



PATIENTS' ADAPTATIONS AFTER ACUTE RESPIRATORY DISTRESS SYNDROME: A QUALITATIVE STUDY

By Katrina E. Hauschildt, PhD, Claire Seigworth, MPH, Lee A. Kamphuis, MPH, Catherine L. Hough, MD, Marc Moss, MD, Joanne M. McPeake, PhD, MSc, BN(Hons), Molly Harrod, PhD, and Theodore J. Iwashyna, MD, PhD, for the Prevention and Early Treatment of Acute Lung Injury (PETAL) Network

Background Many patients confront physical, cognitive, and emotional problems after acute respiratory distress syndrome (ARDS). No proven therapies for these problems exist, and many patients manage new disability and recovery with little formal support. Eliciting patients' adaptations to these problems after hospitalization may identify opportunities to improve recovery.

Objectives To explore how patients adapt to physical, cognitive, and emotional changes related to hospitalization for ARDS.

Methods Semistructured interviews were conducted after hospitalization in patients with ARDS who had received mechanical ventilation. This was an ancillary study to a multicenter randomized controlled trial. Consecutive surviving patients who spoke English, consented to follow-up, and had been randomized between November 12, 2017, and April 5, 2018 were interviewed 9 to 16 months after that.

Results Forty-six of 79 eligible patients (58%) participated (mean [range] age, 55 [20-84] years). All patients reported using strategies to address physical, emotional, or cognitive problems after hospitalization. For physical and cognitive problems, patients reported accommodative strategies for adapting to new disabilities and recuperative strategies for recovering previous ability. For emotional issues, no clear distinction between accommodative and recuperative strategies emerged. Social support and previous familiarity with the health care system helped patients generate and use many strategies. Thirty-one of 46 patients reported at least 1 persistent problem for which they had no acceptable adaptation.

Conclusions Patients employed various strategies to manage problems after ARDS. More work is needed to identify and disseminate effective strategies to patients and their families. (*American Journal of Critical Care*. 2021; 30:221-229)

CE 1.0 Hour

This article has been designated for CE contact hour(s). See more CE information at the end of this article.

VIDEO ONLINE

©2021 American Association of Critical-Care Nurses
doi:<https://doi.org/10.4037/ajcc2021825>

Survivors of acute respiratory distress syndrome (ARDS) and mechanical ventilation experience persistent physical limitations, cognitive impairment, and emotional difficulties.¹⁻³ Despite strength and pulmonary function recovery, more than half of patients still report decreases in physical function 2 years after ARDS.^{4,5} Cognitive impairment at 1 year is estimated to occur in 25% to 78% of patients and includes issues with memory, executive function, and verbal fluency.⁶⁻⁸ Depression, anxiety, and post-traumatic stress disorder are common and long-lasting; approximately 25% of survivors report posttraumatic stress disorder 5 years after ARDS.^{4,9}

No proven therapies to prevent or systematically treat these problems are available.^{10,11} Many patients and families navigate life after ARDS on their own.

Reports by patients and family members have helped identify the problems ARDS survivors face¹²⁻¹⁴ and the services they use or report needing.¹⁵ Understanding how they adapt to problems and what solutions or resources they draw upon to address disability may reveal opportunities to improve recovery after ARDS.

This study elicited patients' adaptations to ARDS-related changes by interviewing survivors 9 to 16 months after diagnosis. We explored how patients

adapted to physical, cognitive, and emotional changes brought about or exacerbated by their hospitalization. We used semistructured interviews to capture the breadth of patients' strategies and to identify unexpected adaptations and resources patients used to address disability after ARDS.

Methods

Sampling and Data Collection

We conducted semistructured interviews with patients in the Reevaluation of Systemic Early Neuromuscular Blockade (ROSE) trial.¹⁶ The ROSE trial was a multisite randomized trial examining use of a 48-hour early continuous infusion of cisatracurium with concurrent deep sedation versus usual care with lighter sedation and no routine neuromuscular blockade. The ROSE trial showed no differences in mortality or patient-centered outcomes. We approached all 79 English-speaking, surviving patients who were randomized between November 12, 2017, and April 5, 2018; consented to long-term survey follow-up; and completed either the 3- or 6-month survey. Patients were mailed a letter and contacted by telephone for recruitment. Respondents received \$10. This study was approved by the Vanderbilt University Medical Center Institutional Review Board as the central institutional review board for this National Institutes of Health multicenter network.

K.H., a qualitative sociologist, conducted telephone interviews. Two other team members took notes. We drew on the National Health and Aging Trends Study model of disability and sense-making theory to develop the interview guide (for additional information and guide, see Supplement 1—available online only at ajcconline.org).^{17,18} Interviews were recorded and transcribed. We pilot tested the interview guide with a similar group of critically ill patients.¹⁹

Data Analysis

We used open and directed approaches to identify patterns in how patients addressed disability and

Many patients and families navigate life after ARDS on their own.

About the Authors

Katrina E. Hauschildt is an advanced fellow in health services research at the Veterans Affairs Center for Clinical Management Research and a research associate in the Pulmonary and Critical Care Division at the University of Michigan, Ann Arbor. **Claire Seigworth**, **Lee A. Kamphuis**, and **Molly Harrod** are research health science specialists at the Veterans Affairs Center for Clinical Management Research, Health Services Research & Development Center of Innovation, Ann Arbor, Michigan. **Catherine L. Hough** is a professor of medicine and chief of the Division of Pulmonary and Critical Care Medicine at the Oregon Health & Science University in Portland. **Marc Moss** is the Roger S. Mitchell Professor of Medicine and division head of Pulmonary Sciences and Critical Care Medicine, University of Colorado School of Medicine, Aurora, Colorado. **Joanne M. McPeake** is a nurse consultant, NHS Greater Glasgow and Clyde, Glasgow Royal Infirmary, Glasgow, United Kingdom, a senior honorary clinical lecturer at the University of Glasgow School of Medicine, Dentistry & Nursing, Glasgow, and a THIS Institute research fellow at the University of Cambridge. **Theodore J. Iwashyna** is the co-director of the research core at the Veterans Affairs Center for Clinical Management Research, Health Services Research & Development Center of Innovation, and the Alpheus W. Tucker, MD, Collegiate Professor of Internal Medicine at the University of Michigan, Ann Arbor.

