

Fulfillment of Patient Expectations after Acute Respiratory Failure

A Multicenter Prospective Cohort Study

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Abstract

Rationale: Discussion of patient expectations for recovery is a component of intensive care unit (ICU) follow-up clinics. However, few studies have formally evaluated recovery-related expectations of ICU survivors.

Objectives: To estimate the prevalence of unmet expectations for recovery 6 months after hospital discharge among adult survivors of acute respiratory failure (ARF).

Methods: This was a prospective, longitudinal, cohort study of survivors of ARF discharged to home from five U.S. medical centers. Expectations for functional recovery were assessed by asking which activities and instrumental activities of daily living (I/ADLs) survivors expected to perform independently at 6 months. Survivors' expectations for overall health status were assessed using a visual analogue scale ranging from 0 to 100. At 6-month follow-up, participants reported which I/ADLs they could perform independently and rated their overall health status using a 100-point visual analogue scale. We defined a participant's functional expectations as being met if they reported independently performing I/ADLs as expected at hospital discharge. Health expectations were considered to be met when self-rated health status at 6 months was no more than 8 points lower than expected at enrollment.

Results: Among 180 enrollees, 169 (94%) were alive, and 160 of these (95%) participated in 6-month follow-up. Functional expectations were met for 71% of participating survivors, and overall health expectations were met for 50%. Expectations for functional independence were high, ranging from 87% (housekeeping) to 99% (using a telephone). General health expectations were variable (median, 85; interquartile range [IQR], 75–95). At 6-month follow-up, self-rated, overall health ranged from 2 to 100 (median, 80; IQR, 60–85). In exploratory analyses, participants with met versus unmet expectations differed most in formal education (functional expectations standardized difference = 0.88; health expectations standardized difference = 0.41).

Conclusions: Expectations of survivors of ARF about independent functioning were high and generally met, but half had unmet general health expectations 6 months after discharge. It is difficult to predict whose health expectations will be unmet, but possessing less formal education may be a risk factor.

Clinical trial registered with www.clinicaltrials.gov (NCT 03797313).

Keywords: critical care outcomes; respiratory distress syndrome; survivorship; functional status

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A complete list of APICS-01 Study Team members may be found before the beginning of the REFERENCES.

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Many adult survivors of critical illness experience impairments in physical function, mental health, and cognition (1–5), referred to as post-intensive care syndrome (6). New or worsening dependencies in the instrumental activities of daily living (IADLs) are also common in this population (7, 8). To help address these issues, clinicians have championed post-intensive care unit (ICU) clinics and peer support groups (9–11). Most post-ICU clinics and support groups deliver complex interventions (12) involving multiple interacting components and multidisciplinary teams offering a bundle of services hypothesized to help survivors and their families (13).

Expectation management is emerging as an important component of ICU recovery programs. A 2020 qualitative study of ICU survivors from the United States, United Kingdom, and Australia identified “normalization and expectation management” as one of five key components present in successful ICU recovery programs (14). Similarly, the Intensive Care Society indicated a research priority focused on developing expectation management strategies to counter overly optimistic depictions of ICU outcomes in popular media (15). Although expectation management has intuitive appeal, neither the mechanism by which it impacts patient-reported outcomes nor its efficacy has been empirically tested. As a first step toward understanding ICU survivor expectations, we designed a multicenter prospective cohort study to estimate the prevalence of unmet expectations for recovery among adult survivors of acute respiratory failure (ARF) 6 months after hospital discharge and to explore characteristics of survivors of ARF with unmet expectations.

Methods

In the OSEAR (Observational Study of Expected ARF Recovery) prospective longitudinal cohort study, we enrolled consecutive adult patients with ARF treated in ICUs (clinicaltrials.gov identifier: NCT 03797313). The OSEAR study recruited from six hospitals within five academic medical

centers in Maryland, Utah, Tennessee, and Massachusetts between January 2019 and January 2021. Adult patients were eligible if the clinical team expected them to be discharged home alive and if they also met one or more of the following criteria: 1) mechanical ventilation via an endotracheal tube for ≥ 24 hours; 2) noninvasive ventilation for ≥ 24 hours that was not used for obstructive sleep apnea or other stable indication; or 3) high-flow nasal cannula with fraction of inspired oxygen ≥ 0.5 and flow rate ≥ 30 L/min for ≥ 24 consecutive hours. Key exclusion criteria included 1) mechanical ventilation at baseline or solely for airway protection; 2) more than mild dementia as determined using Information Questionnaire on Cognitive Decline in the Elderly screening (3, 16); 3) life expectancy < 6 months as per clinical judgement; 4) no fixed address; 5) unable to communicate by telephone in English; or 6) a neurological injury expected to prevent a return to

consciousness. We obtained informed consent from patients with capacity around the time of hospital discharge or shortly after they returned home. Trained research staff conducted follow-up assessments by phone 6 months after hospital discharge. Institutional review boards (IRBs) at all participating sites agreed to rely on the Vanderbilt University Medical Center IRB for this study.

