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ADMISSION TO THE INTENSIVE CARE UNIT AND WELL-BEING IN PATIENTS WITH ADVANCED CHRONIC ILLNESS

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Abstract

Purpose—To describe the association of intensive care with trajectories of functional, emotional, social, and physical well-being in patients with 3 common advanced illnesses

Methods—Cross-sectional cohort study of 42 patients admitted to the intensive care unit selected from 210 patients with stage IV breast, prostate, or colon cancer or stage IIIb or IV lung cancer; New York Heart Association class III or IV congestive heart failure; and chronic obstructive pulmonary disease with hypercapnea ($P_{CO_2} > 46$ mm Hg). Scores on subscales of the Functional Assessment of Chronic Illness Therapy-General survey were measured monthly for 6 months before and after admission to the intensive care unit and were analyzed by using the unit admission date as a point of discontinuous change to illustrate trajectories before and after the admission.

Results—Overall, trajectories of well-being declined sharply after admission to the intensive care unit. Declines in physical, functional, and emotional well-being were statistically significant. During the 6 months after admission, physical, functional, and emotional well-being scores trended back up to baseline while social well-being scores continued to decline.

Conclusions—Well-being trajectories declined sharply after admission to the intensive care unit, with recovery in the subsequent 6 months, and may be characterized by common patterns. These results help to better describe intensive care as a marker for advancing illness in patients with advanced chronic illness.

Clinicians witness the toll that a visit to the intensive care unit (ICU) takes on their patients, yet are unable to clearly define the overall course of this decline. Since 2003, a number of

studies have characterized typical illness trajectories, helping to explain the impact of disease and suggesting opportunities for intervention.

Studies of cancer decedents and residents of long-term care centers have shown that the greatest functional decline occurs in the last 3 months of life, leading to increased dependence in activities of daily living.^{1,2} Other studies^{3,4} have shown distinct, but heterogeneous illness trajectories for patients with organ failure and other advanced chronic diseases.

High levels of pain and psychological symptoms of posttraumatic stress, depression, and anxiety in ICU patients and their caregivers 3 to 6 months after an ICU stay have significant effects on quality of life.^{5–9} Survivors requiring prolonged mechanical ventilation have a 1-year mortality rate higher than expected by physicians and caregivers in addition to poor quality of life, impaired functional and cognitive ability, and burdensome caregiver needs.^{10,11}

No data are available, however, that describe the association of an ICU visit with the well-being of patients with specific underlying illnesses. Further understanding of what drives well-being in this population would help in the development of interventions aimed at a higher quality of life and might improve long-term outcomes. We sought to better describe the relationship of ICU care to trajectories of functional, emotional, social, and physical well-being in patients with 3 advanced, common chronic illnesses.

Materials and Methods

Overview of Study Design

Pathways is a longitudinal cohort study of 210 patients with advanced cancer, congestive heart failure, and chronic obstructive pulmonary disease, designed to document changes in physical, social, emotional, functional, and spiritual well-being at the end of life. Monthly surveys were administered to patients and their caregivers for up to 6 years or until death. Additional details regarding this sample have been reported previously.¹²

Participants

The Pathways study enrolled subjects on the basis of clinical criteria associated, at the time, with an estimated 50% 2-year survival. These included patients with diagnoses of stage IV breast, colorectal, or prostate cancer and stage IIIb or IV lung cancer, New York Heart Association stage III or IV congestive heart failure with left ventricular ejection fraction less than 40%, and chronic obstructive pulmonary disease with a P_{CO_2} greater than 46 mm Hg and at least 1 hospitalization or visit to the emergency department during the past year. For this analysis, we identified Pathways patients who had an ICU stay during the study period and had at least 2 surveys collected before and after that stay (Figure 1).

Outcome Variables

The main outcome is the patient's functional, emotional, social, and physical well-being as measured by using the 4 subsets of the Functional Assessment of Chronic Illness Therapy-General survey (FACIT-G).¹³ This survey contains the 4 subscales of physical, functional, emotional, and social well-being. The physical, functional, and social subscales contain 7 questions and the social subscale contains 6 questions, all of which are answered on a 5-point scale with a score of zero indicating the statement is "not true at all" and a score of 4 indicating the statement is "very much true." The minimum score for each subscale is zero, the maximum score for the physical, functional, and social subscales is 28, and the maximum score for the emotional subscale is 24. We reversed response scores on negatively

phrased questions and then summed item responses to create scales in which higher scores reflected greater well-being.