Corresponding author: Katrina E. Hauschildt, PhD, VA Center for Clinical Management Research, VA Ann Arbor Healthcare System, HSR&D (152), PO Box 130170, Ann Arbor, MI 48113-0170 (email: kehaus@umich.edu).

recovery following ARDS (Supplement 1, available online only).^{20,21} K.H. and C.S. independently open coded each transcript and then compared interpretations to refine codes. K.H., C.S., T.J.I., and C.L.H. discussed emerging patterns and refined the codebook and interview guide. K.H. and C.S. continued coding the remaining transcripts independently, discussing and resolving discrepancies. After consensus, coded transcripts were uploaded into the qualitative analysis software NVivo (QSR International). We identified no new codes in the last 12 interviews, suggesting data saturation.²² Code reports were created for review. Themes identified reflected key aspects of the National Health and Aging Trends Study disability model and Freedman's conceptualization of rehabilitative and accommodative adaptation after critical illness.^{23,24}

Results

Seventy-nine patients from the ROSE trial were alive, eligible, and contacted for inclusion; 46 agreed to participate, 27 were not reached, and 6 declined. The mean interview length was 32 minutes (range, 13-57 minutes). Table 1 presents background characteristics of participants. Illness severity and demographics of interview participants were generally similar to those of the broader sample of eligible ROSE patients (Supplement 2, available online only).

Accommodative and Recuperative Strategies

For physical and cognitive difficulties, all patients reported using at least 1 accommodative or recuperative strategy. Accommodative strategies help patients work around new disabilities, and recuperative strategies focus on recovering previous ability.

Accommodative Strategies. The most common accommodative strategy was the use of assistive devices like canes, walkers, shower chairs, or other tools to navigate physical and mobility limitations (30 of 46 patients, 65%; Table 2). Patients also reported relying on family members to help with daily tasks (eg, cooking, bathing, or climbing stairs), transportation, or both (19 of 46 patients, 41%).

Female patient, age 44 years: I had my in-laws come to stay with my daughter and husband—my mother-in-law. She had been here the whole time I was in the hospital . . . so she was here [when I came home] to help with cooking and help with my daughter.

Many patients reported making changes to their living environments that involved navigating their

Table 1
Patients in interview sample (N=46)

Characteristic	Value ^a
Age, mean (range), y	55 (20-84)
Sex	
Male	29 (63)
Female	17 (37)
Race	
White	32 (70)
Black	4 (9)
Asian, American Indian, or Alaska Native	3 (7)
Not reported	7 (15)
Ethnicity	
Hispanic or Latino	4 (9)
Non-Hispanic/Latino	41 (89)
Not reported	1 (2)
Geographic region	
West Coast (6 sites)	15 (33)
Mountain West (7 sites)	12 (26)
Midwest (3 sites)	6 (13)
South (3 sites)	5 (11)
Northeast (3 sites)	8 (17)
High school diploma or higher	45 (98)
Enrolled in Medicare	17 (37)
Primary cause of lung injury	
Pneumonia	32 (70)
Aspiration	7 (15)
Nonpulmonary sepsis	3 (7)
Other causes	4 (9)
Assessments and measurements	
APACHE III score, ^b mean	98.00
Total SOFA score, ^c mean	7.59
Tidal volume, mL/kg of predicted body weight, mean	6.06
FiO ₂ , mean	0.77
Inspiratory plateau pressure, cm H ₂ O, mean	25.67
PEEP, cm H ₂ O, mean	12.62
PaO ₂ :FiO ₂ , mean	100.14
Imputed PaO ₂ :FiO ₂ , ^d mean	76.30
Treatment status	
Neuromuscular blockade	20 (43)
Usual care	26 (57)
Days after randomization, median (range)	360 (288-484)
12-Month disability score, ^e mean (SD) (n=45)	3.38 (2.4)
12-Month PTSS score, ^f mean (SD) (n=44)	34.5 (20.2)
12-Month MoCA score, ^g mean (SD) (n=44)	23.5 (4.4)
12-Month living arrangement	
Home independently	17 (37)
Home with help	20 (43)
Home with professional help	4 (9)
Intermediate care, rehabilitation, or nursing facility	2 (4)
Other	3 (7)

Abbreviations: APACHE, Acute Physiology and Chronic Health Evaluation; FiO₂, fraction of inspired oxygen; ICU, intensive care unit; MoCA, Montreal Cognitive Assessment; PEEP, positive end-expiratory pressure; PTSS, Posttraumatic Symptom Scale-10; SOFA, Sequential Organ Failure Assessment.

Continued

Table 1
Continued

- ^a Data are presented as number (percentage) unless otherwise noted; percentages may sum to greater than 100% because of rounding.
- ^b The APACHE III score consists of several parts including reason for ICU admission, age, sex, race, preexisting conditions, and other factors; it ranges from 0 to 299 points with higher scores associated with greater mortality.
- ^c The SOFA score measures respiratory, cardiovascular, hepatic, coagulatory, renal, and neurologic dysfunction; it ranges from 0 to 24, and higher scores are associated with increased morbidity and mortality.
- ^d If results of an arterial blood gas analysis were not available at randomization, the ratio was inferred from oxygen saturation as measured by pulse oximetry.
- ^e The disability score ranges from 0 to 10 and is the number of 10 activities of daily living and instrumental activities of daily living items on which the respondent or their proxy reported difficulty due to health conditions at 12 months after randomization; scores of 4 or greater are interpretable as representing severe disability.
- ^f The PTSS score ranges from 0 to 70 and measures the frequency of 10 common symptoms of posttraumatic stress. A total score above 35 is considered suggestive of posttraumatic stress disorder.
- ^g The MoCA is a 30-question test validated to measure mild cognitive impairment and dementia. A score of 25 or less is considered to indicate that the patient is at risk for impairment.