Near hospital discharge, we assessed two kinds of participant expectations for recovery. First, we recorded expectations for functional recovery (functional expectations) by asking participants which activities of daily living (ADLs) (17) and IADLs (18) they expect to perform independently in 6 months. Response options for each IADL and ADL (I/ADL) were “yes,” “no,” and “unsure.” Participants were also asked which ADLs (17) and IADLs (18) they could perform independently immediately before the onset of illness leading to hospital admission and which they considered

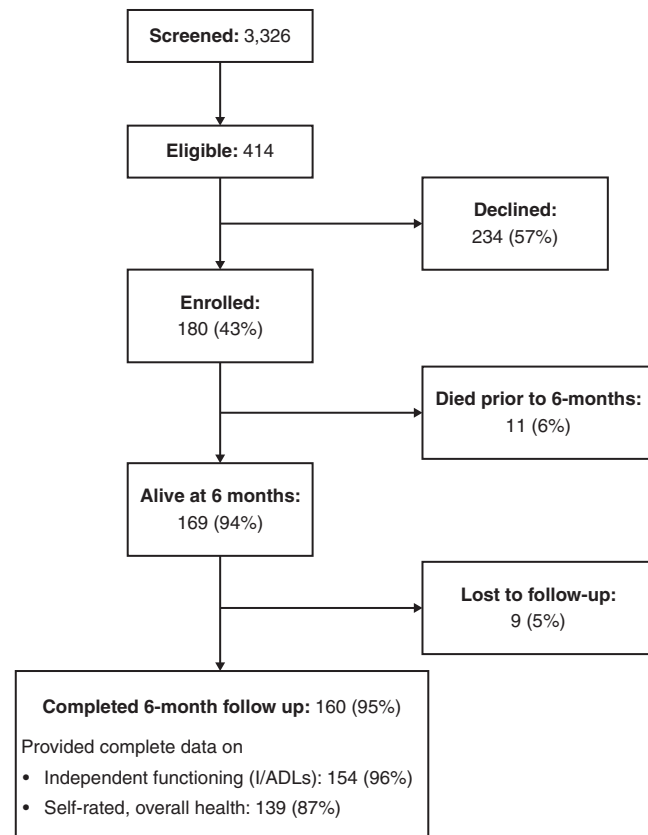


Figure 1. Flow diagram. I/ADLs = instrumental activities of daily living and activities of daily living.

Table 1. How expectation fulfillment was assessed and defined for survivors of acute respiratory failure

	Ascertainment of Patient Expectations at Hospital Discharge	Patient-reported Outcomes at 6-mo Follow-up	Definition of Functional Expectation Fulfillment and the HEG
Functional expectations	<p><i>I am going to read a list of activities. For each activity, tell me if you expect that you'll be able to perform it without help 6 months from now:</i></p> <p>Eating food, showering or bathing, dressing, toileting, transferring, housekeeping, managing money, driving or taking public transportation, cooking, shopping, managing medications, using a telephone (I/ADLs)</p> <p>Response options: yes, no, unsure</p>	<p>The patient or their proxy was asked whether the patient could perform each of the activities independently on the day of the 6-mo follow-up assessment.</p> <p>Response options: independent, dependent</p>	<p>If: 6-mo response = independent for ALL activities with response = yes at discharge, then → functional expectations = fulfilled</p>
Health expectations	<p><i>Please imagine yourself 6 months from now. Think about what you expect your life to be like. Please indicate on this scale how good or bad you expect your health to be in 6 months. The best health state you can imagine is marked 100 and the worst health state you can imagine is marked 0.</i></p> <p>Response options: Visual analogue scale ranging from 0 to 100</p>	<p><i>Now, I would like to ask you to say how good or bad your health is today. I'd like you to try to picture in your mind a scale that looks a bit like a thermometer. The best health you can imagine is marked 100 at the top of the scale and the worst health you can imagine is marked zero at the bottom. I would now like you to tell me the point on this scale where you would put your health today.</i></p> <p>Response options: visual analogue scale ranging from 0 to 100.</p>	<p>HEG = 6-mo response – response at discharge. Health expectations = fulfilled if $\geq -8^*$</p>

Definition of abbreviations: HEG = health expectation gap; I/ADLs = instrumental activities of daily living and activities of daily living.