Baseline Variables

We recorded diagnostic category and demographics, including age at baseline, sex, race, level of education, marital status, and self-reported health (Table 1). Three covariates were chosen a priori to explore how trajectories of well-being were affected by different dimensions of support. We explored differences in the well-being subscales by 3 different covariates measured before the ICU visit: (1) whether or not the patient received help from relatives monthly or less versus weekly or more; (2) whether or not the patient had an identified caregiver; and (3) how much support the patient received from clergy or laity, some or very much versus none or a little.

Analysis

The analysis examined differences in patients' scores on the FACIT-G subscales before and after an ICU stay. The data were limited to assessments 6 months before and 6 months after the ICU stay, and only the first ICU visit during the study period was included. Individual trajectories and spline smoother curves were used to examine overall trends in each of the subscales before and after the ICU stay.¹⁴ To quantify expected changes in quality of life before and after an ICU stay, linear mixed-effects models were fit to each of the subscales. Admission to the ICU is a natural "transition" point for these participants; therefore, in the mixed-effects models, the ICU stay was modeled as a point of discontinuous change.¹⁵ Separate linear mixed effects models were run for each of the subscales and covariates just described. The covariates were included as a main effect and as interactions with the slope before admission, the shift at the point of the ICU stay, and the slope after the ICU stay. PROC MIXED in SAS version 9.2 (SAS, Inc) was used to fit all models and estimate predicted values and 95% confidence intervals of the subscale trajectories.

Results

Sample Composition

Of the 210 patients in the Pathways cohort, 42 patients were included in the final analysis (Table 1). Ten patients had more than 1 ICU visit during the study period; only the first ICU visit was considered. The mean age was 65 years. Just over half (52%) of this cohort described themselves as white, 40% were married, and 57% had more than a high school education. Fewer cancer patients received ICU care (17%) than did patients with chronic obstructive pulmonary disease (40%) and congestive heart failure (43%). Twenty-eight patients (67%) identified a caregiver, 26 (62%) reported help from a relative monthly or less, and 21 (50%) reported at least some clergy support.

Cohort Trajectories

A considerable amount of variability existed within each patient's trajectory as well as between different patients, and spline smoother curves are used to illustrate general trends (Figure 2). Physical, functional, and emotional well-being changed significantly from before to after the ICU visit (Table 2). Physical well-being scores in the 6 months before the ICU stay were stable (slope $P=.74$); the predicted mean immediately before the ICU stay was 20.3 (95% CI, 18.5–22.1) and after the ICU stay was 15.6 (95% CI, 13.4–17.9; shift $P<.001$). Physical well-being scores returned to the pre-ICU levels approximately 3 months after the ICU stay (slope $P<.001$). Functional scores were the lowest of the scores on all 4 subscales and were also fairly stable in the 6 months before the ICU stay (slope $P=.20$), with a predicted mean of 14.5 (95% CI, 12.8–16.3) immediately before the ICU visit and

decreasing to 11.9 (95% CI, 9.5–14.2) afterward (shift $P=.02$). Predicted functional well-being scores increased in the 6 months after the ICU stay (slope $P=.02$), but did not return to pre-ICU levels. The predicted mean score for emotional well-being was stable in the 6 months before the ICU visit (slope $P=.99$) at 19.4 (95% CI, 18.0–20.7) and decreased after the ICU visit to 18.1 (95% CI, 16.6–19.6; shift $P=.006$). Scores for emotional well-being returned to pre-ICU levels approximately 5 months after ICU discharge (slope $P=.08$). Changes in scores for social well-being were markedly different than the changes seen for the other subscales. Predicted scores in the 6 months before the ICU stay were fairly stable (slope $P=.22$), but the mean score after the ICU visit was not significantly different from the mean score before the ICU visit (Table 2; shift $P=.52$). Predicted social-well being scores are the only scores that declined in the 6 months after ICU discharge and the slope for after the ICU visit in this model indicated evidence of significant decline ($P=.02$; Table 3).

Ten patients had more than 1 ICU visit during the study period. Eight of these 10 patients had a repeat ICU visit less than 60 days after their first ICU visit. The remaining 2 patients' repeat ICU visit was more than 4 months after the first ICU visit. Functional and social well-being were substantially lower in this subset of patients both in the 6 months before the ICU stay and in the 6 months after the ICU stay (Table 4). In the 6 months before the initial ICU visit, the mean score for functional well-being in patients with multiple ICU admissions was 13.8 (95% CI, 8.2–19.4) as compared with 15.4 (95% CI, 9.2–21.6) in patients with only 1 ICU admission, and mean score for social well-being in patients with multiple ICU visits was 13.7 (95% CI, 8.8–18.5) as compared with 20.3 (95% CI, 14.8–25.8) in patients with only 1 ICU visit. In the 6 months after the initial ICU visit, patients who had an additional ICU visit had lower mean scores on all well-being subscales compared with those patients who had only 1 ICU visit, particularly in functional and social well-being. In the 6 months after the initial ICU visit, mean scores for functional well-being in patients with multiple ICU visits was 11.2 (95% CI, 5.9–16.45) as compared with a mean of 14.9 (95% CI, 8.7–21.0) in those patients with only 1 ICU admission, and mean social well-being in patients with multiple ICU visits was 13.0 (95% CI, 7.8–18.2) as compared with 20.5 (95% CI, 15.0–26.1) in patients with only 1 ICU visit.

