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Patients' Outcomes After Acute Respiratory Failure: A Qualitative Study With the PROMIS Framework

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Abstract

Background—As mortality rates for patients treated in intensive care units decrease, greater understanding of the impact of critical illness on patients' well-being is needed.

Objective—To describe the survivorship experience of patients who had acute respiratory failure by using the Patient Reported Outcomes Measurement Information System (PROMIS) framework.

Methods—A total of 48 adult patients who had acute respiratory failure completed at least 1 semistructured telephone-based interview between 5 and 18 months after their stay in the intensive care unit. Participants were asked about overall well-being and important health outcomes.

Results—Major themes were identified within each of the 3 PROMIS components: physical health, mental health, and social health. The following themes were particularly prominent: mobility impairments, pulmonary symptoms, fatigue, anxiety and depression symptoms, and decreased ability to work and participate in valued activities. Impacts on overall well-being and on relationships with friends and family members varied among the survivors. Some survivors reported gratitude, increased appreciation of life, and closer relationships to loved ones. Other survivors reported boredom, social isolation, and wishing they had not survived.

Conclusions—Survivors of acute respiratory failure reported substantial issues with their physical, mental, and social health. Holistic assessments of outcomes of survivors of critical illness should capture the complex beneficial and adverse impacts of critical illness on survivors' well-being and social health. (*American Journal of Critical Care*. 2017;26:456-465)

Mortality rates for patients treated in intensive care units (ICUs) have decreased, creating an increase in ICU survivors.¹ Many of these survivors experience new and sometimes long-lasting physical,^{2,3} cognitive,⁴ and mental health⁵⁻⁸ problems. Recognition of these long-term outcomes of critical illness led professional and scientific organizations, including the Society of Critical Medicine; American Thoracic Society; National Heart, Lung, and Blood Institute; and the Multisociety Strategic Planning Task Force for Critical Care Research, to recommend prioritizing research on the outcomes of ICU survivors after hospital discharge.⁹⁻¹⁵ However, lack of standardization in the outcomes assessed among ICU survivors has made interpreting results of this research a challenge.¹⁶

Consensus on a “core outcome set” of agreed-upon, standardized outcome measures for studies of ICU survivors would facilitate comparison across studies.¹⁷ As of June 2016, a total of 6 projects to develop core outcome sets related to critical care had been registered (www.comet-initiative.org).

The first step in developing a core outcome set is to identify outcomes that are important to patients.¹⁸ The Patient Reported Outcome Measurement Information System (PROMIS) was developed by the National Institutes of Health and includes a framework for thinking about the physical, mental, and social components of health (www.nihpromis.org).¹⁹ Although the system is still in development, the validity of PROMIS instruments has been assessed for many patient groups, including patients with heart disease,²⁰ rheumatoid arthritis,^{21,22} and chronic obstructive pulmonary disease.²³ However, PROMIS instruments are designed for patients living with chronic diseases²⁴ and may not address outcomes specific to survivors of critical illness, who often have a rapid onset of new or worsening impairments in functioning and an unexpected recovery or unpredictable return to previous functioning. Therefore, we interviewed survivors of acute respiratory distress syndrome (ARDS) and acute respiratory failure (ARF) who were enrolled in national, multicenter studies to understand how the patients' experiences of survivorship relate to the PROMIS framework.

Methods

Participants

A convenience sample of patients being followed up longitudinally as part of the ARDS Network Long-term Outcomes Study (ALTOS) and the Recovery of Muscle After ARF (ROMA) study were eligible to participate in qualitative interviews. In the ALTOS study, patients were recruited from 35 hospitals that participated in the Statins for Acutely Injured Lungs From Sepsis (SAILS) trial of the ARDS Network.²⁵⁻²⁷ In the ROMA study, an observational study that involved assessment for ICU-acquired neuromuscular dysfunction, ARF patients were recruited from 6 hospitals.

Participating survivors described mental health symptoms, changes in cognitive functioning, and psychosocial impacts of mental health.