Table 2
Patients' accommodative strategies

Strategy	No. reporting this strategy
For physical problems	
Assistive devices (shower chairs/bars, walkers, hand grippers, portable oxygen, etc)	30
Rely on family for assistance/support with daily tasks	14
Rely on family for transportation	8
Navigate home differently (eg, use first floor) or change living arrangements (eg, live with relatives)	17
Limited return to work/different job/retired	15 ^a
Formal in-home caregiver	7
Take frequent rests/breaks	6
Medical marijuana	2
For cognitive problems	
Writing notes/making lists	8
Reminders/assistance from family	6
Assistance/adaptations at work	2

^a Three people reported returning to work part time but later starting a full-time schedule.

homes differently (for example, using only 1 floor) or moving, most often to live with family members who could offer physical assistance (17 of 46 patients, 37%). Fifteen patients (33%) accommodated physical limitations by returning to work part time, changing jobs, or permanently leaving the workforce.

Female patient, age 47 years: I have a downstairs apartment [now], just 1 step in the door and I'm here. . . . It's pretty good now. I got a walk-in shower. I have a bench seat in the shower. I'm good.

Interviewer: What was it like before?

Patient: Oh, it was terrible. Someone would have to get in the shower with me, get my left leg over the tub, and it was just misery. Taking the risk on falling, slipping, it was pure hell.

Patients reported accommodating cognitive issues by writing things down (8 of 46 patients, 17%) and relying on family members to provide information or to jog patients' memories (6 patients, 13%). Two patients reported accommodations at work, including increased supervision.

Female patient, age 57 years: I remember some, but I don't remember a lot. Sometimes when people tell me stuff—like do something later in the day—I forget it almost after they say it.

Interviewer: What do you do to help yourself remember things?

Patient: I write it down. That's the only way I'm going to remember some stuff.

Recuperative Strategies. Recuperative strategies for physical issues were also commonly reported (Table 3). Most patients reported receiving some outpatient physical or occupational therapy (32 of 46 patients, 70%). Patients described outpatient therapies as being focused on recovery, although these services often include accommodative instruction. Additional efforts to improve endurance or strength were very common patient-initiated strategies for physical problems (19 of 46 patients reported some endurance-focused strategies: add daily tasks, 8 patients; exercises to build strength, 6 patients; walk increasing frequency or distance, 5 patients; continue breathing exercises, 5 patients).

Interviewer: Was there anything else that was difficult physically?

Male patient, age 63 years: Just endurance, trying to walk.

Interviewer: How did you tackle that?

Patient: I did it in the pool. I got a pool, so I went in the pool a lot . . . and just kept walking around the pool with the grandkids and stuff . . . it was less wear and tear on my body.

Patients sought to recover cognitive abilities by using puzzles, word searches, or video games to stimulate memory and cognitive skills (7 of 46 patients, 15%). Two patients described receiving outpatient therapy to address cognitive issues.

Interviewer: What sort of cognitive problems did you have?

Male patient, age 60 years: Working on basic problems, like working with my bank accounts, things like that. I made real silly errors there for a while. . . . Logic puzzles helped a lot—especially

with the math. I'm able to do math in my head again.

Strategies for Emotional Problems

When we asked patients how they were dealing with the emotional problems they reported, no clear distinction between accommodative and recuperative strategies emerged. (See Table 4 for emotional strategies.) Common strategies to address emotional issues were talking to and receiving encouragement from family members (19 of 46 patients, 41%), focusing on the positive things in their lives (15 patients, 33%), and seeking out formal treatment through therapy or medications (15 patients, 33%).

Female patient, age 62 years: When I first got out of the hospital, everything was challenging. I cried at everything. I got upset very easily. It was like a whole different personality for about a month.

Interviewer: What did you do to deal with what was going on?

Patient: I have a super good therapist that I started seeing and they switched my meds around.

Prayer and support from their faith also helped patients address emotional issues (11 of 46 patients, 24%). For some respondents, being hospitalized was a distinct emotional challenge and they described coming home as providing emotional relief (11 of 46 patients, 24%).

Male patient, age 20 years: I have even more faith in God and what he's doing. . . . I think that God is a real important part of my recovery . . . even though it sucked to be where I was—that's where I was supposed to be, and I'm going to be okay.

Contextual Factors Influencing Adaptations

Contextual factors were related to strategy use. Social support was important in helping patients identify and facilitate strategies necessary for recovery. Patients' family members helped them solve problems around disabilities, encouraged them throughout recovery, and sometimes coaxed patients toward formal services, especially around emotional difficulties.

Male patient, age 70 years: They got me a new dog. [My wife] said you need a dog just so you have to get up all the time.

Male patient, age 55 years: [My wife] was a very important advocate, both in terms of helping me keep track of medications and appointments and helping to keep

Table 3
Patients' recuperative strategies

Strategy	No. reporting this strategy
For physical problems	
Formal outpatient PT/OT	32
Manage/maintain overall health (avoid illness, make dietary changes, quit smoking, etc)	17
Continue formal PT/OT exercises at home/on their own	10
Add daily tasks over time	8
Self-initiated exercises to build strength over time (did not participate in any outpatient PT/OT)	6
Continue breathing exercises	5
Walk increasing frequency or distance over time	5
Transition to less-assistive devices/support over time (eg, walker to cane, decrease oxygen levels)	3
Staying busy/finding things to do/having a routine	3
Avoid assistance that might cause additional decline (elevators, wheelchair, etc)	2
Draw/paint to build dexterity	1
See chiropractor	1
For cognitive problems	
Solve games/puzzles (word searches, puzzles, video games, etc)	7
Getting back into routine/daily tasks/using brain more	4
Formal outpatient therapies	2
Use memory/cognitive skills mobile or computer apps	1
Improve overall health	1
Listen to audiobooks he's heard before	1

Abbreviations: OT, occupational therapy; PT, physical therapy.

Table 4
Strategies for emotional problems

Strategy	No. reporting this strategy
Emotional support/assistance from family	19
Focus on the positives/survival	15
Talking to a therapist/counselor	11
Prayer/belief in God	11
Return home	11
Medications	9
Spending time with family/friends	7
Acceptance of limitations	7
Find distractions/things that help patient relax	5
Finding/focusing on motivations/purpose	3
Keeping busy	3
Understanding illness	3
Self-medicate	2
Avoid thinking about hospitalization	2
Different job	1

me focused on recovery—keeping a positive outlook and helping me learn to live within my limitations.

Male patient, age 58 years: When I have anxiety, sometimes I talk to somebody—sometimes I pick up the phone and call friends.

Previous familiarity with the health system also facilitated identifying strategies. Patients reported

relying on their own or family members' professional clinical training (as therapists, nurses, etc) to navigate recovery. Patients also reported drawing on previous illness or injury experiences. Continuing exercises from physical therapy sessions after formal services ended was commonly reported (10 of 46 patients, 22%).