Covariate Analysis

Predicted values from the mixed-effects models with 95% confidence intervals as shaded regions illustrate the association of each of the covariates with the social well-being subscale as well as the association of caregiver presence with functional well-being (Figure 3). The general trends described in the preceding section can be seen for each of the subscales. Results from these mixed-effects models with interaction terms indicated that the amount of help from relatives, the presence of a caregiver, and the amount of perceived clergy or laity support had little impact on physical or emotional well-being; no interaction terms were statistically significant ($P>.05$, results not shown). The amount of help from relatives and perceived clergy or laity support also had little effect on scores for functional well-being. Patients with caregivers had higher and more stable functional well-being in the months before and after the ICU visit.

In contrast, all 3 of the covariates affected scores for social well-being. Compared with patients who received less help from relatives, patients with greater than weekly help had increasing scores for social well-being in the months before an ICU visit followed by stable and slightly decreased scores for well-being in the 6 months after the ICU visit. Compared with patients who lacked a caregiver, patients with a caregiver had substantially higher scores for social well-being in both the 6 months before and after the ICU visit, with increased social well-being in the months before the ICU visit. Finally, patients with at least some clergy or laity support also showed greater social well-being throughout the entire study period than did those patients who had little or no support.

Individual Trajectories

Individual patients' trajectories of well-being fell into 3 general patterns on visual examination: (1) sharp decline with recovery, (2) sharp decline with a new lower baseline, and (3) continuous decline. Patients from the cohort are used as examples of these 3 trajectories and their data are plotted against the average trend for that well-being subscale (Figure 4).

Discussion

This study is the first to characterize trajectories of well-being in patients with common, advanced diseases who are receiving care in the ICU. Although these diseases have their own well-being trajectories, this study better characterizes the impact of ICU care on the well-being of such patients. Results of this study indicate an overall decrease in well-being after a stay in the ICU, which then increases during the subsequent 6 months. Despite this increase, overall functioning often remains poor with residual disability. Physical scores decline the most, and functional scores are the lowest overall. Emotional scores are the highest and are also well preserved throughout the ICU stay, suggesting emotional resilience. Social scores are well preserved around the ICU stay; however, these are the only scores that decline in the 6 months after ICU discharge. The individual patients' stories and trajectories complement these cohort trajectories by helping to describe further the general patterns and showing how the patterns can be applied to individual patients.

Physical well-being was affected most after the ICU stay, and many clinicians have undoubtedly witnessed this physical decline in their patients. Because physical well-being consists of symptoms such as pain, nausea, and generally feeling unwell, a focused assessment before discharge may help identify areas for potential intervention. Multiple studies have shown that interventions such as intensive communication, proactive palliative care, and ethics consultations can decrease ICU length of stay without adverse effects on mortality; however, symptom assessment has not been documented to improve patients' outcomes.^{16–19} Further study is needed to assess the effectiveness of such interventions in controlling signs and symptoms when patients are making the transition from the ICU to home.

Functional well-being declined after the ICU stay. That the scores for functional well-being were also the overall lowest scores may be explained by the severity of the underlying chronic illness. Functional well-being was also noticeably lower in patients with multiple ICU visits as compared with patients who had only 1 ICU stay. The presence of identified caregivers resulted in higher and more stable scores for functional well-being; however, this difference was not found with the presence of relatives or clergy support, suggesting that different types of social support have different effects on well-being. This finding may help to describe further the variability of individual patients' trajectories in functional well-being (Figures 4A and 4B). Functional well-being consists of enjoyment of work and leisure, ability to sleep, and general fulfillment in life, thus it potentially describes symptoms of developing depression. Previous work has described the prevalence of these symptoms in family members and identified characteristics that are predictors of their development.^{20,21} Potential for screening patients with advanced chronic illness for development of depression before discharge warrants further study.