We invited 59 survivors to participate in a 30-minute, 1-on-1, semistructured telephone interview. We completed 48 interviews between 5 and 18 months after the start of mechanical ventilation (median, 9 months; interquartile ratio, 7-13 months). Among the 59 survivors invited to be in our study, 2 did not complete an interview because they died, 1 refused to participate, and 8 could not be contacted. Verbal informed consent was obtained before the interview. The institutional review board at Johns Hopkins University approved this study.

Interviews

Semistructured, telephone-based interviews were conducted by using a written interview guide (see Supplement—available online only at ajcconline.org) from November 2013 through May 2015. The interview guide was initially developed and revised on the basis of feedback from 5 experts: 3 clinical experts in ARDS and 2 experts in patient-reported outcomes. Questions were iteratively modified throughout data collection to gather more information about major themes discussed in the previous interviews. Some interviews were shortened because of the participant's health. Interviewers would probe and ask follow-up questions according to a participant's responses to fully describe the participant's experiences globally and within each of the categories.

Health care providers in ICUs need to understand the impact of critical illness on patients and on patients' families.

The first segment of the interview consisted of open-ended questions about the survivor's health, well-being, and recovery after being hospitalized with ARDS or ARF. Example questions include "How have you been doing since you came home from the hospital?" and "How would you describe your health now?" In the second part of the interview, we used open-ended questions to specifically query the participants about experiences related to the physical, mental, and social health domains of the PROMIS framework. Questions from the second part of the interview included "How do you feel physically?" and "How would you describe your mood now?" All qualitative interviews were conducted by 2 trained researchers, audiotaped, and transcribed by a professional medical transcriptionist.

Analysis

Transcripts of the interviews were analyzed by using NVivo 10.0 software (QSR International Pty Ltd). Three of us (M.N.E., Y.P., and P.M.-T.) read all transcripts and inductively developed a written codebook that contained theme names and definitions based on thematic analyses.²⁸ After a codebook was established, all of the transcripts were independently coded by 2 of us (Y.P. and P.M.-T.) by using the constant comparative approach.²⁹ Themes were iteratively added to the codebook as interviews were conducted. Discrepancies were addressed by the third reviewer (M.N.E.). After open coding was completed, themes were organized according to the PROMIS framework. Frequencies of themes across participants were tabulated by using content analysis.³⁰ Coding was compared between the coders by using percentage agreement and the Cohen κ coefficient.

Results

Demographic characteristics for participants are reported in Table 1. Coding between the 2 raters had moderate to high agreement (mean percent agreement, 92.4; SD, 4.5; κ coefficient, 0.5). Thematic saturation was reached according to the strategy outlined by Francis et al,³¹ in which no new codes or information was added for at least 3 interviews.

Physical Health

Participants described impairments in physical health as one of their biggest concerns during recovery (Table 2). One participant stated that “being able to move and do things” was the most important aspect of the participant’s health. Most survivors described their physical functioning in terms of their mobility or need for mobility aids or both. Mobility aids were a visual reminder of impairments, a tangible barrier to overall functioning, and a major motivator to take difficult steps toward recovery. One participant noted, “I started to think about motivating, getting myself to do the things that I need to do, get up and instead of using a walker just try to walk on my own.” Survivors connected mobility to their ability to complete activities of daily living such as bathing, grooming, cooking, and household activities. Survivors also discussed the impact of impaired mobility on their ability to participate in work outside the home and in sports or exercise.

In addition to physical mobility, participants identified impairments in gastrointestinal, neuromuscular, sensory (eg, hearing and vision), and urological function. Moreover, many participants reported a number of pulmonary symptoms. Participants frequently described symptoms including dyspnea, coughing, or chest tightness: “It felt like there were two sections of chain-link fence hooked to each lung and I was trying to drag them up a gravel driveway with my lungs.” Furthermore, continued use of supplemental oxygen was a major difficulty; 1 participant stated, “I feel like I have a 10-foot leash to my saturator.”