Male patient, age 60 years: I learned a long time ago how to do acupressure and all that stuff...from my chiropractor, I learned a lot of it—I had my neck surgery in 1987. . . . I got a lot of little pieces of paper saying do this—from my therapists, from my chiropractor.

Male patient, age 68 years: A really close friend of mine is an RN [registered nurse]. So when I came home, this friend of mine made sure that I had a walker, a bath chair—that I had everything that they wanted me to have. She did my MediSet [medication organizer] with all the medicines in it—she set all that up—I would not have been able to do that when I got home.

Persistent Problems Without Successful Adaptations

Some patients reported physical, emotional, and cognitive issues that they had not been able to adapt to or recover from; 31 of 46 patients (67%) reported at least 1 issue without a successful adaptation (ie, a persistent problem). Of the 46 patients, 28 (61%), 13 (28%), and 10 (22%) reported unremedied physical, emotional, and cognitive problems, respectively.

Female patient, age 62 years: The hard part is I just have no energy. I mean I go to PT [physical therapy] for an hour and a half and I come home and sleep for 3 hours, because I do not have the stamina and that's what agitates me the most.

Male patient, age 49 years: My thought processes seemed to have changed, where before, I could string a sentence together fairly well . . . now I found myself stuttering, trying to find the right word to fit the sentence. . . . I'm 48 years old—I shouldn't have that many problems with it, but right now, I feel like—what's the word I'm looking for—it's just hard.

When asked about addressing an ongoing problem, some patients reported they were unsure of whether services would help or felt that treatments were not working. Although

two-thirds of patients reported participating in formal outpatient rehabilitation services, few sought additional therapy if disabilities or problems persisted after services ended. One patient reported doing physical therapy for a month and trying to continue exercises on her own but also voiced concern that she was still quite limited.

Female patient, age 51 years: [Physical therapy] did come to my home—right after, for 6 or 8 visits, and then they said I was fine. I feel like I'm kind of at a stalemate now, and I—it's kind of depressing, like I'm not sure that I'm going to get much better than I am now. It's hard to think of . . . but this may be as good as it gets.

Only 4 patients who reported persistent problems attempted no strategies to address the issue. Thus, strategies of unclear efficacy were more common than were failures to attempt any resolution. Persistent problems were noted across every demographic group and treatment randomization status (Supplement 3, available online only). Some strategies that patients reported may also be of limited effectiveness and potentially maladaptive. These strategies included avoiding thinking about their hospitalization (2 of 46 patients, 4%) and self-medicating (2 patients, 4%) as conscious strategies for emotional problems and using medical marijuana (2 patients, 4%) for physical problems.

Discussion

Our study explored the strategies patients use to address disability after ARDS hospitalization. The prevalence of problems after ARDS in our study population was consistent with the published literature.^{1,25} All patients reported efforts to address physical, emotional, and/or cognitive issues following ARDS. Patient-driven strategies included novel ways of managing disability and increasing progress over time as well as extensions of skills learned in structured rehabilitative services accessed earlier in their recovery. Social support and previous familiarity with the health care system helped patients generate and use many of the strategies reported. However, many patients also reported persistent problems for which they had not identified an acceptable accommodation. For the great majority of persistent problems, patients reported having insufficient, rather than no, strategies.

We found that patients and their family members were actively involved in developing self-management strategies to correct or attenuate the impact of new problems, often with modest support from the

health care system. For some patients, familiarity with health system resources because of previous illness or chronic conditions proved beneficial²⁶; they drew on earlier experiences and knowledge in identifying strategies and accommodations. Yet whether or not survivors had access to formal health care system services, most exerted agency by actively working to fill the gaps.

This active exploration by survivors and their caregivers implies that neither clinical care nor trials should assume that just because a patient was not prescribed something, nothing is being done. In either clinical or research contexts, efforts to set goals²⁷ and activate patients and family members^{28,29} may benefit from identifying patients' current self-management approaches. Clinicians may have a role not only in prescribing new strategies but also in helping survivors select the most effective strategies and replace less effective or potentially harmful strategies. Ways to identify and selectively disseminate more effective adaptations, such as through moderated peer support, may help patients and family members learn about and implement useful adaptations.³⁰

Throughout the interviews, the critical role of informal caregivers in the development of strategies was clear. This finding is consistent with the literature on the importance of social support.³¹ Yet after ARDS, those informal caregivers may have new, acute challenges. Cameron et al³² noted that most caregivers experience high levels of depressive symptoms, consistent with findings after sepsis (the most common cause of ARDS).³³ Netzer³⁴ and Sullivan et al³⁵ found high levels of learned helplessness in family members of patients in the intensive care unit, which may limit family members' effectiveness in the early post-intensive care unit period.^{34,35} This finding suggests that efforts to support families during and immediately after critical illness may indirectly benefit patients, and clinicians should consider supporting caregiver involvement in post-intensive care unit follow-up and recovery.

For clinicians seeking to improve patients' ability to function physically, these interviews emphasized the particularly potent role of assistive devices²³ but also their incomplete dissemination among patients. Patients' access to assistive technologies may depend on the kinds of follow-up care they receive (rehabilitation therapy, pulmonary clinic, or primary care visits), which clinicians can support. These interviews also emphasized the evolution of disability and accommodative and recuperative strategies for months after ARDS, consistent with

longitudinal cohort data.^{1,36} Whether patients might benefit from serial evaluations by physical and occupational therapists during recovery may warrant exploration. Many patients in our study reported ongoing efforts to engage in self-directed exercise without clinician supervision.

For clinicians seeking to improve patients' cognitive and behavioral functioning, fewer clear adaptations were available. Patients emphasized the importance of being home. Early supported discharge by a skilled multidisciplinary team, which aims to offer patients earlier hospital discharge with coordinated rehabilitation in the patient's home, is now commonplace among *stroke* patients with mild to moderate disability.³⁷ For these patients, early supported discharge shortens the initial hospital stay and reduces long-term dependency and admission to institutional care; patients are also more likely to be independent in daily activities at 6 months.³⁸ Some ARDS survivors described emotional and cognitive improvement upon returning home, and early supported discharge might provide similar benefits for ARDS survivors. However, the extent to which returning home improves mental and emotional function or is a marker of such improvement is unclear. These interviews also suggest that additional research is needed for identifying effective coping strategies.