*We used 8 points as indicative of a meaningful difference between expectations and self-rated overall health at 6-month follow-up based on previous work identifying 8 as a conservative minimal clinically important difference for the EQ-5D visual analog scale (21, 22).

important to perform independently within 6 months of hospital discharge. Second, we recorded expectations about overall health status (health expectations) using a visual analogue scale (VAS) ranging from 0 to 100, with higher scores representing better expected health 6 months after discharge (Table 1). Although there are no validated methods for measuring health expectations after critical illness, a VAS has been used in research on expectations for recovery after lung transplant (19).

During 6-month follow-up interviews, participants or their proxies were asked if they could perform each ADL and IADL independently, and participants (not proxies) reported their perceived overall health using the EQ-5D VAS (20). Participants were not reminded of their expectations for 6 months that they previously reported at hospital discharge. We defined a participant's functional expectations as being met if they reported independently performing the I/ADLs they expected to be able to perform at discharge (Table 1). Health expectations

were met when overall, self-rated health at 6 months was no more than 8 points lower than expected at enrollment (Table 1). We used 8 points as indicative of a meaningful difference between expected and self-rated health status because previous work has identified 8 points as a conservative minimal clinically important difference for the EQ-5D VAS (21, 22).

Participant demographics, including age, sex, and race, were collected from the electronic medical record, as were insurance status, admission diagnosis, Acute Physiology and Chronic Health Evaluation II score (23), surgical status, length of stay, the presence of acute respiratory distress syndrome or coronavirus disease (COVID-19), and ability to perform ADLs (17) at hospital discharge. The area deprivation index (24) and median household income of ZIP code were collected as indicators of socioeconomic status. At enrollment, a standardized questionnaire was used to assess formal education, history of anxiety and depressive disorders, frailty via the Clinical Frailty Scale (25), and resilience

via the Connor-Davidson Resilience Scale-10 (26, 27). Participants' perceived social support was assessed via the Multidimensional Scale of Perceived Social Support (28, 29).

Patient attributes were summarized using descriptive statistics stratified by follow-up status (i.e., assessment complete, deceased, lost to follow-up). For each IADL and ADL (I/ADL), we calculated the proportion of participants who 1) performed it independently before admission; 2) expected to perform it independently at 6 months after discharge; 3) considered it important to perform independently by 6 months; and 4) reported they could perform it independently at the 6-month follow-up assessment. We calculated the proportion of participants with fully met functional and health expectations using the definitions above. Differences in the characteristics of participants with met versus unmet functional and health expectations were described using the standardized difference statistic (30, 31). The standardized