Emotional well-being also declined after an ICU stay. However, scores for emotional well-being were some of the highest scores on the 4 well-being subscales. Although our study shows decreased functioning and increased symptoms after an ICU stay, these findings did not translate into feelings of sadness, worry, or losing hope. Patients may be getting emotional strength from other sources, such as religion, culture, and family. This finding is

consistent with prior work showing greater spiritual well-being associated with fewer symptoms of anxiety and depression.²²

Social well-being was not affected immediately after the ICU stay; the 95% confidence intervals show substantial overlap in the predicted means before and after the ICU stay, with expected scores in the range from 18 to 21. This subscale was the only one on which scores decreased in the 6 months after the ICU visit (Table 2 and Figure 4c). Scores for social well-being were lower in patients who had multiple ICU admissions as compared with patients who had only 1 ICU stay. This could reflect the social isolation in advanced, chronic illness. Covariate analysis revealed less decline in social well-being in patients who had support from a caregiver, relatives, or clergy, illustrating the importance of having a multidimensional support system. Before this study, little data had shown that the presence of a caregiver improves outcomes.^{23–26} As the intensity of caregiving increases, caregivers experience psychological symptoms as well as exhaustion, general deterioration in health, and even increased mortality.^{27–30} Further research is needed to improve social support and balance the needs of patients with the needs of caregivers.

This study is limited by its small sample size; therefore, any statistical and clinical differences may not be generalizable beyond this study. The diseases studied have inherent well-being trajectories that could not be controlled for when evaluating the effects of ICU care. The subgroups of interest were well distributed, but quite small, which limits the interpretation of negative findings because there may be significant differences that this study is not powered to detect. For example, small differences in slope for some of the well-being subscales may be present but undetected, although differences this small may not be clinically relevant.

The differences in well-being seen in patients who had multiple ICU admissions were not statistically significant, possibly because of the small sample size. Selection bias is most likely introduced by requiring 2 data collection points after the ICU stay, as the 6 patients who were excluded by this requirement most likely experienced worse physical and functional outcomes after the ICU visit. These results do not show causality between the ICU visit and these changes in well-being, although it is plausible that illness and treatment play a direct role in the development of these trajectories, especially in patients with multiple admissions. ICU care is most likely a marker for worsening disease, and these results help to better describe the effects of worsening disease on patients' experience of these 3 common, advanced, chronic illnesses.

Future researchers should continue to evaluate for causal links between critical illness and adverse outcomes. Interventions to prevent these observed declines in well-being might include, upon discharge from the ICU, palliative care consultations for symptoms, screening for major depressive disorder, and helping establish social support. Latent growth curve analysis may be used to recognize subgroups of trajectories and the patient-related factors characteristic of these subgroups. Further study of those patients with multiple ICU visits with a larger sample size may be instructive for that subpopulation of patients and their families. Further development of well-being trajectories using a larger sample size may be instructive to health care providers, patients, and caregivers about what the future holds for ICU survivors.

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Figure 1.
Flow of patients through the selection process for the study.
Abbreviation: ICU, intensive care unit.

Figure 2. Individual profiles show trends in well-being (light gray) with respect to months before and after visit to intensive care unit (ICU). Mean trend lines (shown in black) represent the fitted penalized B-spline curve.

Figure 3.

Effects of caregiver support on functional well-being and effects of caregiver, family, and clergy support on social well-being. Separate mixed-effects models were run for each of the subscales and covariates. The covariates were included as a main effect and as interactions with the slope before admission, the shift at the point of the ICU stay, and the slope after the ICU stay. Lines represent predicted values, and shaded regions represent the 95% confidence intervals generated from the mixed-effects models. In the social well-being mixed-effects models, the following covariate coefficients were statistically significant: (1) the interaction between help from relatives and the post-ICU slope ($P = .001$) and (2) the main effect of presence of a caregiver ($P < .001$).

Figure 4.

Individual profiles (solid lines) and mean trend lines (dashed lines) for responses on well-being subscales with respect to months before and after visit to intensive care unit (ICU). A, HG was a 58-year-old man with severe chronic obstructive pulmonary disease admitted to the medical ICU for hypercarbic respiratory failure that required mechanical ventilation. He ultimately required tracheostomy and placement of a feeding tube, and he was discharged still dependent on mechanical ventilation. In the next month, he was weaned off of mechanical ventilation and had his tracheostomy decannulated. Shortly thereafter, his feeding tube was removed. At one of the last home visits, he stated, "just seem like I'm getting a little more control of my situation, of this illness that I have, getting a little handle on it better, by being asked questions and thinking about it, I'm feeling a little better. I want to go out in the yard and work ... I gather all my strength with the help of the good Lord and He is good. My father celebrated his 96th birthday and he gets around better than I do. He can walk farther than I can." B, CA was a 70-year-old woman with heart failure admitted to the medical ICU with pulmonary edema in the setting of hypertensive emergency. One month after discharge, she said, "I was in the hospital, it bothered me that the medicine they gave me made me hallucinate. I really got angry. Five months later, I had trouble shopping and walking ... it was hard for me to keep up with my shopping list and gifts. My daughter and my sister helped me with my shopping and the wrapping. Throughout her visits, she spoke of what gives her inner strength. I was born with a don't give-up characteristic. I don't let anything get me down and keep me down. I do have faith and I am determined to go on. At her last visit, she said, I have a lot of determination that this is not going to keep me down. I also have a lot of faith that things will get better." C, JN was a 77-year-old man with severe chronic obstructive pulmonary disease admitted to the medical ICU for

