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Patients' and Their Caregivers' Interest in Learning About Post-ICU Syndrome and Seeking Help for It

Abstract: Critical Illness Recovery Programs report low attendance. We aimed to provide information about postintensive care syndrome and to learn which patients would pursue help in a Critical Illness Recovery Clinic.

All patients who checked in to our Lung Center were given a survey regarding their ICU experience and offered information about postintensive care syndrome and an appointment in the clinic.

Nine hundred and twenty respondents reported having had an ICU experience: 37% of former ICU patients reported difficulty returning to their normal lives afterward compared with 21% who were family or close friends of a former ICU patient. Only 5% requested information and less than 1% requested a dedicated appointment.

More than one of three former ICU patients and one in five close friends or relatives of former ICU patients reported difficulty returning to their normal lives after their ICU experience. Very few pursued the opportunity to learn more about it or seek help.

Key Words: critical illness; postintensive care syndrome; postintensive care unit syndrome

To the Editor:

Patients who have experienced a critical illness and those close to them often find themselves with psychological and cognitive problems that were not present prior to their critical illness. Meanwhile, critical care recovery programs created to help them have reported low attendance in their clinics (1–3).

We provided information about postintensive care syndrome (PICS) and investigated the characteristics of ICU survivors and their caregivers that might predict who would be more likely to seek help. Our hope was that this would serve to raise awareness of PICS and would lead to a more patient-centered approach in recruiting for these clinics.

MATERIALS AND METHODS

Every patient who presented to the Brigham and Women's Hospital Lung Center for a scheduled appointment was given a short survey that was voluntary, strictly confidential, and asked

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if they or someone close to them had been admitted to an ICU. If they replied affirmatively, they were asked when it occurred and if they had difficulty returning to their normal life afterward. They were offered information about our program, to speak with someone in person about it for a brief Q & A, or to arrange for a dedicated visit at a later date.

Our initial plan was to collect surveys from January 6, 2020, to March 27, 2020, but the coronavirus pandemic led to premature discontinuation, so the last surveys were collected March 12, 2020.

The Institutional Review Board was notified of this QI project and waived the need for approval.

RESULTS

2,271 surveys were collected. Among respondents, 925 (41%) responded that they had an ICU experience either as a patient or caregiver of a patient (Table 1). Six hundred and four of our respondents (65% of those who had an ICU experience) identified themselves as having been the patient and 18 surveys were incompletely filled out, so 586 were included in the analysis. A total of 316 of our respondents (35% of those who had an ICU experience) identified themselves as having been a close family member

TABLE 1. Patient Respondents

	Total Respondents (n)	Respondents Who Reported Difficulty Returning to Their Normal Lives After Their ICU Experience
Total (n)	586	
Males	323	
Females	263	
Age (mean yr)		
Males	65	
Females	60	
Time since ICU		
< 1 yr (n)	235	89/235 (38%)
1–5 yr (n)	218	82/218 (38%)
5 yr (n)	133	45/133 (34%)
Requested information, n (%)	29 (5)	24 (11)
Requested to speak with a critical care specialist at present, n (%)	19 (3)	18 (8)

More than one of every three patient respondents reported having had difficulty returning to their normal lives after the ICU but only about one of every 10 chose to learn about postintensive care syndrome when presented with the opportunity.

TABLE 2. Nonpatient Respondents

	Total Respondents (n)	Respondents Who Reported Difficulty Returning to Their Normal Lives After Their ICU Experience
Total (n)	302	
Male	100	
Female	202	
Age (mean yr)		
Males	61	
Females	61	
Time since ICU		
< 1 yr (n)	64	15/64 (23%)
1–5 yr (n)	97	16/97 (16%)
5 yr	141	25/141 (18%)
Requested information, n (%)	3 (1)	3 (1)
Requested to speak with a critical care specialist at present, n (%)	1 (0.3)	1 (0.3)

Approximately one of every five relative or other close caregiver of an ICU patient reported having had difficulty returning to their normal lives after the ICU but only 1% chose to learn about postintensive care syndrome when presented with the opportunity.

or friend of a former ICU patient, 14 surveys were incompletely filled out, so 302 were included in the analysis (Table 2). Among those who reported having been a patient, 37% reported having had difficulty returning to their normal life; this compares with 19% who reported being the family member or friend of a critically ill patient and having difficulty returning to their normal life. Only 29 of former patients (5%) requested information and 3% requested to speak with a “critical care specialist” at the time of the appointment or subsequently. Only 1% of family members or friends of a critical care patient requested further information. Of those who reported having had difficulty returning to their normal life, 11% of former patients and 1% of caregivers of former patients requested further information and only two patients pursued a follow-up appointment.

DISCUSSION

It is widely recognized that PICS is prevalent among those who experience a critical illness as both patient and caregiver (4). This project is the first to evaluate patient and caretaker interest in learning more about PICS, a first step toward seeking help, and was designed with the intent of encouraging patients to seek help in our post-ICU multidisciplinary clinic.

Our results suggest that lack of interest even when information was readily available may be part of the challenge. Approximately

33% of former ICU patient-respondents and 20% of nonpatient caregivers of a former patient recognize that they had difficulty returning to their normal, pre-ICU, lives but were not interested in pursuing information.

We can only speculate on the reasons for their apparent lack of interest in pursuing information or evaluation. Some of their lives likely did eventually return to normal. Others may have recovered to a “new, acceptable normal.” These patients may perceive an improvement in their quality of life not explained by changes in physical or cognitive function, a phenomenon referred to as “response shift” (5). It is possible that some respondents had already sought help and treatment for PICS from others of their providers or that some of these patients preferred to put their experience behind them or at least not to revisit it. Others may have been skeptical that anything could be done to help them after having such a traumatic experience with the medical system. This survey was, of course, subject to recall bias especially among the patient-respondents.

Their lack of interest, however, may be the lack of a clear deliverable for improving patients’ recovery. The promise of an accelerated or more complete path to recovery is especially difficult to make in light of the enormous variability of patients’ ICU experiences, their pre-ICU social determinants of health, and post-ICU issues. What may be lacking is a patient-centered, scalable, innovative system for identifying each patient’s unique needs and the flexibility to be able to act upon them.

CONCLUSIONS

Patients who survive a critical illness and those close to them may have experienced their critical illness as a trauma with profound impact on their quality of life and ability to return to their prior level of functioning. Reaching out to these “walking wounded” presents a challenge that may first require more education about PICS, a system for identifying those more amenable and in need of help, and a more convincing promise that we can address their specific needs.

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All work was done at Brigham and Women’s Hospital.

This QI project was supported in part by a grant from the Ariadne Labs, T.H.Chan School of Public Health, Harvard University.

The authors have disclosed that they do not have any potential conflicts of interest.

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DOI: 10.1097/CCE.0000000000000285