We note several limitations of our study. First, we interviewed patients; caregivers may have identified additional strategies. Given the significant role of social support that we identified, caregivers may have implemented strategies that patients were not aware of or did not report. Second, because we relied on patients' reports of strategies used, we are not able to assess the actual use or frequency of these strategies. Third, we interviewed patients with sufficient social support to have been enrolled in a randomized clinical trial. Many of these patients had a legally appointed representative sign consent for that trial. These patients may have had higher levels of social support than did the 6% of patients who lacked an available surrogate when assessed for eligibility for the original trial.¹⁶ Fourth, because of the exploratory nature of this project, we were not able to determine the efficacy of particular strategies.

Efforts to support families may indirectly benefit patients, and clinicians should consider supporting caregiver involvement in follow-up and recovery.

Conclusions

Patients in our cohort of 46 ARDS survivors, especially those supported by their families, engaged in a range of activities to attempt to address disability after ARDS. However, many patients had ongoing problems and had not developed effective strategies for adapting. Patients without social support may be at greater risk. Our work suggests that clinicians should consider implementing standard screening for impairments following ARDS and that future work is needed to analyze the effectiveness of patient- and family-generated strategies and accommodations and whether their dissemination to survivors would be beneficial.

ACKNOWLEDGMENTS

We acknowledge all the investigators, coordinators, and staff members from the sites contributing to the Prevention and Early Treatment of Acute Lung Injury (PETAL) Network. We are thankful for the opportunity to share and receive feedback on this manuscript from the Multi-disciplinary Intensive Care Research Workgroup and to Erin Ice for assisting with the manuscript's descriptive statistics. Finally, we are very grateful for our interview participants' time and candor.

FINANCIAL DISCLOSURES

This work was supported by grants U01 HL123031 and R01 HL132232 from the National Institutes of Health. This work does not represent the official position of the United States Government or the Department of Veterans Affairs.

REFERENCES

- Herridge MS, Cheung AM, Tansey CM, et al; Canadian Critical Care Trials Group. One-year outcomes in survivors of the acute respiratory distress syndrome. *N Engl J Med*. 2003;348(8):683-693. doi:10.1056/NEJMoa022450
- Herridge MS, Moss M, Hough CL, et al. Recovery and outcomes after the acute respiratory distress syndrome (ARDS) in patients and their family caregivers. *Intensive Care Med*. 2016;42(5):725-738. doi:10.1007/s00134-016-4321-8
- Wilson ME, Barwise A, Heise KJ, et al. Long-term return to functional baseline after mechanical ventilation in the ICU. *Crit Care Med*. 2018;46(4):562-569. doi:10.1097/CCM.0000000000002927
- Bienvu OJ, Colantuoni E, Mendez-Tellez PA, et al. Depressive symptoms and impaired physical function after acute lung injury: a 2-year longitudinal study. *Am J Respir Crit Care Med*. 2012;185(5):517-524. doi:10.1164/rccm.201103-0503OC
- Fan E, Dowdy DW, Colantuoni E, et al. Physical complications in acute lung injury survivors: a two-year longitudinal prospective study. *Crit Care Med*. 2014;42(4):849-859. doi:10.1097/CCM.0000000000000040
- Needham DM, Dinglas VD, Morris PE, et al; NIH NHLBI ARDS Network. Physical and cognitive performance of patients with acute lung injury 1 year after initial trophic versus full enteral feeding. EDEN trial follow-up. *Am J Respir Crit Care Med*. 2013;188(5):567-576. doi:10.1164/rccm.201304-0651OC
- Hopkins RO, Weaver LK, Pope D, Orme JF, Bigler ED, Larson-Lohr V. Neuropsychological sequelae and impaired health status in survivors of severe acute respiratory distress syndrome. *Am J Respir Crit Care Med*. 1999;160(1):50-56. doi:10.1164/ajrccm.160.1.9708059
- Mikkelsen ME, Christie JD, Lanken PN, et al. The adult respiratory distress syndrome cognitive outcomes study: long-term neuropsychological function in survivors of acute lung injury. *Am J Respir Crit Care Med*. 2012;185(12):1307-1315. doi:10.1164/rccm.201111-2025OC
- Davydow DS, Desai SV, Needham DM, Bienvu OJ. Psychiatric morbidity in survivors of the acute respiratory distress syndrome: a systematic review. *Psychosom Med*. 2008;70(4):512-519. doi:10.1097/PSY.0b013e31816aa0dd
- Hodgson C, Cuthbertson BH. Improving outcomes after critical illness: harder than we thought! *Intensive Care Med*. 2016;42(11):1772-1774. doi:10.1007/s00134-016-4526-x
- Brown SM, Bose S, Banner-Goodspeed V, et al; Addressing Post Intensive Care Syndrome 01 (APICS-01) Study Team. Approaches to addressing post-intensive care syndrome among intensive care unit (ICU) survivors: a narrative review. *Ann Am Thorac Soc*. 2019;16(8):947-956. doi:10.1513/AnnalsATS.201812-913FR
- Czerwonka AI, Herridge MS, Chan L, Chu LM, Matte A, Cameron JI. Changing support needs of survivors of complex critical illness and their family caregivers across the care continuum: a qualitative pilot study of Towards RECOVER. *J Crit Care*. 2015;30(2):242-249. doi:10.1016/j.jccr.2014.10.017
- Eakin MN, Patel Y, Mendez-Tellez P, Dinglas VD, Needham DM, Turnbull AE. Patients' outcomes after acute respiratory failure: a qualitative study with the PROMIS framework. *Am J Crit Care*. 2017;26(6):456-465. doi:10.4037/ajcc2017834
- Haines KJ, Quasim T, McPeake J. Family and support networks following critical illness. *Crit Care Clin*. 2018;34(4):609-623.
- King J, O'Neill B, Ramsay P, et al. Identifying patients' support needs following critical illness: a scoping review of the qualitative literature. *Crit Care*. 2019;23(1):187. doi:10.1186/s13054-019-2441-6
- Moss M, Huang DT, Brower RG, et al; National Heart, Lung, and Blood Institute PETAL Clinical Trials Network. Early neuromuscular blockade in the acute respiratory distress syndrome. *N Engl J Med*. 2019;380(21):1997-2008. doi:10.1056/NEJMoa1901686
- Freedman VA. Adopting the ICF language for studying late-life disability: a field of dreams? *J Gerontol A Biol Sci Med Sci*. 2009;64(11):1172-1174; discussion 1175-1176. doi:10.1093/geron/glp095
- Cardillo L. Sense-making as theory and method for researching lived experience: an exemplar in the context of health communication and adolescent illness. *Electronic J Commun*. 1999;9(2). Accessed January 22, 2020. <http://www.cios.org/EJCPUBLIC/009/2/009223.html>
- Kallio H, Pietilä AM, Johnson M, Kangasniemi M. Systematic methodological review: developing a framework for a qualitative semi-structured interview guide. *J Adv Nurs*. 2016;72(12):2954-2965. doi:10.1111/jan.13031
- Bradley EH, Curry LA, Devers KJ. Qualitative data analysis for health services research: developing taxonomy, themes, and theory. *Health Serv Res*. 2007;42(4):1758-1772. doi:10.1111/j.1475-6773.2006.00684.x
- Emerson RM, Fretz RI, Shaw LL. *Writing Ethnographic Fieldnotes*. 2nd ed. University of Chicago Press; 2011.
- Giacomini MK, Cook DJ. Users' guides to the medical literature: XXIII. Qualitative research in health care: A. Are the results of the study valid? *JAMA*. 2000;284(3):357-362. doi:10.1001/jama.284.3.357
- Freedman VA, Kasper JD, Spillman BC. Successful aging through successful accommodation with assistive devices. *J Gerontol B Psychol Soc Sci*. 2017;72(2):300-309. doi:10.1093/geronb/gbw102
- Freedman VA, Kasper JD, Spillman BC, et al. Behavioral adaptation and late-life disability: a new spectrum for assessing public health impacts. *Am J Public Health*. 2014;104(2):e88-e94. doi:10.2105/AJPH.2013.301687
- Marra A, Pandharipande PP, Girard TD, et al. Co-occurrence of post-intensive care syndrome problems among 406 survivors of critical illness. *Crit Care Med*. 2018;46(9):1393-1401. doi:10.1097/CCM.00000000000003218
- Strömbäck U, Engström Å, Wälivaara BM. Realising the seriousness – the experience of suffering a second myocardial infarction: a qualitative study. *Intensive Crit Care Nurs*. 2019;51:1-6. doi:10.1016/j.iccn.2018.12.002
- McPeake JM, Harhay MO, Devine H, et al. Exploring patients' goals within the intensive care unit rehabilitation setting. *Am J Crit Care*. 2019;28(5):393-400. doi:10.4037/ajcc2019436
- Major ME, van Nes F, Ramaekers S, Engelbert RHH, van der Schaaf M. Survivors of critical illness and their relatives: a qualitative study on hospital discharge experience. *Ann Am Thorac Soc*. 2019;16(11):1405-1413. doi:10.1513/AnnalsATS.201902-156OC
- Haines K. Rehabilitation. In: Netzer G, ed. *Families in the Intensive Care Unit: A Guide to Understanding, Engaging,*