In addition, survivors described increased fatigue and major impairments to their stamina and sleep habits (Table 3). Insufficient stamina to complete valued activities was a major source of frustration for many. One participant stated, “I can’t do the things I want to because I’m just out of breath.” Some participants reported having to plan out their daily activities to conserve energy: “I can’t wait until the afternoon to exercise or I’d be too tired.” Several participants also reported significant sleep disturbances, including insomnia and reliance on sleep aid medications since discharge from the hospital.

Mental Health

Participating survivors described mental health symptoms, changes in cognitive functioning, and psychosocial impacts of mental health (Table 4). Primary mental health complaints included indications of posttraumatic stress disorder, anxiety, and depression. One survivor remarked, “I would love to get out of depression and not be depressed, for one day in my life, and not to have anxiety or any of that.” Survivors also described more subtle changes to mood, including increased irritability or anger and worrying. Some participants reported decreased patience for everyday annoyances: “I just get more anxious or more edgy or more something than I used to.” Other participants reported a marked increase in worrying,

particularly about becoming sick again. This fear of repeated illness led them to avoid situations they thought might expose them to germs or to obsess about hand hygiene. One participant said, “I was deathly afraid of getting sick again, so I’d avoid things.”

Survivors also often described impairments to cognitive functioning. Specifically, participants described memory loss, difficulty with organization and planning, inattention, and difficulties in finding words. One participant reported, “I am not real good at remembering, and I have to write things down, and then I lose the things.” Another participant described thinking as “being in a fog.” These cognitive impairments impeded the survivors’ ability to participate in valued activities such as reading, spending time with friends, and completing daily tasks.

Participants described their illness as affecting their overall well-being in both positive and negative ways. Some participants reported greater gratitude for their life or valuing their health more. One participant stated, “I guess I’d started to take life a little bit for granted, but now I am so extremely grateful to be alive.” Some participants reported an increased awareness of the fragility of life, and some even identified critical illness as a major turning point in their life. One participant experienced critical illness as a result of an overdose of an illicit substance and reported being motivated to return to treatment after ICU discharge. Others reported focusing on more healthy behaviors such as exercise or healthy diets to improve their health. Conversely, other participants reported adverse impacts on their wellbeing, including increased boredom and loss of independence. One participant described these feelings as follows: “I am basically a parasite, ... a parasite, it leaves you an emptiness inside.” Others reported that they wished they had not survived. One participant said, “I think I would have been better off if I just would have died. I wouldn’t be having to deal with what I’m dealing with now.”

Social Health

The social health component of the PROMIS framework encompasses an individual’s perceived ability to perform his or her usual social roles and participate in activities including work, leisure, and maintaining relationships with friends and family. Survivors reported problems in all aspects of social health (Table 5). Many participants focused on changes in employment status; some survivors were able to return to work, others returned to reduced hours or light duty, and some became completely disabled and unemployed. Changes to work status were especially distressing because of increased financial strain, inability to provide for dependent family members, and feelings of being a burden.

Participants also reported decreased ability to engage in social activities, such as hobbies, volunteer work, or involvement with their church or community. One participant stated, “I have been a person who appreciates the environment ... and I haven’t been able to enjoy it.” Critical illness changed relationships with friends and family members both positively and negatively. Some survivors had grown closer to loved ones; 1 survivor stated, “He told me if I would live, he would never stop taking care of me ... so he has gone out of his way to do all that,” and perceived increased family support. Another participant stated, “He does everything he possibly can for me.” In contrast, other survivors reported isolation and

withdrawing from friends and family, such as the participant who stated, “I’m just getting real depressed because I lost family members.”

