I can't afford that.'

Participants discussed how these changes to money and work were a direct mechanism for mental health problems. One participant from the US spoke about how changes to her health insurance had increased feelings of anxiety:

'There was an issue with the insurance….the first time said they weren't going to cover any of our hospital bills. You can imagine…'We're going to lose our house, oh my God…' The anxiety of it all. ….'

A participant from the UK discussed changes to her employment situation following critical illness and subsequent emotional disruption:

'I've changed jobs, I was a teacher before, but now I've gone into office work and I'm still trying to adjust. My GP wrote a letter saying I wasn't fit to go back to teaching because of the kind of asthma I've got…At the time I was devastated, I was really, really devastated.'

Caregivers suffered similar loss of money and work, albeit via different mechanisms. One participant (patient) spoke about how their partner had lost their job due to new/increased caregiving responsibilities following hospital discharge:

'I was working when I went in, and so was she and she had to take time off from work, and they had let her go from work, after she wasn't making her units, and it made it rough on us.'

Skills and Education

The increased disability caused by critical illness resulted in an inability to return previous roles and activities. One participant, who had a highly skilled role, described the impact of cognitive disability on function:

'*My brain's just not making the connection…I'm retired but I was a judge and for a long time I wouldn't go back to court…. I can tell my brain is not making the connection.'*

Similarly, a participant who had been in a skilled academic role could no longer return to their previous appointment, because of critical illness-caused cognitive decline:

'My identity was a writer and professor had been built around being smart and so those issues manifested themselves as word finding, executive functioning…I couldn't go back to work though. I was having cognitive difficulties…my request to have support for my particular cognitive deficits has been denied.'

Such loss of skills required survivors to re-evaluate future career and employment prospects. One younger participant spoke of having to change educational pathways:

'*it's changed my career path. I'm only 20…I just turned 21. And so I'm still really young. I'm in college. I changed my major because of it.'*

Housing, Transportation, and Neighbourhoods

New critical illness related disability significantly disrupted housing, transportation and residency in those survivors interviewed. Patients needed to move house due to physical inability:

"It took, again, a lot of coordination and a lot of….Everyone pitched in…but it did provide a lot of stress, just in managing food and managing cleaning, and all the little things that you have to do from day to day. One of the reasons we began looking to move…having such a large house was a big struggle for her. Even going up and down stairs."

A participant from Australia spoke about the challenges to find funding for the housing adaptations which were required following critical illness and the financial and emotional stress this caused:

'when he came home whether the house had to be reconfigured for a wheelchair or anything like that…the financial circumstances that's another challenge… he was a breadwinner and now he's not and who de we rely, what do we do?'

The burden of transportation rose for survivors, who now needed to attend more medical appointments. Yet many critical illness survivors could no longer drive, so this ongoing health burden caused disruption for the entire family unit:

'It wasn't necessarily one doctor's appointment that stood out, but it was the fact that there were so many of them, and I think it was so significant because we had to drive an hour each way to get there.'

These changes influenced recovery for many, especially for those living in rural areas, as accessing appropriate and reliable healthcare became harder:

'I mean around here you're not going to find any medical help that's going to be decent. We're just so far removed from everything….quite a disadvantage of being so far away from everything.'

Changes to how participants could access transport also had a direct impact on recovery. For example, one participant spoke about how their inability to drive led to feelings of isolation:

'I couldn't drive for quite a long time, so I felt fairly dependent, I felt pretty trapped in.'

Family, Friends and Social connections

Critical illness changed survivors' social networks and relationships within families. For example, participants spoke about the negative impact of physical and emotional changes on wider social networks:

'and so our community sort of vanished… I still have these huge scars and I'm not who I was before. I think for most people, they couldn't deal with it.'

Critical illness also led to fractures in family networks. In some cases, families struggled to manage the enormity of the situation, which led to challenges during recovery. For example, one survivor from the UK highlighted the impact which it had on the family unit:

'I was doing something in the kitchen, and I couldn't do it and I ended up smashing stuff all over the kitchen and my brother came in and I started shouting at him, saying you know this is my life?'

These changes had consequences during recovery. Participants described isolation, challenges re-engaging with activities of daily living, and mental health problems related to these changes. A participant from the US described how these changes had impacted their mental health and behaviour:

'No one talked to me about how I might be when I get home, like emotionally…I react to things… I feel bad 'cause its like hell for my family. I have these… I can't control them…just absolute fits of anger and rage… and just crying.'

