Financial Toxicity After Acute Respiratory Distress Syndrome: A National Qualitative Cohort Study

Katrina E. Hauschildt, MA[1,2]; Claire Seigworth, MPH[3]; Lee A. Kamphuis, MPH[3]; Catherine L. Hough, MD[4]; Marc Moss, MD[5]; Joanne M. McPeake, PhD, MSc, BN(Hons)[6,7]; Theodore J. Iwashyna, MD, PhD[2,3,8]; for the National Heart, Lung, and Blood Institute (NHLBI) Prevention and Early Treatment of Acute Lung Injury (PETAL) Network

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Objectives: The financial burdens and subsequent related distress of medical care, referred to as financial toxicity, may limit access to beneficial treatments. However, financial toxicity after acute care is less described–and may be an important but underexplored mechanism preventing full recovery after critical illnesses such as acute respiratory distress syndrome. We sought to identify the mechanisms by which financial toxicity manifested in patients with acute respiratory distress syndrome, protective factors against such toxicity, and the consequences of financial toxicity to survivors' lives following acute respiratory distress syndrome.

Design: We conducted semistructured interviews following patients' hospitalization and during recovery as an ancillary study to a multicenter randomized clinical trial in acute respiratory distress syndrome. Patients were 9–16 months post randomization at the time of interview.

Setting and Participants: The Reevaluation Of Systemic Early Neuromuscular Blockade trial examined the use of early neuromuscular blockade in mechanically ventilated patients with moderate/severe acute respiratory distress syndrome. We recruited consecutive surviving patients who were English speaking, consented to follow-up, and were randomized between December 11, 2017, and May 4, 2018 ($n = 79$) from 29 U.S. sites.

Measurements and Main Results: We asked about patients' perceptions of financial burden(s) that they associated with their acute respiratory distress syndrome hospitalization. Forty-six of 79 eligible acute respiratory distress syndrome survivors (58%) participated (from 22 sites); their median age was 56 (interquartile range 47–62). Thirty-one of 46 reported at least one acute respiratory distress syndrome-related financial impact. Financial toxicity manifested via medical bills, changes in insurance coverage, and loss of employment income. Respondents reported not working prior to acute respiratory distress syndrome, using Medicaid or Medicare, or, conversely, generous work benefits as factors which may have limited financial burdens. Patients reported multiple consequences of acute respiratory distress syndrome–related financial toxicity, including harms to their mental and physical health, increased reliance on others, and specific material hardships.

Conclusions: Financial toxicity related to critical illness is common and may limit patients' emotional, physical, and social recovery after acute respiratory distress syndrome hospitalization for at least a year. (*Crit Care Med* 2020; XX:00–00)

Key Words: cost of illness; insurance; Medicaid; health status disparities; quality of life; social determinants of health

Growing evidence suggests financial burden related to medical treatment is common and consequential. Zafar and Abernethy (1) defined financial toxicity as the "objective financial burdens and subjective financial distress" resulting from out-of-pocket costs associated with medical treatment, most often studied in advanced cancer (2, 3). Critical illness hospitalizations are resource intensive (4) and associated with subsequent unemployment (5–8) and caregiver burden (9). Less is known about the financial toxicity of hospitalization for critical illness in general and acute respiratory distress syndrome (ARDS) in particular (5, 10, 11). Financial toxicity may be an important but underexplored mechanism causing incomplete recovery after severe illness, including ARDS (12, 13).

Survivors of critical illness have been reported to have high rates of overall financial stress, which persists months after

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[1] Department of Sociology, College of Literature, Science, and Arts, University of Michigan, Ann Arbor, MI.

[2] Institute for Social Research, University of Michigan, Ann Arbor, MI.

[3] Veterans Affairs Center for Clinical Management Research, HSR&D Center of Innovation, Ann Arbor, MI.

[4] Department of Medicine, Division of Pulmonary, Critical Care, and Sleep Medicine, University of Washington, Seattle, WA.

[5] Department of Medicine, Division of Pulmonary Sciences and Critical Care Medicine, University of Colorado School of Medicine, Aurora, CO.

[6] NHS Greater Glasgow and Clyde, Glasgow Royal Infirmary, Glasgow, United Kingdom.

[7] University of Glasgow, School of Medicine, Dentistry and Nursing, Glasgow, United Kingdom.