Discussion

In semistructured interviews guided by the PROMIS framework, survivors of ARDS and ARF reported new problems with physical, mental, and social health. Descriptions of physical impairment often focused on having restricted mobility, pulmonary symptoms, and decreased stamina. Depression and anxiety about becoming ill again dominated descriptions of mental health. Changes in employment status and ability to participate in valued activities affected survivors’ social health. Changes in overall well-being and interpersonal relationships varied; some survivors reported newfound gratitude, increased appreciation for their lives, and closer relationships to loved ones, whereas others reported boredom, social isolation, and wishing they had not survived at all. These differences in response to critical illness have been described in previous qualitative research³²⁻³⁸ and highlight the importance of caregivers understanding a patient’s values and social support system when treatment recommendations are made.

Empirical evidence of the long-lasting effects of critical illness on physical^{3,39-41} and cognitive functioning,^{4,42} mental health,^{5-8,43} sleep quality,⁴⁴ and employment status⁴⁵ is well documented. Accordingly, survivors’ reports of these issues are unsurprising. A previously published qualitative analysis⁴⁶ of interviews with ARDS survivors and their informal caregivers included dramatic descriptions of the strain and emotional distance that arose within families as a result of new disabilities, the burden of caregiving, and unemployment. These issues were echoed by the cohort of survivors in our study who brought up unemployment and dependence on family members for help with everyday activities. Unique to our study was the disparity between survivors whose experience of critical illness engendered newfound gratitude for life and closer relationships with loved ones despite new problems and survivors for whom survivorship was overwhelmingly isolating and onerous.

We used the 3 overarching components of physical, mental, and social health within the PROMIS framework as a logical starting point for exploring important health outcomes and experiences of ARDS and ARF survivors. However, PROMIS measurement instruments, which were developed for patients with chronic diseases, cannot be assumed to be well matched to the experiences of survivors of critical illness. Unlike chronic diseases, which usually have a slow onset and stable or worsening progression, critical illnesses often are marked by an abrupt decline in function followed by an uncertain duration and extent of recovery.⁴⁷ Whereas some survivors experienced a rapid and unexpected onset of disease, others had a worsening of a preexisting chronic disease that required ICU admission. Consequently, the experiences of survivors of critical illness often include abrupt changes in social roles and relationships and coping with the uncertain progression of their recovery. Moreover, unlike other patients with well-described chronic illnesses, ARDS and ARF survivors, their caregivers, and their health care providers are often unaware of the high prevalence of post-ICU impairments.⁴⁶

Health care providers who work with patients in the ICU may benefit from understanding the impact of critical illness on patients and patients' families. Although some patients and families may appear to cope well with critical illness, others may struggle to cope not only during the ICU stay but for many months after discharge. When speaking to patients and their families, ICU clinicians, including nurses, should not assume that all patients will experience progression of physical or cognitive recovery the same way.

As clinical researchers work to develop core outcome sets of agreed-upon, standardized measures for use in clinical studies to understand and improve post-ICU outcomes after critical illness, focusing on outcomes that are easiest and most expedient to quantify will be a temptation. Biomarkers and short questionnaires about the ability to perform everyday activities may be easy to collect and analyze, but they do not provide data on loneliness, newfound gratitude for simple pleasures, the shame of being a burden, or strengthened relationships with loved ones. Measuring social health and well-being in meaningful and interpretable ways most likely will be difficult but will be important to more fully determine the experiences of survivors of critical illness. Qualitative research can be key to providing contextual understanding of the experiences of these patients that can inform the development of core outcome sets.⁴⁸

Qualitative research has inherent limitations, including potential for both participant and researcher bias. We attempted to minimize these limitations by interviewing patients from different geographical locations and with variations in disease severity. We also used methods such as triangulation approaches, including double coding, resolving discrepancies, and establishing a codebook, to improve the credibility of our findings. Furthermore, we used a semistructured approach. We began with broad queries to allow patients to describe their health initially and then asked more focused specific questions about each of the PROMIS domains. Despite initially encouraging patients to identify the themes centrally important to their experiences by using broad questions, probing queries about specific domains in our interview guide most likely influenced which specific outcomes were mentioned, as was our intention in wanting to evaluate survivors' experiences within the context of the PROMIS framework.