- and Supporting at the Bedside. Springer International Publishing; 2018:343-356. doi:10.1007/978-3-319-94337-4_25
30. McPeake JM, Boehm LM, Hibbert E, et al. Key components of ICU recovery programmes: what did patients report provided benefit? *Crit Care Explor*. 2020;2(4):e0088. doi:10.1097/CCE.0000000000000088
 31. Berkman LF, Glass T. Social integration, social networks, social support, and health. In: Berkman LF, Kawachi I, eds. *Social Epidemiology*. Oxford University Press; 2000:137-173.
 32. Cameron JI, Chu LM, Matte A, et al; RECOVER Program Investigators (Phase 1: towards RECOVER); Canadian Critical Care Trials Group. One-year outcomes in caregivers of critically ill patients. *N Engl J Med*. 2016;374(19):1831-1841. doi:10.1056/NEJMoa1511160
 33. Davydow DS, Hough CL, Langa KM, Iwashyna TJ. Depressive symptoms in spouses of older patients with severe sepsis. *Crit Care Med*. 2012;40(8):2335-2341. doi:10.1097/CCM.0b013e3182536a81
 34. Netzer G, ed. *Families in the Intensive Care Unit: A Guide to Understanding, Engaging, and Supporting at the Bedside*. Springer International Publishing; 2018.
 35. Sullivan DR, Liu X, Corwin DS, et al. Learned helplessness among families and surrogate decision-makers of patients admitted to medical, surgical, and trauma ICUs. *Chest*. 2012;142(6):1440-1446. doi:10.1378/chest.12-0112
 36. Herridge MS, Tansey CM, Matté A, et al; Canadian Critical Care Trials Group. Functional disability 5 years after acute respiratory distress syndrome. *N Engl J Med*. 2011;364(14):1293-1304. doi:10.1056/NEJMoa1011802
 37. Langhorne P, Baylan S; Early Supported Discharge Trialists. Early supported discharge services for people with acute stroke. *Cochrane Database Syst Rev*. 2017;7(7):CD000443. doi:10.1002/14651858.CD000443.pub4
 38. Fisher RJ, Gaynor C, Kerr M, et al. A consensus on stroke: early supported discharge. *Stroke*. 2011;42(5):1392-1397. doi:10.1161/STROKEAHA.110.606285

To purchase electronic or print reprints, contact American Association of Critical-Care Nurses, 27071 Aliso Creek Road, Aliso Viejo, CA 92656. Phone, (800) 899-1712 or (949) 362-2050 (ext 532); fax, (949) 362-2049; email, reprints@aacn.org.

CE 1.0 Hour Category A

Notice to CE enrollees:

This article has been designated for CE contact hour(s). The evaluation demonstrates your knowledge of the following objectives:

1. Analyze the difference between recuperative and adaptive strategies of recovery.
2. Identify potential adaptive strategies that can be suggested for use by patients after acute respiratory distress syndrome (ARDS).
3. Describe the roles of family and social supports in promoting adaptation and recuperation

To complete the evaluation for CE contact hour(s) for this article #A21502, visit www.ajconline.org and click the "CE Articles" button. No CE evaluation fee for AACN members. This expires on May 1, 2023.