[8] Department of Internal Medicine, Division of Pulmonary and Critical Care, University of Michigan, Ann Arbor, MI.

DOI: 10.1097/CCM.0000000000004378

return home and is associated with experiences of anxiety and depression (10). Other reported economic impacts include out-of-pocket expenses, loss of savings, housing instability, bankruptcy, and delayed medical care (14–18). Anticipatory guidance about financial toxicity for patients and caregivers requires understanding the mechanisms through which critical illness survivors experience financial burden. Further, understanding if burdens limit emotional and physical recovery is necessary for designing interventions to prevent or ameliorate it.

We sought to understand how patients felt they were impacted financially after surviving ARDS. We explored the types of financial burdens patients experienced, how they coped with burdens, and the impact of financial distress on their recovery. We further sought to identify factors patients perceived as buffering against financial toxicity despite this severe illness. Our work was an adjunct to a multicenter randomized clinical trial (RCT).

METHODS

Study Design and Sample

Reevaluation Of Systemic Early Neuromuscular Blockade (ROSE) was a multisite ($n = 47$) RCT that showed no differences in mortality or patient-centered outcomes when patients with moderate-to-severe ARDS were treated with a 48-hour early continuous infusion of cisatracurium with concomitant deep sedation or a usual care approach without routine neuromuscular blockade and with lighter sedation targets (19). Ninety-seven percent of ROSE patients consented to long-term follow-up, and 89%, 86%, and 85% of survivors were surveyed at 3, 6, and 12 months, respectively. We approached surviving ROSE patients randomized between December 11, 2017 and May 4, 2018, who spoke English and had completed either the 3- or 6-month survey follow-up, to complete a semistructured interview ($n = 79$). There was no selection on outcomes or treatment; six patients were excluded because of severe cognitive or speech difficulties. Patients were mailed a letter and then contacted by telephone for recruitment. Respondents received a $10 gift card. The Vanderbilt University Medical Center Institutional Review Board, acting as central Institutional Review Board for this National Institutes of Health multicenter network, approved this study.

Data Collection

Interviews by phone with patients 9–16 months post randomization were focused on identifying the problems patients experienced and adaptations they developed following their ARDS hospitalization. We developed the interview guide using the National Health and Aging Trends Study model of disability and sense-making theory to develop questions that allowed patients to identify the problems, adaptations, barriers, and facilitators important to their recovery (20, 21) (**Appendix A**, Supplemental Digital Content 1, http://links.lww.com/CCM/F479). Patients were specifically asked how they or their family had been impacted financially by their ARDS hospitalization. The guide was pilot-tested among another group of critically ill patients. An experienced qualitative researcher (K.E.H.) conducted interviews while one or two team members took detailed notes. Recorded interviews were transcribed and deidentified by a professional transcription service.

Data Analysis

We used both open and directed approaches to identify descriptive themes and subthemes (22, 23). Two researchers (K.E.H., C.S.) independently coded each transcript and then compared interpretations to refine codes. After 23 interviews were coded and a preliminary codebook developed, four researchers (K.E.H., C.S., T.J.I., and C.L.H.) discussed emerging themes and refined the coding framework and interview guide. K.E.H. and C.S. independently coded each remaining transcript and resolved discrepancies. After consensus, coded transcripts were uploaded into NVivo (NVivo Qualitative Data Analysis Software; QSR International Pty Ltd, Victoria, Australia). We saw no new codes added in the last 12 interviews, suggesting data saturation (24).

RESULTS

Seventy-nine ROSE patients from 29 sites were alive, eligible, and contacted for inclusion; 27 were not reached, and six declined. Forty-six patients (58%) from 22 sites agreed to participate. Interviews were 13–57 minutes (mean 32 min). Thirty-one of 46 patients (67%; 95% binomial CI: 52%–80%) reported some negative financial impact that they attributed to their ARDS hospitalization. All patterns described below were represented across multiple sites, states, and regions (patient descriptives in **Table 1**). Although patients' comments revealed varying levels of financial strain prior to ARDS, we focus on new financial toxicity patients reported resulted from their hospitalization and/or new disabilities.