Comprehensive assessments of outcomes important to survivors of critical illness should include measures of physical, mental, and social health.

Conclusions

The purpose of this study was to qualitatively describe the experience of survivors of ARDS and ARF within the context of the PROMIS framework. Many of the outcomes within physical and mental health were expected on the basis of existing empiric research. Patients also reported significant positive and negative changes to social health, including changes in social relationships, employment, and valued activities. Comprehensive attempts to assess outcomes of importance to survivors of critical illness should include measures of physical, mental, and social health for inclusion in core outcome sets.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

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1. Identify areas of patient-reported impairments following discharge from the intensive care unit (ICU).
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Table 1

Baseline characteristics and intensive care data for 48 patients

Variable	Value ^a
Patient data	
Age, y	53 (15)
Women, No. (%)	26 (54)
White, No. (%)	39 (81)
Prior residence, home independently. No. (%)	42 (88)
Body mass index ^b	32 (8)
Diabetes, No. (%)	15 (31)
Intensive care data	
APACHE III score	100 (34)
Duration of mechanical ventilation, d	9.8 (10)
ICU length of stay, d	13 (10)
Hospital length of stay, d	22 (17)

Abbreviation: APACHE III, Acute Physiology and Chronic Health Evaluation III.

^aFigures are means (SD) unless stated otherwise.^bCalculated as weight in kilograms divided by height in meters squared.

Table 2

Qualitative themes of patient-reported descriptions of physical health

Qualitative theme	Exemplar quote
Physical functioning	
Mobility and need for aids	The biggest shock for me was waking up in the ICU [intensive care unit] and having lost all my ability to move. It was terrifying and I'm still recovering from that. I couldn't move my fingers when I woke up, let alone my legs and it took several months, even to be able to walk using a walker. (Male, 46 years old, 12 months after mechanical ventilation)
Activities of daily living	I'm doing my own things, my own showers, cooking and doing laundry and cleaning up and stuff like that. I'm just basically happy to do that now that I can do it. (Female, 52 years old, 8 months after mechanical ventilation)
Balance/stability	I've got, for some reason like my equilibrium, it throws me off, my right side. I have fallen quite a few times in the shower already because of my equilibrium. I walk with a cane. To keep my balance, so I won't fall down. (Male, 35 years old, 8 months after mechanical ventilation)
Pain	I still have tightness in my ribs and stuff from all the tubes and crap, but everybody tells me that takes forever to heal. (Male, 42 years old, 18 months after mechanical ventilation)
Muscle weakness	Had a little bit of a problem with the fact that I was flat on my back for a week, well over a week, and that caused me to lose some muscle tone. (Male, 65 years old, 12 months after mechanical ventilation)
Muscle soreness	I mean I thought that my legs would never quit hurting because I had no muscle, no muscle, zero, and so I started at ground zero. (Female, 62 years old, 7 months after mechanical ventilation)
Inflammation, swelling	I really do wish I could do something to stop the swelling and the pain. (Female, 62 years old, 7 months after mechanical ventilation)
Numbness	My feet are so sore, which is ironic because they're also so numb I can't, I forget where they are unless I look at my feet, you know, so it's been kind of strange to have a pain in something that you can't feel. (Female, 62 years old, 7 months after mechanical ventilation)
Pulmonary	
Coughing	I cough a lot and I think it's just an irritation in the lungs still, but nothing seems to be helping it. (Female, 55 years old, 7 months after mechanical ventilation)
Shortness of breath	I find myself sitting down a lot, catching my breath. (Male, 63 years old, 6 months after mechanical ventilation)
Chest tightness	There's some stiffness where the, across my chest where the surgeries were ... (Male, 45 years old, 16 months after mechanical ventilation)
Prone to respiratory infections	One time when I got the pneumonia before I went in the last time, I felt fine, you know? And I fell asleep and then around 2 AM or whatever I woke up and I was ill, I was sick. (Male, 67 years old, 6 months after mechanical ventilation)
Supplemental oxygen	If I didn't have to have this darn oxygen with me all the time, I could certainly be a much happier person. (Male, 67 years old, 6 months after mechanical ventilation)
Gastrointestinal	
Nausea	My stomach just couldn't get used to the food those first 2 months. (Female, 60 years old, 6 months after mechanical ventilation)
Appetite	I ain't got no appetite for nothing, and no food tastes good; I'd just rather not have it. (Female, 62 years old, 5 months after mechanical ventilation)
Vomiting	Sometimes I eat and afterwards I have, I vomit or whatever afterwards. (Male, 67 years old, 6 months after mechanical ventilation)
Swallowing dysfunction	And I even had to learn how to swallow you know, swallow my food so I didn't choke. (Female, 63 years old, 9 months after mechanical ventilation)
Bowel changes	I couldn't figure out why all of the sudden I was having diarrhea so bad, and when you can't walk, to have diarrhea is pretty bad. (Female, 57 years old, 15 months after mechanical ventilation)
Other	
Sensory changes	My vision didn't work right either. I couldn't see things clearly. (Female, 63 years old, 9 months after mechanical ventilation)