Table 2. Participant demographics, stratified by 6-month follow-up status

	6-mo Evaluation Complete (n = 139)	Alive, but 6-mo Surveys Incomplete (n = 21)	Dead (n = 11)	Lost to Follow-up (n = 9)
Age, yr	53 (44–64)	46 (33–60)	62 (58–68)	40 (34–52)
Sex, male	75 (54)	12 (57)	8 (73)	4 (44)
Race				
Asian	2 (1)	1 (5)	0 (0)	0 (0)
Black	41 (29)	7 (33)	2 (18)	2 (22)
White	87 (63)	13 (62)	9 (82)	6 (67)
Multiracial	1 (1)	0 (0)	0 (0)	0 (0)
Unknown	8 (6)	0 (0)	0 (0)	1 (11)
Formal education*				
Eighth grade or less	2 (1)	1 (5)	0 (0)	0 (0)
Some high school	18 (13)	2 (10)	1 (9)	0 (0)
High school or GED	27 (19)	8 (38)	4 (36)	3 (33)
Some college or 2-yr degree	32 (23)	4 (19)	2 (18)	3 (33)
4-yr degree	36 (26)	1 (5)	1 (9)	2 (22)
>4-yr degree	12 (9)	3 (14)	2 (18)	1 (11)
Median income of ZIP code	\$72K (\$55K–\$95K)	\$72K (\$48K–\$76K)	\$87K (\$71K–\$103K)	\$53K (\$50K–\$74K)
ADI national percentile	38 (18–64)	61 (33–73)	17 (16–48)	42 (38–58)
Insurance status				
Private	98 (71)	11 (52)	8 (73)	4 (44)
Medicare	41 (29)	10 (48)	4 (36)	2 (22)
Medicaid	18 (13)	5 (24)	2 (18)	5 (56)
Uninsured	3 (2)	2 (10)	0 (0)	0 (0)
Clinical Frailty Scale; range, 1–8	3 (2–4)	3 (2–4)	3 (2–4)	3 (2–3)
ICU admission diagnosis				
Respiratory (including pneumonia)	57 (41)	15 (71)	5 (45)	1 (11)
Cardiovascular	30 (22)	2 (10)	2 (18)	2 (22)
Gastrointestinal	11 (8)	1 (5)	0 (0)	3 (33)
Oncology	7 (5)	0 (0)	2 (18)	0 (0)
Sepsis (excluding pneumonia)	10 (7)	1 (5)	1 (9)	2 (22)
Trauma	4 (3)	0 (0)	0 (0)	0 (0)
Other	20 (14)	2 (10)	1 (9)	1 (11)
Surgical status				
Not surgical	96 (69)	19 (90)	11 (100)	7 (78)
Elective	27 (19)	2 (10)	0 (0)	0 (0)
Emergent	16 (12)	0 (0)	0 (0)	2 (22)
ARDS	47 (34)	2 (10)	4 (36)	6 (67)
Tested positive for COVID-19 during admission	30 (22)	1 (5)	2 (18)	2 (22)
APACHE II score	21 (15–26)	19 (18–26)	22 (20–27)	19 (11–25)
Length of hospital stay, d	14 (11–22)	21 (16–30)	10 (7–14)	15 (8–29)
Baseline history of depression	42 (30)	10 (48)	4 (36)	3 (33)
Baseline anxiety disorder	12 (9)	5 (24)	0 (0)	0 (0)
CD-RISC score	35 (29–40)	35 (31–37)	38 (34–40)	33 (29–34)
MSPSS total score	72 (62–81)	72 (60–81)	75 (62–84)	70 (52–72)
MSPSS significant other subscale	6 (4–7)	6 (5–6)	7 (5–7)	5 (2–6)
MSPSS family subscale	6 (6–7)	6 (6–6)	7 (6–7)	7 (6–7)
MSPSS friends subscale	6 (5–6)	6 (6–6)	6 (5–7)	5 (4–6)

Definition of abbreviations: ADI = area deprivation index; APACHE = Acute Physiology and Chronic Health Evaluation; ARDS = acute respiratory distress syndrome; CD-RISC = Connor-Davidson Resilience Scale; COVID-19 = coronavirus disease; GED = General Education Development; ICU = intensive care unit; MSPSS = Multidimensional Scale of Perceived Social Support.

Data are presented as median (interquartile range) or *n* (%).

*Missing for 15 participants.

difference statistic (*d*) is unaffected by sample size and ranges from 0 to 1, with greater numbers indicating more differences between groups. Analyses were performed using R version 4.2.0 (R Foundation for Statistical Computing).

Results

Between January 2019 and January 2021, 180 survivors of ARF were enrolled (Figure 1). At 6-month follow-up, 169 (94%) were alive, and 160 of these (95%) participated in

follow-up. A total of 154 (96%) and 139 (87%) contributed data on independent functioning and perceived health, respectively. Participants who were lost to follow-up or who did not complete the 6-month evaluation were younger on

Table 3. Expectations and importance of functional recovery after acute respiratory failure

Activity	Performed Independently Immediately before the Onset of Illness Leading to Hospital Admission* (n = 180)	Performed Independently at Hospital Discharge (n = 180)	Patient Expects to Be Able to Perform Independently at 6 mo [†] (n = 180)	Patient Reports It Is "Important" or "Very important" to Perform Independently [‡] (n = 177)	Performed Independently at 6-mo Follow-up (n = 154)
Eating	99	94	98	97	99
Showering or bathing	96	61	97	96	93
Dressing	97	64	98	96	94
Toileting	97	70	98	98	97
Transferring	96	75	98	94	94
Housekeeping	83	— [§]	87	87	77
Managing money	94	— [§]	95	92	90
Driving or taking public transportation	91	— [§]	91	90	81
Cooking	87	— [§]	93	87	90
Shopping	85	— [§]	93	90	78
Managing medications	94	— [§]	98	95	94
Using a telephone	99	— [§]	99	95	98

Data are presented as percentages.