respiratory failure. He improved rapidly and was transferred to the medical care area the next day. After this visit, JN had very little to say during his home visits, perhaps reflective of his declining social well-being. JN spoke some about his family, One of my twin daughters is a drug addict and she finally went into rehab in New York. They are going to give her a little boost to get her life together. That is something that made me happy. Six months later, he stated, My daughter went to a drug rehab program. She is anxious to get her life back together. This is her last chance with me.

Consent was obtained from the participants to use these images and quotations.

Table 1Description of sample (N = 42)^a

Variables	No. (%)
Sex	
Female	18 (43)
Male	24 (57)
Race	
White	22 (52)
Nonwhite	20 (48)
Disease category	
Cancer	7 (17)
Chronic obstructive pulmonary disease	17 (40)
Chronic heart failure	18 (43)
Self-rated health	
Poor	7 (17)
Fair	23 (55)
Good	11 (26)
Excellent	1 (2)
Received help from relatives	
Monthly or less	26 (62)
More than weekly	16 (38)
Caregiver present	
Yes	28 (67)
No	14 (33)
Clergy support	
Some or very much	21 (50)
A little or none	21 (50)

^aMean age of participants was 65 (SD, 12) years.

Table 2

Change in well-being from just before to just after the stay in the intensive care unit (ICU)

Well-being subscale	Score, mean (95% CI)		<i>P</i> ^a
	Just before ICU	Just after ICU	
Physical	20.3 (18.5–22.1)	15.6 (13.4–17.9)	<.001
Functional	14.5 (12.7–16.3)	11.9 (9.5–14.2)	.02
Emotional	19.3 (18.0–20.7)	18.0 (16.6–19.6)	.006
Social	19.4 (17.5–21.3)	19.8 (17.9–21.7)	.52

^a *P* value is for the mean shift at the point of the ICU stay.

Table 3

Decline in social well-being after stay in intensive care unit (ICU)

Time relative to ICU stay	Social well-being score, mean (95% CI) ^a
Just before	19.4 (17.5–21.3)
Just after	19.8 (17.9–21.7)
1 month after	19.4 (17.7–21.3)
2 months after	19.1 (17.4–20.9)
3 months after	18.8 (17.1–20.6)
4 months after	18.5 (16.7–20.2)
5 months after	18.1 (16.3–20.0)

^aPredicted estimates and confidence intervals derived from a mixed-effects model including the slope before admission, the shift at the point of the ICU stay, and the slope after the ICU stay. The slope after the ICU visit in this model indicated evidence of significant decline ($P = .02$).

Table 4

Lower functional and social well-being in those with multiple visits to the intensive care unit (ICU)

6 months before ICU	Mean (SD)	
	Multiple visits (n = 10)^a	Single visit (n = 32)^b
Functional well-being	13.8 (5.7)	15.4 (6.2)
Social well-being	13.7 (4.9)	20.3 (5.5)
6 months after ICU	Mean (SD)	
	Multiple visits (n = 10)^c	Single visit (n = 32)^d
Functional Well-being	11.2 (5.3)	14.9 (6.1)
Social well-being	13.0 (5.2)	20.5 (5.6)

^a Mean (SD) of 48 Functional Assessment of Chronic Illness Therapy-General (FACIT-G) subscale scores in the 6 months before the ICU visits from the 10 patients with multiple ICU visits.

^b Mean (SD) of 167 FACIT-G subscale scores in the 6 months before the ICU visits from the 32 patients with a single ICU visit.

^c Mean (SD) of 46 FACIT-G functional subscale (45 social subscale) scores in the 6 months after the ICU visits from the 10 patients with multiple ICU visits.

^d Mean (SD) of 162 FACIT-G subscale assessments in the 6 months after the ICU visits from the 32 patients with a single ICU visit.