Discussion

This international, multi-centre study suggests a complex interplay between SDoH and recovery from critical illness. It is already well-established that upstream policy and contextual factors, as well as individual hardship, are associated with worsened onset of critical illness and outcomes; the early months of the COVID-19 epidemic particularly highlighted this(19). These qualitative results demonstrate how critical illness precipitated adverse changes in the recovery environment. These changes and other behavior changes resulted in lost connections with family and social support, loss of the instrumental, social, and psychological benefits of work, and having numerous other practical difficulties. Together these changes impeded successful access to and benefit from even traditional health services. Our findings provide evidence that the relationship between social determinants and recovery plays out across multiple domains of SDoH and recovery, as well as bi-directionally. Further, they demonstrate that the "social determinants of recovery" are not fixed nor the same as patients' pre-illness statuses, suggesting a need to assess these mechanisms, and their impact, across time.

These findings can be situated in a broader body of work that suggests their generalizability. Inadequacies of the U.S. health and social safety net are well-described, but it is notable that the data for this study also included examples from Australia and the United Kingdom. Loss of employment and/or financial hardship after AMI, acute respiratory distress syndrome, or traumatic injury are not uncommon(6, 20, 21). Studies have likewise found many suffer from significant financial costs and related material hardship due to chronic and ongoing illness, such as cancer(22) and heart disease(23).

Some, but not all, of the difficulties here seem to be a failure of the insurance functions of existing organizational arrangements to buffer patients and their families against purely financial shocks of critical illness. This interpretation is reinforced by findings that specifically financial stress is central after acute respiratory failure(5), as well as work on surprise billing(24) and risk for high bills after surgery(25), or decades-old findings about patients self-management of diabetes in the presence of

cost concerns(26). Additionally, substantial evidence supports our findings that critical illness leads to other financial hardship through job loss, unpaid family caregiving, and new nonmedical expenses due to new disability(4, 7, 27). Moreover, recent data from the UK suggest that patients who have ongoing disability due to critical illness, are more likely to require government funded welfare support in the years following discharge, in comparison to contemporary hospital controls(28); concerns are emerging about COVID-19 patients(29, 30).

Efforts to address these resulting financial hardships through direct payments to patients and caregivers have shown promise; the Medicaid Cash and Counseling program found improved patient and caregiver wellbeing alongside improved health outcomes(31, 32). Similarly, the US Department of Veteran Affairs' Program of Comprehensive Assistance to Family Caregivers suggests financial support provides crucial assistance in varied ways, depending on specific needs(33). In the UK, efforts to include social welfare consultation as part of critical illness recovery programs have also shown promise(11). These issues may become more prominent as moves to telehealth and remote monitoring require patients to bring more of their own technology to fully access services, potentially exacerbating inequities(34, 35).

Other challenges do not appear to be purely financial and would not be remediated by even theoretically complete insurance against total healthcare costs. Particularly prominent are the impacts of critical illness on social isolation. Social isolation is not benign; the influence of social relationships and social isolation on mortality is comparable to smoking, obesity and alcohol(36). initiatives across the UK and the US have successfully introduced innovation to support social isolation. For example, in Chicago, one health system added a social connection question to a pre-existing health screening tool, alongside care pathways such a friendly caller initiative to promote community socialisation during the COVID-19 pandemic(37). Peer support programmes which link individuals who have had similar healthcare experiences may also be advantageous, with evidence suggesting

peer support could be a mechanism for reducing social isolation and improving global mental health(16).

These data in the context of emerging literature have implications for clinicians and health systems seeking to promote full recovery of critically ill and other patients by addressing SDoH(38, 39). First, the data suggest that assessments of risk might include not just current hardship, but the extent to which the patients' reserves (broadly construed) are sufficient to prevent future hardship. It is unclear to what extent currently suggested patient-level risk assessments of SDoH(40, 41) are capable of predicting changes of the type these patients described. Second, given the myriad ways in which SDoH impacted each other following critical illness, understanding the impact of post-illness interventions (or lack thereof) must also be scrutinized across multiple domains, understanding that positive and negative consequences may be different for each patient. Certainly, targeted interventions to assure access to follow-up care, such as transportation support (e.g., Uber or Lyft vouchers) or telehealth support (e.g., device provision and training) can address some impacts. However, the multi-faceted and interactive results of our study also suggest that broader programs of direct assistance after critical illness, which address financial and non-financial resources, should be explored and potentially advocated for.