*Reported by the participant or their proxy at the time of enrollment.

[†]Participant instruction was as follows: I am going to read a list of 13 activities. For each activity, tell me if you expect that you'll be able to perform it without help 6 months from now. For each activity say: "yes," "no," or "unsure."

[‡]Participant instruction was as follows: Now I'm going to read the same list of activities, but this time I want to know how important performing each activity without help is for your personal satisfaction with your life in 6 months. Remember, the question is: "How important is it to me that I can do this activity without help 6 months from now?"

[§]Instrumental activities of daily living performance are not relevant in the hospital setting.

average, had longer hospital stays, and lived in neighborhoods with greater levels of deprivation (Table 2).

All functional expectations were met or exceeded for 109 (71%) survivors. Participant expectations for functional independence within 6 months were generally high, ranging from 87% (housekeeping) to 99% (using a telephone) (Table 3). For all I/ADLs except cooking and housekeeping, >90% of participants felt it was important or very important to be able to perform the activity independently within 6 months of discharge. Functional independence among these survivors at 6 months ranged from 77% (housekeeping) to 99% (eating food) (Table 3). The greatest loss of independence was observed in using transportation, with 91% of participants driving or taking public transportation before hospitalization compared with 81% of those participating in 6-month follow-up.

Health expectations, evaluated at hospital discharge using a VAS, ranged from 30 to 100 (median, 85; interquartile range [IQR], 75–95, with 100 representing the best health state). At 6-month follow-up, perceived health ranged from 2 to 100 (median, 80; IQR, 60–85). Health Expectations were met for 70 (50%) survivors, meaning that their health was no

more than 8 points lower than the expected health reported at hospital discharge. Among the 109 survivors with met functional expectations, 43 (39%) had unmet health expectations, with 11 (10%) not contributing data on perceived health at follow-up.

Participants with met versus unmet expectations differed most in formal education (functional expectations $d = 0.88$; health expectations $d = 0.41$) (Table 4). Only five people (9%) with unmet functional expectations had a 4-year, post-secondary degree, compared with 47 (43%) of people whose functional expectations were met. Participants with unmet functional expectations had greater frailty before hospital admission (median Clinical Frailty Scale score, 4 vs. 3; $d = 0.76$), were more likely to be female (62% vs. 37%; $d = 0.53$), lived in neighborhoods with higher levels of deprivation (median area deprivation index, 57 vs. 37; $d = 0.47$), reported less social support (median Multidimensional Scale of Perceived Social Support, 68 vs. 73; $d = 0.43$) and lower resilience (median Connor-Davidson Resilience Scale-10, 32 vs. 35; $d = 0.41$), and had higher rates of depression (44% vs. 25%; $d = 0.40$). Compared with functional expectations, differences between participants with met versus unmet health expectations were generally smaller, with all standardized

differences <0.40 except for completed formal education (Table 4).

Discussion

In this multicenter prospective cohort study, 71% of survivors participating in 6-month follow-up reported independently performing all the I/ADLs they had expected to be capable of performing when surveyed at hospital discharge. Before ARF, the vast majority of participants lived independently. Despite nearly half being unable to bathe or dress independently at the time of hospital discharge, their expectations for recovery were generally optimistic. For each I/ADL except housekeeping and cooking, >90% of participants felt it was important to be able to perform the activity independently and expected to do so within 6 months. For the majority of participants, these functional expectations were met. However, only half of survivors perceived their overall health to be as good as they expected at discharge. In exploratory analyses, women with less formal education living in neighborhoods with higher levels of deprivation were especially prone to unmet expectations for functional independence. However, few survivor characteristics were strongly