Mechanisms of Financial Burden

Medical Bills. Patients reported medical bills from both their hospitalization and subsequent medical care. Some used money set aside for retirement, depleted their savings, or simply could not pay. Out-of-pocket costs described by patients varied substantially, as did perceptions of whether those costs constituted a burden. One patient described regular calls from collection agencies (**Table 2** for additional evidence).

Female, 51: "I had to be life flighted up there, that was 80-some thousand just for the flight. And they did pay a huge part of that but not all of it and…8 or 9 days in the ICU, that's very expensive also. So, yeah, we just…we scrape by."

{Q: Has it affected your savings?}

"Oh my gosh, yeah, we have none of that. That's gone."

Female, 69: "[My current state of residence] won't help because it was in [another state]…I would have to go back to [where the ARDS occurred] and apply for their financial help; I can't do that either. So, half of them have already been sent to collections, and the hospital I got a bill for $258K and I can't remember what percentage of that was mine, but they called constantly. I go, 'I'm sorry, I don't have any money to give you.'"

TABLE 1. Patients in Interview Sample

Characteristics[a]	Value[bc]
Age, yr, median (interquartile range)	56 (47–62)
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	2 (4)
Geographic region	
West Coast	15 (33)
Mountain West	12 (26)
Midwest	6 (13)
South	5 (11)
Northeast	8 (17)
HS degree or higher[d]	45 (98)
Enrolled in Medicare[d]	17 (37)
Primary cause of lung injury	
Pneumonia	32 (70)
Aspiration	7 (15)
Nonpulmonary sepsis	3 (7)
Other causes	4 (9)
Assessments and measurements	
Acute Physiology and Chronic Health Evaluation III score, mean (SD)	98 (26)
Total Sequential Organ Failure Assessment score, mean (SD)	8 (3)
Tidal volume, mL/kg of predicted body weight, mean (SD)	6.1 (0.7)
F_{IO_2}, mean (SD)	0.77 (0.21)
Inspiratory plateau pressure, cm H_2O, mean (SD)	25.7 (5.5)
Positive end-expiratory pressure, cm H_2O, mean (SD)	12.6 (3.4)
Pa_{O_2}:F_{IO_2}, mean (SD)[e]	98 (31)
Randomization assignment	
Neuromuscular blockade	20 (43)
Usual care	26 (57)
Days post enrollment at time of interview, median (interquartile range)	360 (324–385)
Disability score at 6-mo follow-up, mean (SD)[f]	3.24 (± 2.4)

[a] Characteristics were measured at time of Reevaluation Of Systemic Early Neuromuscular Blockade randomization unless otherwise noted.

[b] Data are presented as number (percentage) unless otherwise noted; percentages may sum to greater than 100% due to rounding.

[c] Differences between respondents and non-respondents are described in **Appendix B** (Supplemental Digital Content 2, http://links.lww.com/CCM/F481).

[d] Medicare enrollment information and educational attainment were assessed at 3-mo follow-up.

[e] If an arterial blood gas was not available at randomization, the ratio was inferred from oxygen saturation as measured by pulse oximetry.

[f] The disability score ranges from 0 to 10 and is the count of 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 mo post randomization, with higher scores representing worse disability, and scores of 4 or greater interpretable as representing severe disability.