The American Association of Critical-Care Nurses is accredited as a provider of nursing continuing professional development by the American Nurses Credentialing Center's Commission on Accreditation, ANCC Provider Number 0012. AACN has been approved as a provider of continuing education in nursing by the California Board of Registered Nursing (CA BRN), CA Provider Number CEP1036, for 1.0 contact hour.

1. Describe to me what happened after being diagnosed with ARDS and your recovery in the hospital and/or rehab center.
 - a. Services like therapy, other care, anything about the staff?
 - b. Anything or anyone that were particularly helpful during your recovery?
2. What kind of recovery programs/care did you receive (at the hospital or in rehab)?
 - a. What did you accomplish? (try to understand decision-making process, goal setting)
 - b. Are you still receiving those services/when did you stop receiving recovery services?
3. Tell me a bit about your life and your transition to home or wherever you are now.
 - a. How did you know you were ready to transition home?
 - b. How did you get around the house?
 - c. What goals did you have once you got home?
4. What kinds of follow-up care did you receive after transitioning home (or where you are now)?
 - a. Continued recovery services?
 - b. Seen by PCP? (or whoever is managing follow-up)
5. What things do you remember being particularly hard for you physically?
 - a. What have you done to overcome these problems?
 - b. What problems have you solved?
6. What do you remember being particularly hard for you cognitively?
 - a. What have you done to overcome these problems?
 - b. What problems have you solved?
7. What do you remember being particularly hard for you emotionally?
 - a. What have you done to overcome these problems?
 - b. What problems have you solved?
8. Since the hospitalization when you had ARDS, have there been any periods where you made a lot of progress—where things really got better in your life? [PROMPTS: If so, how did that happen? Who or what helped the most?]
9. What kind of things have stood in the way of your recovery or prevented you from improving as best as possible?
10. What services would be helpful now? [PROBE: why aren't you getting those services? How do you think you could access them?]
11. Have you had any problems with money since your ARDS? Can you tell me about those? [PROBE: housing/bills/insurance/income/savings/skipped medical services or medications?]
 - a. Who or what helped you deal with those problems?
12. How did your partner/friends/family feel after your ARDS?
13. How has your social life changed? [PROBE: mobility/access/driving]
14. What would you advise other patients who have just survived ARDS to do to best recover? [PROBE: where the suggestion/solution originated]
15. Is there anything else you would like to share with us about your recovery after your ARDS?

Additional Methodological Information

In order to ensure that interviews were consistent and that multiple records of interviewee responses were obtained, all interviews were conducted by K.H., a female qualitative sociologist, while 2 other team members (C.S., L.K., and/or 2 other study staff members) took detailed notes and could ask additional follow-up questions at the end of the interview.

Broadly, we sought to explore accommodations and recovery following patients' hospitalization for acute respiratory distress syndrome (ARDS). We referred to Freedman's theoretical model of disability and adaptation, which undergirds the National Institute on Aging's National Health and Aging Trends Study (NHATS) and defines disability as the patient's ability to perform essential self-care, domestic, and social activities and defines adaptations as "behavioral responses to changes in capacity and . . . the receipt of help, take-up of assistive technology, changes to the environment, and other compensatory strategies."¹ Our questions sought to allow patients to identify the problems, adaptations, barriers, and facilitators important in their recovery.

We used sense-making theory to develop questions that allowed patients to speak about the aspects of their experience and recovery that mattered most to them.² Respondents were asked to think aloud about the timeline of events during their recovery and to walk through their recovery journey, with queries about what helped them be successful as well as potential obstacles. In addition to the notes generated by study staff and team members, interviews were recorded and transcribed by a professional transcription service. We pilot tested the interview guide among a group of 10 survivors of in-hospital cardiac arrest³ and revised the interview guide to ask more specifically about various points in their recovery (hospital, discharge, return home) and about social or financial changes or problems resulting from their ARDS.

Data Analysis

We primarily used an open coding approach to identify patterns in how patients addressed disability and recovery following ARDS, with a limited set of deductive codes drawn from the NHATS disability model.^{1,4,5} These codes reflected key domains of adaptation and recovery, including hospital and out-of-hospital services, rehabilitation, social support, health behaviors, and assistive equipment, but we also relied on open coding to fully capture the breadth of respondents' experiences (initial draft codebook below).

K.H. and C.S. independently coded each transcript and then compared interpretations to refine codes. A preliminary codebook was developed from the first 23 interviews. On the basis of this codebook, code reports were generated and K.H., C.S., T.J.I., and C.L.H. then discussed emerging patterns in these reports and refined the codebook and interview guide. Changes to the interview guide included specific follow-up probes regarding financial issues and fewer questions about patients' hospitalizations because many could not remember much of their time in the hospital. Changes to the codebook including breaking apart large codes into sub-codes based on group consensus. K.H. and C.S. each coded the remaining transcripts independently, meeting to discuss and resolve any discrepancies to ensure consensus on each code application.

After consensus, coded transcripts were uploaded into NVivo (QRS International), a qualitative analysis software. With this software, code reports were generated for each code and were reviewed by K.H. and C.S. to ensure that all data were representative of the code definitions. We identified no new codes in the last 12 interviews, suggesting data saturation.⁶ Code reports were created for review and themes were refined to distinguish between rehabilitative and accommodative adaptations to disability, drawing on Freedman's conceptualization of accommodation in successful aging and adaptation to disability.^{7,8} The validity of data analysis was enhanced through our group consensus process and the involvement of coders with varying backgrounds (K.H. has a PhD in sociology, C.S. has a master's degree in public health, and T.J.I. and C.L.H. are board certified in critical care medicine and are experts in survivorship).