Table 4. Participant demographics, stratified by expectation outcome

	Functional Expectations*			Health Expectations†		
	Met (n = 109)	Unmet (n = 45)	d‡	Met (n = 70)	Unmet (n = 69)	d‡
Age, yr	53 (43–63)	53 (44–64)	0.17	55 (45–66)	52 (43–61)	0.18
Sex, male	69 (63)	17 (38)	0.53	43 (61)	32 (46)	0.31
Race			0.22			0.25
Asian	2 (2)	1 (2)		1 (1)	1 (1)	
Black	33 (30)	14 (31)		18 (26)	23 (33)	
White	68 (62)	27 (60)		47 (67)	40 (58)	
Multiracial	0 (0)	1 (2)		0 (0)	1 (1)	
Unknown	6 (6)	2 (4)		4 (6)	4 (6)	
Formal education§			0.88			0.41
Some high school or less	12 (11)	10 (22)		13 (19)	7 (10)	
High school or GED	23 (21)	9 (20)		10 (14)	17 (25)	
Some college or 2-yr degree	22 (20)	13 (29)		15 (21)	17 (25)	
4-yr degree	34 (31)	3 (7)		19 (27)	17 (25)	
>4-yr degree	13 (12)	2 (4)		8 (11)	4 (6)	
Median income of ZIP code	\$75K (\$54K–\$101K)	\$67K (\$47K–\$77K)	0.20	\$75K (\$57K–\$101K)	\$67K (\$51K–\$88K)	0.18
ADI national percentile	37 (16–59)	57 (33–72)	0.47	38 (15–58)	45 (22–68)	0.29
Admission diagnosis			0.20			0.31
Respiratory (including pneumonia)	48 (44)	21 (47)		30 (43)	27 (39)	
Cardiovascular	25 (23)	7 (16)		14 (20)	16 (23)	
Gastrointestinal	8 (7)	3 (7)		8 (11)	3 (4)	
Other	28 (26)	14 (31)		18 (26)	23 (33)	
Surgical status			0.23			0.20
Not surgical	74 (68)	35 (78)		50 (71)	46 (67)	
Elective	23 (21)	6 (13)		11 (16)	16 (23)	
Emergent	12 (11)	4 (9)		9 (13)	7 (10)	
ARDS	38 (35)	11 (24)	0.23	15 (21)	15 (22)	0.02
Tested positive for COVID-19 during admission	25 (23)	6 (13)	0.25	24 (34)	23 (33)	0.01
APACHE II score	21 (14–26)	20 (15–24)	0.12	22 (16–28)	20 (14–24)	0.36
Length of hospital stay, d	15 (11–22)	13 (9–22)	0.15	14 (11–20)	15 (11–22)	0.13
Baseline history of depression	28 (26)	20 (44)	0.40	18 (26)	24 (35)	0.20
Baseline anxiety disorder	10 (9)	5 (11)	0.06	6 (9)	6 (9)	<0.01
Clinical Frailty Scale; range, 1–8	3 (2–3)	4 (3–4)	0.76	3 (2–4)	3 (2 to 4)	0.21
CD-RISC score	35 (30–40)	32 (26–38)	0.41	36 (29–40)	34 (29–39)	0.07
MSPSS total score	73 (66–83)	68 (56–76)	0.43	72 (63–79)	72 (60–81)	<0.01

Definition of abbreviations: ADI = area deprivation index; APACHE = Acute Physiology and Chronic Health Evaluation; ARDS = acute respiratory distress syndrome; CD-RISC = Connor-Davidson Resilience Scale; COVID-19 = coronavirus disease; GED = General Education Development; MSPSS = Multidimensional Scale of Perceived Social Support.

Data are presented as median (interquartile range) or n (%).

*Functional expectations were met when survivor’s 6-month independent activities of daily living and instrumental activities of daily living performance fully met or exceeded their expectations at hospital discharge.

†Health expectations were defined as being met if a participant’s self-rated overall health minus expected health was ≥ –8.

‡The standardized difference in means or proportions divided by standard error. This metric is indifferent to sample size. Absolute value ranges from 0.0 to 1.0, with values closer to 1.0 indicative of greater difference between participants with met versus unmet expectations.

§Missing for 12 people.

associated with unmet expectations about general health.

Patient expectations about recovery are complex and dynamic. Studying expectations is challenging because there are few validated measurement methods that are not treatment specific (32–34). Much clinical expectations research to date has focused on people undergoing elective orthopedic surgery and the relationship between their preoperative expectations and postoperative outcomes and satisfaction (35). However, findings from these studies may not be applicable to survivors of ARF for a couple of

reasons. First, expectations about elective surgery are usually formed during outpatient appointments in which surgical teams purposefully shape expectations and patients have time to absorb information. In contrast, decisions about treatment for ARF often must be made quickly and with patient surrogates, rather than patients, because most ICU patients lack capacity at some point during their stay (36). Furthermore, many intensivists report hesitancy to discuss likely post-ICU outcomes with patients and their families (37). Second, compared with people undergoing total hip replacement, the

etiology of ARF is heterogeneous, and many patients with ARF have underlying chronic diseases with poor long-term prognoses. As a result, it is important to replicate research about expectations in cohorts of ICU survivors.