TABLE 2. **Selected Excerpts Demonstrating Mechanisms of Financial Toxicity**

Medical bills
Male, 62: “I had to dip into my 401K. Actually, to this day, we’re still paying the medical bills off...see, I’m older, you know. I took it out of my 401K that I had from work. You know, you get whacked with the extra penalties. You have taxes and stuff on it.”
Male, 58: “Yeah, well especially earlier in the year because with my health insurance, my Medicare supplement, I have a $3,400 out-of-pocket limit, which I reached months ago…Now of course January first is coming, and it always starts back at zero again…so you know once next year comes and I start getting all these whopping bills for my dialysis treatment, I’ll never be able to catch up.”
Male, 47: “It [impacted me] a lot, to be honest with you. Yeah, because…I’m with [insurance company], so we have to pay 20% of the bill. So, the bill was $60,000+. Again, it was very good hospitals, I mean from [the first] and [second] hospital as well and going to rehab…We had the savings, we used some of the savings and when I called the hospital, I put it on monthly payments as well…I was shocked by how much [that bill was].”
Insurance coverage issues
Female, 56: “I’m hoping that the bills were covered…So, I’m just waiting to get the letters in the mail saying, ‘This wasn’t taken care of and this wasn't taken care of…’ My husband is very stressed out. He is very stressed out, but—I just let him know, I’m on Medicaid and of course they’re gonna let me know what’s up sooner or later.”
Male, 61; “I am dead broke. That’s a fact." {I: It's just wiped out everything? Did you have insurance at the time that this happened?} “I did, but…that eventually lapsed because I wasn’t working.”
Male, 59: “That’s still going on yet today with insurance and medical bills…especially when I had to go on COBRA [Consolidated Omnibus Budget Reconciliation Act health insurance]…It’s like when the payments were due, for some reason they put a stop on the health insurance and any bills I had after that date would be rejected even though I’d paid the [COBRA] bill…I wonder if that’s an isolated thing or not. I don’t know but it happened almost every month and I’d get those [bills] for 15, 10, 20 thousand and once I’d contact the insurance company, then my employer…from several hours of phone conversations—they’d actually get those taken care of.”
Male, 60: “I’m getting antibiotics and I’m supposed to take them, but I’m supposed to take a probiotic to fight the antibiotic in my stomach and they won’t pay for the probiotic, but you know, they pay for the anti[biotic]…I’m on a six-week thing of antibiotics right now, because of a urinary tract infection that I keep getting since I had my heart attack…basically I’ve had it once a month.”
Female, 48: {I: What sort of recovery services have you used since moving down to [new state, to live with your guardian]?} "I haven’t had any recovery service. I haven’t had insurance. I have been my own recovery service"....{I: Did you have health insurance when this happened?} “Yes, I did.”....{I: When did you lose that coverage?} “When I left [home state]. I had [their] Medicaid.”
Income losses
Male, 55: “I had to sell my business. I’m on disability now…I owned a fire prevention company in [state]. We used to clean the kitchen exhaust systems in restaurants throughout the state. Degreased the restaurants, like their exhaust hoods in the kitchen and on the roof…Yeah, I sold everything.”
Male, 70: “It was getting mighty tight before I went back to work. You know, my savings was gone and the workman’s comp insurance was kind of slow on paying the bills…I just had to eat that 2 or 3 months, and that’s what really depleted my savings and stuff.”
Male, 68: “I haven’t got any money coming in anymore. I had little jobs before, you know, that I had done. I don’t do that anymore so that’s shortened up my money to about 500 bucks a month.”
Male, 49: “Unfortunately, the, you know, the time away from work—that’s going to take me years and years to fix…we didn’t lose our house or vehicles. We’re still on track. You know, I’m self-employed so I can work as little or as much—I tend to push myself a little too hard, and a little bit harder to make up, you know, make up for where we lost in all of that.” {I: Do you feel like it set you back in terms of like financial goals you had for the future?} “Yes, we’re set back a little bit, but I mean not bad. It’s probably set me back probably 4 or 5 years.”

Insurance Coverage Issues. Patients also spoke of experiencing confusion and stress due to the complexity of insurance coverage, and/or forgoing services not covered by their insurance. Others described how they lost insurance coverage because of their ARDS hospitalization.

Male, 46: “Out of the blue they say, ‘This is not covered.’ But you were looking through tons of explanation of benefits—you’re like, ‘Well, why is it not covered?’…basically, my stay in the hospital was two different calendar years. And I had two different coverages, so anything prior to the end of December was under the coverage I had. And then I had a different coverage in the new year.”

Income Losses. Numerous patients disclosed losses in income from being unable to work, temporarily or permanently. Some changed jobs after ARDS, but reported being able to work fewer hours and receiving lower wages. New physical and cognitive limitations shaped survivors’ return to work.

Male, 59: "I've been unable to return to my previous work… I was a manager at a [retail] store…[The hospitalization] put a pretty good strain on me and that was probably one of my tougher struggles, adjusting to the financial difference…Just budgeting again to a new reality, not making what I used to make…the new job pays only about half of what the previous job did."

Factors Which Limited Financial Burdens

Some patients reported minor or no financial burdens. Patients who were not working when they experienced ARDS reported that their hospitalization did not result in lost income (**Table 3** for additional evidence).

Male, 62: "I can see some people, like if they were working and then this hit them and they had to lose their work income, that would be an issue, but I was already on disability because of my Parkinson's."