Continued

Draft Codebook based on NHATS

Factor	Dimension
Hospital services	Access to care in the initial hospital where ARDS was treated (and ROSE randomization occurred) and services that were of particular help, as well as barriers overcome
Other health system services	Services obtained from other health systems after initial hospital discharge
Family and social support	How family members adapted to postdischarge disability; other sources of support; specific behaviors of family members that facilitated or hindered recovery
Physical health	Onset of new medical diagnoses; changes in management; new relationships with clinicians
Mental health	Experiences of depressed mood, anxiety or other mental health related symptoms
Rehabilitation	Use of formal physical or occupational or cognitive therapy, and which kind;
Health behaviors	Physical activity, healthy diet, sleep, stress and coping strategies
Accommodative equipment	Use of new support devices such as canes, vision aids, motorized wheelchairs; adaptive physical changes (eg, new toilet seats, shower bars)

REFERENCES

1. Freedman VA. Adopting the ICF language for studying late-life disability: a field of dreams? *J Gerontol A Biol Sci Med Sci*. 2009;64(11):1172-1174; discussion 1175-1176. doi:10.1093/gerona/glp095
2. Cardillo L. Sense-making as theory and method for researching lived experience: an exemplar in the context of health communication and adolescent illness. *Electronic J Commun*. 1999;9(2). Accessed January 22, 2020. <http://www.cios.org/EJCPUBLIC/009/2/009223.html>
3. Kallio H, Pietilä AM, Johnson M, Kangasniemi M. Systematic methodological review: developing a framework for a qualitative semi-structured interview guide. *J Adv Nurs*. 2016;72(12):2954-2965. doi:10.1111/jan.13031
4. Bradley EH, Curry LA, Devers KJ. Qualitative data analysis for health services research: developing taxonomy, themes, and theory. *Health Serv Res*. 2007;42(4):1758-1772. doi:10.1111/j.1475-6773.2006.00684.x
5. Emerson RM, Fretz RI, Shaw LL. *Writing Ethnographic Fieldnotes*. 2nd ed. University of Chicago Press; 2011.
6. Giacomini MK, Cook DJ. Users' guides to the medical literature: XXIII. Qualitative research in health care: A. Are the results of the study valid? *JAMA*. 2000;284(3):357-362. doi:10.1001/jama.284.3.357
7. Freedman VA, Kasper JD, Spillman BC. Successful aging through successful accommodation with assistive devices. *J Gerontol B Psychol Sci Soc Sci*. 2017;72(2):300-309. doi:10.1093/geronb/gbw102
8. Freedman VA, Kasper JD, Spillman BC, et al. Behavioral adaptation and late-life disability: a new spectrum for assessing public health impacts. *Am J Public Health*. 2014;104(2):e88-e94. doi:10.2105/AJPH.2013.301687

Supplement 1 Continued

Abbreviations: ARDS, acute respiratory distress syndrome; NHATS, National Health and Aging Trends Study; PCP, primary care physician; ROSE, Reevaluation of Systemic Early Neuromuscular Blockade trial.

Characteristic	Respondents (n=46)	Nonrespondents (n=33)
Age, mean, y	54.9	48.2
Female, %	37	33
White, ^a %	82	85
Hispanic, ^b %	9	6
Geographic region, %		
West Coast	33	21
Mountain West	26	12
Midwest	13	12
South	11	33
Northeast	17	21
High school diploma or higher, ^c %	98	71
Enrolled in Medicare, %	37	15
Primary cause of lung injury, %		
Pneumonia	70	61
Aspiration	15	12
Nonpulmonary sepsis	6	12
Other causes	9	15
Assessments and measurements		
APACHE III score, mean (SD)	98 (26)	86 (27)
Total SOFA score, mean (SD)	8 (3)	7 (4)
Tidal volume, ^d mL/kg of predicted body weight, mean (SD)	6.1 (0.7)	6.3 (1.1)
FiO ₂ , ^e mean (SD)	0.77 (0.21)	0.78 (0.21)
Inspiratory plateau pressure, ^f cm H ₂ O, mean (SD)	25.7 (5.5)	26.8 (5.6)
PEEP, cm H ₂ O, mean (SD)	12.6 (3.4)	12.8 (2.9)
PaO ₂ :FiO ₂ , ^g mean (SD)	98 (31)	97 (28)
Randomization assignment		
Intervention: neuromuscular blockade, %	44	46
6-Month disability score, ^h mean (SD)	3.24 (2.4)	3.11 (2.8)

Supplement 2 Baseline characteristics of respondents and nonrespondents.

Abbreviations: APACHE, Acute Physiology and Chronic Health Evaluation; FiO₂, fraction of inspired oxygen; PEEP, positive end-expiratory pressure; SOFA, Sequential Organ Failure Assessment.

^a Race information provided by 39 respondents and 27 nonrespondents.

^b Ethnicity information provided by 44 respondents and 32 nonrespondents.

^c Educational attainment information provided by 46 respondents and 31 nonrespondents.

^d Tidal volume assessed for 40 respondents and 30 nonrespondents.

^e FiO₂ assessed for 43 respondents and 31 nonrespondents.

^f Inspiratory plateau pressure assessed for 30 respondents and 14 nonrespondents.

^g The ratio of the PaO₂ to FiO₂ was assessed in 41 respondents and 27 nonrespondents. If results of an arterial blood gas analysis were not available at randomization, the ratio was inferred from oxygen saturation as measured by pulse oximetry.

^h Disability assessed for 46 respondents and 27 nonrespondents. The disability score ranges from 0 to 10 and is the number of those 10 activities of daily living/instrumental activities of daily living items on which the respondent or their proxy reported difficulty due to health conditions at 6 months after randomization, with higher scores representing worse disability and scores of 4 or greater interpretable as representing severe disability.

Characteristic	Reported at least 1 persistent problem	
	Yes (n=31)	No (n=15)
Age, mean (SD), y	58.1 (10.2)	48.9 (16.1)
Sex		
Male	17	12
Female	14	3
Race		
White	22	10
Black	3	1
Asian, American Indian, or Alaska Native	2	1
Not reported	4	3
Ethnicity		
Hispanic or Latino	3	1
Non-Hispanic/Latino	27	14
Not reported	1	0
Treatment status		
Neuromuscular blockade	14	6
Usual care	17	9
Disability score, 12 months, mean (SD)	4.37 (2.1) (n=31)	1.4 (1.6)
PTSS score, 12 months, mean (SD)	39.7 (19.5) (n=29)	24.6 (18.3)
MoCA score, 12 months, mean (SD)	22.8 (4.6) (n=29)	24.8 (4.0)

Supplement 3 Patients reporting persistent problems by demographic characteristics and randomization status.

Abbreviations: MoCA, Montreal Cognitive Assessment; PTSS, Posttraumatic Symptom Scale-10.