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Exemplar quote	Qualitative theme
I think that it kind of wrecked my hearing. (Female, 65 years old, 9 months after mechanical ventilation)	

Table 3

Qualitative themes of patient-reported descriptions of fatigue or sleep concerns

Qualitative theme	Exemplar quote
Fatigue or stamina	I used to have to lie down for at least an hour in the middle of the day and now if I can grab 15 or 20 minutes and put my feet up I can recover and go on. (Female, 62 years old, 7 months after mechanical ventilation)
Planning out activities to conserve energy	If I do more than the routine, I have to stop and think about okay, you know, this is making me tired, I am losing my breath. (Female, 71 years old, 5 months after mechanical ventilation)
Naps	I take naps like 2 hours a day every day, and if I don't, I'm wiped out. (Male, 46 years old, 12 months after mechanical ventilation)
Sleep disruption	I do wake up once or twice, or toss and turn a lot. (Female, 53 years old, 13 months after mechanical ventilation)
Sleep apnea	They said I have sleep apnea, so I sleep with the machine, and sometimes, I just don't feel like I'll wake up. (Female, 68 years old, 14 months after mechanical ventilation)
Sleep medications	Before I got sick, I would lay down at 8:30 and I would be totally zonked out until my alarm went off, and when I got home from the hospital, I would be wide awake and then I would doze a little bit and then I'd be awake and I'd doze a little bit and then I'd be awake, and I couldn't like go under really deeply to sleep. So I started taking something to help my mind to calm down so that I could sleep better; so ever since I've been out of the hospital, if I don't take something, I'll doze, but I won't sleep. (Female, 57 years old, 15 months after mechanical ventilation)
Trouble falling asleep	I mean I toss and turn, I don't know, I can be in bed by 10 and I will toss and turn until 3 o'clock in the morning and finally go to sleep. (Female, 53 years old, 7 months after mechanical ventilation)