Limitations

Strengths of this study include its international, multicenter approach to understanding the interplay between SDoH and recovery from critical illness. However, although the sample size is considerable for a qualitative study, we recognize that we have utilised a convenience sample, with a small portion of all critical care survivors in these countries. The sample size was not uniform across the three countries involved, which may have also influenced the reported results. We also do not have detailed in-hospital information for each patient.

We acknowledge that the primary aim of these interviews was not to delineate the socio-economic problems which participants faced during recovery from critical illness. As such, important concepts may have been missed in this analysis. For example, we did not find cross-country differences; this is an important construct which could have been missed. Finally, we have used a broad definition of the term 'rural' in this analysis to ensure that it is applicable internationally. However, there are international variances in rural and urban interfaces, as such we may be under or over reporting this as an issue.

Conclusion

In conclusion, this international, multi-center study has explored how critical illness changes social circumstances, impacting recovery and health. Our findings suggest that increased attention to issues such as one's social network, economic security, education and skills, access to healthcare, and living environment are required following critical care discharge. Targeting interventions toward these domains, including specific emphasis on social support and education, could potentially improve outcomes.

Ethics and consent to participate:
The study design and protocol were approved by the Western Health Low Risk Human Research Ethics Panel (Australia, Ref: HREC/17/WH/170); the Vanderbilt University Institutional Review Board (US coordinating site, Ref: 171299); and the Southwest (Cornwall and Plymouth, Ref: 18/SW/0137) Research Ethics Committee (UK). All participants provided informed consent.

Consent for publication:
N/A
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The dataset used is available on reasonable request from the corresponding author.
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Author Contribution:
Conception and design: JMcP, CMS, KJH, TJI, MEM
Data Extraction and Primary Analysis: JMcP, KH, CMS, TJI and LB
Analysis and interpretation: LB, JMcP, TJI
Reporting, drafting and revising the manuscript for important intellectual content: JMcP, CMS, KJH, TJI, MEM, LB, EH, KH, RB, AB, BB, TE, WH, AH, JJ, AJ, JK, KK, JMcC, JM, AMY, TQ, AS, DW, MS, GN, ROH,
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Figure and Table Legends:

Table One: Participant Demographics
Table 2: Modification of SDoH at the individual level and potential effects of such modifications on recovery from critical illness.

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Supplemental File 1: Patient Interview Schedule

1. Can you tell me about the how you have been getting on since you left hospital?
2. Thinking back to what you recall of your time in ICU, and then walking through your recovery from hospital to home to now – what were the most important moments for you? What stands out the most to you?
3. Thinking about this time from ICU to home, what were some of the challenges you encountered along the way?
4. How did you try and solve some of these challenges?
5. Can you describe any successful parts of your recovery
6. Thinking about your involvement in the ICU recovery programme, how did you feel when you received the invitation to take part?
7. What motivated you to participate? Why do you think you were able to participate at the time you did?
8. How did you feel when you first went to the program? Did that experience change over time?
9. How has the programme influenced your recovery?
10. Has anyone commented on changes which they have seen in you, if so what have they said?
11. What do you think are the most important parts of a support programme?
12. How could we better support patients and their families following discharge from ICU?
13. If another patient was thinking about participating in such a programme, what would you say to them?
14. Is there anything else you would like to add or ask?

Informal Caregiver Interview Schedule

1. Can you tell me about how you have been getting on since your loved one left hospital?

2. Thinking back to what you remember about being in the ICU, and then the recovery period through to now – what were the most important moments for you? What stands out the most to you?

3. Thinking about this time, what were some of the challenges you encountered along the way?

4. How did you try and solve some of these challenges?

5. What were some of your greatest successes as your provided support to your loved one?

6. Thinking about your involvement in the program (quote relevant program), how did you feel when you received the invitation to join this program?

7. What motivated you to participate? What made it possible for you to participate when you did?

8. How did you feel when you first went to the program? How did that experience change over time?

9. How has the program influenced your experience as a caregiver following ICU?

10. What do you think are the most important parts of a support program from ICU discharge to post-hospital?

11. How could we better support patients and their caregivers following discharge from ICU? 12. Can you describe what you think would help people cope better with recovery after being in ICU?

13. Is there anything else you would like to add or ask?

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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