Patients enrolled in public insurance programs (Medicaid/Medicare/other programs, $n = 22$) generally reported minor or no out-of-pocket medical expenses. Some were already insured by Medicare or Medicaid, while some became eligible due to their ARDS hospitalization and subsequent disability.

Male, 42: "Now I have Medicare and Medi-Cal, and thank God it covers basically most of everything that I go in for. It covers my primary doctor, it covers my emergency visits, my prescriptions. I now have a co-pay, but it's not much. It's like a $1.25."

Some survivors with minor or no burdens reported being retired from well-paying (and pension-providing) jobs and benefitting from Medicare coverage and supplemental private insurance, whereas others described ongoing reliance on public assistance programs, such as disability payments, housing support, and Medicaid. Fifteen patients reported no financial burdens: four reported they were retired, nine reported receiving Medicaid or Medicare, and three reported receiving Supplemental Security Income disability; they attributed these factors to not experiencing new financial problems after their ARDS hospitalization.

The three patients who were employed and not on public insurance yet reported minor or no financial burden said they were "very lucky" with generous work and insurance benefits.

Male, 55: "Financially, I have felt very little impact. I've been fortunate I think in two ways…Our health insurance has been amazing in terms of what it has covered, both in terms of the hospital stay and the rehab and recovery…And the other thing that was very helpful was that my employer has short-term disability coverage…even though I was out of work for 6 months, I was still making my salary at 100%."

Consequences of Financial Burden

The consequences of financial burdens were wide-ranging. Patients described specific ways that financial burdens limited their mental and physical health recovering from ARDS. Patients also reported increasing reliance on others for material support, and some experienced new or exacerbated material hardships. Some patients experienced more than one

TABLE 3. Selected Excerpts Demonstrating Factors Limiting Financial Toxicity

Not working
Female, 44: "I usually just work on Sundays at my job, and I've been there for 20 years now…So, yeah, I lost some work, you know…but it wasn't major because I just worked a little bit each week. So, I'm lucky that way. Yeah, I lost money, but it wasn't major because I don't work full-time."
Female, 76: "… I've been lucky. This can be devastating and of course age is part of it too. If I were a family bread winner of 35 or 45 it would be devastating to the family. It would affect everything from the family's lifestyle to even the possibilities of the children's future education." {I: You were you retired when this happened?} "Yes."
Female, 50: "I have a disability, so they—Social Security pay me—so I think it's enough for me."
Male, 64: "I get social security disability plus I'm still considered employed from my company and so I get long-term disability from my company. So, money is not a problem now."
Public health insurance
Male, 70: "Financially we had no—we had good insurance. I'm retired so I have the Medicare. Then also we have [additional] good insurance for myself and that—being in the hospital and the rehab and all, everything got paid 100%. We never got one bill, as far as that goes. Everything got paid."
Male, 57: {Patient's brother speaking} "You know, [my brother] is on Medicare and Med-Cal and a lot of the expenses were covered, not all of them, but it's been very little financial problems with them."
Male, 35: {I: Have you had any financial difficulties or money problems because of happened?} "No, my insurance covers it." {I: Your insurance has covered everything that you've needed?} "Yeah, through my Medicaid."
Generous benefits
Male, 44: "I mean I was out on FMLA. So—I'd been with this company long enough that I was paid for 100 percent for everything, even though I was out."
Female, 61: "Well my hospital bill is 2 million dollars. Million! We've paid $750. So, [my husband] worked at the university for 35 years and we have excellent insurance. So, that is not a problem in the least but we would have lost every single thing we owned if we didn't have insurance."

consequence (for additional evidence, see **Appendix C**, Supplemental Digital Content 3, http://links.lww.com/CCM/F480).

Emotional Distress. Patients described being depressed and concerned by their reliance on others and anxious about insurance issues, unpaid bills, and mounting expenses. Some described how financial worries also impacted their spouses or adult children.

Female, 51: "I actually did go back to work this school year, cause I teach, but at the end of October, I had to be done, I couldn't do it…If I could do that, then I'd be okay, and when I couldn't do that, not so much…My poor husband, I don't know how he does it daily. I know he worries everyday…I mean, it's hard enough on my end, I can't imagine being on his…that worry and financial burden."

Physical Well-Being. Few patients can weigh financial considerations during the acute treatment of their ARDS, but some sacrificed additional recovery services based on costs. Patients described how their insurance delayed or did not cover recovery services they felt were needed.