Table 4

Qualitative themes of patient-reported descriptions of mental health

Qualitative theme	Exemplar quote
	Cognitive functioning
Memory	I feel that I have a tendency to forget a little bit more and my brain's a bit more scattered. (Male, 34 years old, 12 months after mechanical ventilation)
Organization and planning	When I'm trying to organize or plan anything, it's just overwhelming. I can't do it. (Male, 31 years old, 7 months after mechanical ventilation)
Difficulties with attention	My attention span is shorter. It takes me longer to read a book than it used to. (Female, 71 years old, 5 months after mechanical ventilation)
Difficulties finding words	I have a hard time thinking of what I want to say or spitting out what I want to say, I just kind of go blank, and I can't quite grasp what I was trying to get across to people. (Female, 57 years old, 15 months after mechanical ventilation)
	Emotional functioning
Depression	I am a useless person. I am basically a parasite and the amount of being a parasite is, a parasite is just an emptiness inside, it leaves you an emptiness. You wonder, you don't know why wake up, you know. (Male, 67 years old, 6 months after mechanical ventilation)
Anxiety	The anxiety has gotten crazy. (Female, 38 years old, 9 months after mechanical ventilation)
Irritability, anger	I don't have the patience I used to have, I just kind of get bothered or annoyed, or I'm done with people earlier. (Female, 55 years old, 7 months after mechanical ventilation)
Posttraumatic stress disorder	Just the whole thing is an unwanted thought. (Female, 35 years old, 17 months after mechanical ventilation)
Worrying about getting sick	I was deathly afraid of getting sick again. (Male, 45 years old, 16 months after mechanical ventilation)
	Psychosocial impact of illness
Gratitude	Now I never take things for granted because life is different, different to me. ... There is a reason for everything that happens in my day, throughout my day. (Male, 62 years old, 13 months after mechanical ventilation)
Wish they had not lived	I just constantly wonder why. Why, why and, you know, some days I just think, well, I just wish I would have died instead of being brought back and being put on the ventilator. (Female, 38 years old, 9 months after mechanical ventilation)
Positive outlook	I'm like just every day, I am more than I used to be before I went to the hospital. I am thankful for being here. (Male, 62 years old, 13 months after mechanical ventilation)
Value health more	I kind of view it as like a turning point ... you know, sometimes you've got to hit rock bottom to finally open your eyes to what you're doing, and that kind of, that's how I view being hospitalized. (Male, 26 years old, 12 months after mechanical ventilation)
Boredom	You know, it gets boring. You know, I never was one to watch TV. I could tell you every show on TV now. (Female, 52 years old, 6 months after mechanical ventilation)
Independence	I am an independent person. And I don't want to be bothered with nobody. (Female, 62 years old, 5 months after mechanical ventilation)

Table 5
Qualitative themes of patient-reported descriptions of social health, including work status

Qualitative theme	Exemplar quote
Change in employment status	I want to go back to work. We had to move from a 2 bedroom to a 1 bedroom because I'm out of work now and disability hasn't started. If it's going to start, I don't even know. I feel like I'm being punished for being sick. (Female, 55 years old, 7 months after mechanical ventilation)
Disability	Right now I'm getting temporary disability, so it don't look like I'm going to be going back to work anytime soon, honestly. (Male, 29 years old, 6 months after mechanical ventilation)
Hobbies	I used to do search a word but I can't see the words no more. I loved search a word. But I can't see them no more and television, I really can't see it that good. (Female, 62 years old, 5 months after mechanical ventilation)
Household chores	Well I'm cooking more. I don't really do any like housework or anything like that, but I could like straighten up my bathroom you know. I could do that, stuff like that. I fold clothes. I don't wash them. (Female, 60 years old, 6 months after mechanical ventilation)
Caregiving	I don't have the patience, babysitting grandkids that I did. Before I could keep them for weeks, and now it's like after a day I'm ready for them to go home, I just can't handle what I used to handle, emotionally. (Female, 57 years old, 15 months after mechanical ventilation)
Family and friend activities	I go to lunch with people, I keep my grandchildren. I go to bible study. ... I go to my children's basketball games, I go to their birthday parties and go out to dinner with friends. (Female, 62 years old, 7 months after mechanical ventilation)
Social events	I've decreased the activities I do, mainly because of both financial and energy level. I used to do more active things with my down time. ... And nowadays, you know it's just pretty much me relaxing and trying to keep calm. (Male, 34 years old, 12 months after mechanical ventilation)
Changes in friends or family relationships	It's like, the boys are more considerate of me, they see me more as the mother they almost lost and wouldn't have had if, you know, so they do better. (Female, 52 years old, 6 months after mechanical ventilation)
Loneliness or isolation	As a matter of fact, well, just because I don't get a lot of human interaction on a normal day, this conversation with you is actually going to make my day. (Male, 65 years old, 12 months after mechanical ventilation)