The vast majority of survivors of ARF expected to, and the majority were able to, perform most I/ADLs independently within 6 months, indicative of a ceiling effect for this method of assessing functional expectations in this population. However, nearly 4 in 10 survivors with fully met functional expectations for recovery

reported that their overall health was significantly worse than expected. These data empirically demonstrate that there are important determinants of self-rated health that are not captured by independent functioning. The gap in expectation fulfillment between daily functioning and perceived health may be caused by symptoms such as fatigue and pain (38). Expanding the assessment of functional expectations to include questions about how challenging ICU survivors expect activities to be may help explain this gap and raise the ceiling on functional expectation assessment. Alternatively, a 2021 psychometric evaluation of the World Health Organisation Disability Assessment Schedule 2.0 among adult ICU survivors found no ceiling or floor effects at the 6-month follow-up assessment, suggesting it may be a superior option for measuring function and participation in this population (39).

The concept of health expectations is distinct from the related concepts of perceived health and health-related quality of life (HRQoL). Measures of HRQoL evaluate a person's "level of ability, daily functioning, and ability to experience a fulfilling life" (40, 41). In contrast, perceived health is purposefully subjective and unconcerned with objective measures of functioning. It is also one of the strongest predictors of subjective well-being or happiness (42). As we showed in a recent analysis of more than 800 survivors of ARF, there is substantial variability in perceived health among people with similar self-reported symptoms and daily functioning (43). Confusingly, some HRQoL instruments, such as the EQ-5D (20), ask about both daily functioning and perceived health. Thus, for this study, we purposefully separated daily functioning from perception by asking about expectations for future functioning (ADLs/IADLs) and for future perceived health.

Observed differences between people with met versus unmet functional expectations after ARF suggest that unexpected functional impairments are not

limited to people with specific diagnoses or particularly severe illness. Rather, unmet expectations were most common among survivors who lacked social supports of health, including formal education, neighborhood resources, and social support, and those with frailty and depression. We hypothesize that these factors are associated with unmet expectations in three ways. First, factors like frailty increase the risk of new impairments in independent functioning after critical illness (44). Second, factors like education may be indirect indicators that a survivor did not receive understandable information about recovery after critical illness. Finally, personality traits and mental health comorbidities may contribute to the formation of inappropriate expectations. Testing these hypotheses in future studies will require careful consideration of potential causal pathways.

Limitations

Incomplete outcome assessments (12%) are a limitation of this study. Conjectures about outcomes in this subgroup are difficult, given their relative youth and lengthy hospital stays. However, overall cohort retention (95%) at 6 months was excellent. Also, the COVID-19 pandemic began mid-enrollment, but the small number of participants positive for COVID-19 limited our ability to identify significant differences in this subgroup. We also did not collect data on whether clinical teams provided patients with information about ICU survivorship or recovery. At follow-up, 28 participants (18%) reported receiving extra postdischarge support or enrollment in a posthospital care navigation program, but it is impossible to know how this may have shaped expectations, given the heterogeneity of such programs. Finally, our analyses dichotomized participants as having met or unmet expectations, which may be an oversimplification. Future analyses should explore degrees of expectation fulfillment by looking at the number of functional expectations met and the gap between expected and perceived health.

Conclusions

Expectation management has been identified as a key component of ICU recovery programs, but there has been minimal empirical research on the expectations of ICU survivors. In this prospective, multicenter study in the United States, we found that survivors of ARF generally have high expectations for overall health and daily functioning at the time of hospital discharge. Six months later, expectations about independent functioning (I/ADLs) were met or exceeded for 71% of survivors, whereas expectations about overall health were met for only 50% of survivors. Exploratory analyses suggest that it is difficult to predict, at hospital discharge, whose health expectations will go unmet, but survivors with less formal education and less community or social support may be at higher risk of unmet expectations about functional independence. Before developing and testing interventions for expectation management, further research is needed to understand how expectations for recovery are formed and how unmet expectations impact patient outcomes, including engagement in treatment regimens and quality of life. ■

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