Male, 51: "[Physical therapy] was very short, a couple weeks maybe; then it was over, and I just laid around basically. My insurance did not cover any more, so they had to cut me."

Other patients with new health conditions or disabilities described delayed or insufficient coverage of other services needed to manage their physical well-being.

Male, 42: "I started dialysis and I wasn't able to get a ride to the outpatient center that would provide the dialysis…Over the holidays, I missed a few sessions of dialysis and it went really bad for me. I had my edema come back and I swelled up…I can't count on [the] government funded insurance—they offer transport, but—you have to give them an exact time and unfortunately, with dialysis, I can't give them an exact time."

Increased Reliance on Others. To deal with financial burdens, patients spoke of relying on family and friends for material support, including help with medical bills or other expenses. Some patients moved in with family because of their health needs but were unable to leave because they could no longer afford to live independently. Others sought out charitable organizations.

Female, 69: "My eldest daughter, she pays for my cable, she pays for the lights … I'm a burden to my family because I have to rely on their finances for me to survive."

Male, 58: "My daughters set up a Go Fund Me page, and we got quite a number of donations from people for that, which really helped, which was really appreciated, so we've been using that money when things have just come up."

Material Hardships. Not all patients had family members they could turn to for support, especially long-term support.

Male, 48: "In the next couple of months, I may end up being homeless because of the financial aspect of it. You know, there are bills that have to be paid and I'm not able to cover it so, if it ends up falling back on [my girlfriend] or her family, which she doesn't want … I've got to deal with it."

DISCUSSION

Patients 9–16 months after ARDS frequently reported some form of financial toxicity they identified as new and resulting from their ARDS hospitalization and its sequelae. Financial burdens included medical bills from their hospitalization and subsequent care, stress related to confusing, limited, or lost insurance coverage, and temporary or permanent income losses. Patients described not working prior to their ARDS hospitalization, having few out-of-pocket medical expenses due to Medicaid or Medicare insurance, or receiving generous work benefits as factors which may have limited some forms of financial toxicity. Financial toxicity was described as causing stress that impacted patients' mental and physical health, limiting patients' rehabilitation and recovery, increasing their reliance on others, and causing material hardships.

These burdens, when present, were consequential for patients and families. Patients said medical bills, insurance coverage issues, and income losses "impacted [them] a lot" (Table 2, Section 1, Quotation 3), were "going to take years and years to fix" (Table 2, S3, Q5), and made their "blood pressure… out-of-whack" (Appendix C, S1, Q4, Supplemental Digital Content 2, http://links.lww.com/CCM/F480). Insufficient insurance coverage for rehabilitation or new ongoing health problems led to foregone care and ongoing financial issues: "I wasn't going to say, 'Oh, I'll do it at any cost'" (Appendix C, S2, Q3, Supplemental Digital Content 2, http://links.lww.com/CCM/F480); "I'll never be able to catch up" (Table 2, S1, Q2). Patients reported costs were born by children, parents, and in-laws, who helped pay medical and living expenses patients could not afford due to their ARDS: "I have to rely on their finances" (quoted above, and also Appendix C, Reliance on Others, Supplemental Digital Content 2, http://links.lww.com/CCM/F480). These burdens exerted an emotional toll on caregivers and partners: "my poor husband … he worries every day." (quoted above); "My husband is very stressed out" (Table 2, S2, Q2).

Much of the research on financial toxicity has focused on patients with cancer; it has demonstrated that patients report significant financial burdens from out-of-pocket expenses, particularly from drug therapies and ambulatory care (25, 26). Our data suggest financially toxic expenses can result from lengthy hospitalizations and rehabilitation. Our findings offer an important qualitative supplement to studies of financial burden among survivors of critical illness (5, 10, 18) and emphasize the need to examine how financial toxicity may differ between patients with cancer and patients with other illness. Patients' abilities to prepare for, or make decisions based on, expenses from their ARDS hospitalization are different from chronic illnesses. But, as in cancer patients (3), income losses from ARDS caused significant distress and impacted patients' entire financial lives, health-related and otherwise.

Financial toxicity also affected patients' social lives, and patients' expressed frustration in requiring material support from others. As Cox et al (27). noted, being unable to contribute financially or work impacts patients' sense of self-worth. Role reversals may also impact caregivers, although we did not assess caregivers' perspectives (15). Given evidence of marked psychologic distress among caregivers following critical illness (9, 28), financial toxicity may extend to caregivers.

How might this be altered? First, follow-up could include screening for financial toxicity, given its potential to impact treatment receipt (29). Second, improving recovery care could minimize patient disability and subsequent financial burden from inability to return to work (30). Third, follow-up services could link to resources that help patients with costs. McPeake et al (31) offered social welfare consultation as part of a rehabilitation intervention, and nearly a third of patients took advantage of this resource. In some cases, patients may qualify for additional benefits; several patients reported protective effects of Medicaid/Medicare.

Our observations are limited by study design. First, all but one respondent had a high school degree, and financial impacts may be different amongst patients with less education. Second, we used patients' reports of perceived financial toxicity, rather than using formal quantitation. Patients' narratives, despite the limitations of recall and selective disclosure, offer a nuanced picture of how financial toxicity arises and spills into other aspects of patients' lives—complementing work using hospital bills and income data (32, 33). Some patients experienced multiple co-morbidities, and this occasionally made it difficult to disentangle financial impacts of their ARDS hospitalization from financial strain resulting from previous medical expenses. However, our patients reported the ability to disentangle these effects in most cases. We did not interview caregivers or family members of surviving patients, nor of those who died prior to follow-up (17); future research should consider their inclusion. Finally, patients who participated in the RCT, or the subset we interviewed, may have experienced differing financial toxicity than patients who did not participate. Such non-response could mean that the financial impacts of ARDS may be broader than those we identified.

CONCLUSIONS

In our cohort, financial impacts of ARDS were perceived to lead to ongoing stress and were perceived to limit patients' emotional, physical, and social recovery after ARDS hospitalization for at least many months. This suggests the hypothesis that there may be broad consequences of unremediated financial toxicity, via multiple mechanisms, that might modify (and limit) the effects of other interventions to promote recovery from acute illness.

ACKNOWLEDGMENTS

We would like to thank all the investigators, coordinators, and staff from the sites contributing to the Prevention and Early Treatment of Acute Lung Injury (PETAL) Network. We would also like to thank Erin Ice for assisting with the descriptive statistics of the article. Finally, we thank the patients who were interviewed for this study for their time and candor.

The National Heart, Lung, and Blood Institute (NHLBI) Prevention and Early Treatment of Acute Lung Injury (PETAL) Clinical Trials Network collaborators are listed in **Appendix D** (Supplemental Digital Content 4, http://links.lww.com/CCM/F541).

Drs. Iwashyna and Hough, Ms. Kamphuis, and Dr. Moss conceived of and designed the study. Drs. Hough, Moss, and Iwashyna obtained funding. Ms. Hauschildt conducted the interviews with assistance from Ms. Seigworth and Ms. Kamphuis. Ms. Hauschildt, Ms. Seigworth, and Drs. Hough and Iwashyna conducted the data analysis. Ms. Hauschildt drafted the initial article. All authors conducted critical revision of the article for important intellectual content and approved the final version of the article.

Supplemental digital content is available for this article. Direct URL citations appear in the printed text and are provided in the HTML and PDF versions of this article on the journal's website (http://journals.lww.com/ccmjournal).

Supported, in part, by grants U01 HL123031 and R01 HL132232 from the National Institutes of Health.

Ms. Hauschildt, Ms. Kamphuis, and Drs. Hough and Iwashyna received support for article research from the National Institutes of Health. Ms. Kamphuis' and Dr. Hough's institutions received funding from the National Heart, Lung, and Blood Institute. Ms. Kamphuis and Dr. Iwashyna disclosed government work. Dr. McPeake's institution received funding from Society of Critical Care Medicine and the Health Foundation. The remaining authors have disclosed that they do not have any potential conflicts of interest.

Address requests for reprints to: Katrina Hauschildt, MA, University of Michigan, 500 S. State Street, 2800 Plymouth Road, NCRC Building 16, Room 326 W, Ann Arbor, MI 48109. E-mail: kehaus@umich.edu

This work does not represent the official position of the U.S. Government or the Department of Veterans Affairs.

Participants were recruited from a national cohort. Interviews were conducted by phone by team members at the University of Michigan.

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