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PSYCHIATRIC ILLNESS IN THE NEXT-OF-KIN OF INTENSIVE CARE UNIT
PATIENTS

A Thesis Submitted to the
Yale University School of Medicine
in Partial Fulfillment of the Requirements for the
Degree of Doctor of Medicine

By
Janelle Katie Moulder

2009

PSYCHIATRIC ILLNESS IN THE NEXT-OF-KIN OF INTENSIVE CARE UNIT PATIENTS.

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The prevalence of psychiatric symptoms in next-of-kin (NOK) of intensive care unit (ICU) patients has been reported at higher than 70% when screening is performed using the Hospital Anxiety and Depression Scale (HADS). The primary purpose of this study was to assess the ability of the HADS to predict psychiatric illness, diagnosed with the aide of a validated tool, the Structured Clinical Interview for DSM-IV (SCID). In addition, we asked NOK to rate aspects of the ICU experience to determine possible associations with psychiatric diagnosis. Thirty-four NOK were enrolled in this study from July 2006 to November 2006. Subjects were interviewed to gather demographic information, their perception of the ICU experience, and to administer the SCID and the HADS. At least 6 months later, subjects were contacted by telephone to determine presence of psychiatric morbidity after the ICU experience. Fifty-six percent of all NOK experienced symptoms of either anxiety or depression during the ICU admission and 24% had psychiatric illness. The HADS had 100% sensitivity and 58% specificity when used as a screening tool for psychiatric diagnosis. Those with any SCID diagnosis were more likely to be a spouse (50% vs. 9%, $p = 0.013$) or a primary caregiver (60% vs. 8%, $p = 0.003$). Most NOK identified the healthcare team as supportive, though a subgroup of NOK who slept in the ICU reported that they found the healthcare team less supportive. This small study suggests the HADS is able to predict psychiatric illness in NOK of ICU patients. The ability to implement this tool as part of clinical practice to better meet the needs of families in the ICU warrants further investigation.

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INTRODUCTION

Prevalence of Psychiatric Illness in the General Population

Estimates on the prevalence of mental illness in America range from 20—30%.^{1,2} A recent analysis of the prevalence, comorbidity, and severity of DSM-IV (Diagnostic and Statistical Manual on Mental Disorders, 4th edition) disorders from the US National Comorbidity Survey Replication focused specifically on a 12-month period and defined the severity of various types of mental disorders, including both anxiety and mood disorders.² Comparing classes of disorders, anxiety disorders were the most prevalent class at 18.1%, with mood disorders following at 9.5%. Comparing individual disorders, major depressive disorder was the most prevalent, with 6.7% of the population affected. The prevalence of patients with any DSM-IV disorder was 26.2%; of these patients, 40% were affected by 2 or more disorders. The severity of the disorder was positively correlated with comorbidity (i.e. additional psychiatric disorders present), where severity was defined by disability secondary to the disorder, including suicidal attempts. In the majority of patients affected by major depressive disorder, the disorder was of moderate severity. Mood disorders as a class tended to be more severe than anxiety disorders. Unfortunately, in both primary care and inpatient medicine settings, these disorders go unrecognized by providers approximately 50% of the time.³⁻⁶

Major Depressive Disorder (MDD), Generalized Anxiety Disorder (GAD), and Post-Traumatic Stress Disorder (PTSD) are some of the most widely recognized psychiatric illnesses. With 20% of the US population experiencing some psychiatric illness in any

given year, these clinical entities can cause significant barriers to normal living, limiting the ability to make decisions, carry out daily responsibilities, or be in the company of others.⁷⁻¹⁰ Each of these disorders has well-defined criteria, set forth by the American Psychiatric Association in the Diagnostic and Statistical Manual on Mental Disorders (DSM-IV-TR).¹¹ An appreciation for the specific symptoms of each disorder is important to understand how they impair an individual's ability to function and the impact the symptoms can have on daily activities.

Major Depressive Disorder

MDD is characterized by depressed mood or anhedonia, nearly all day, every day for at least two weeks.¹¹ For a clinical diagnosis, depressed mood and/or anhedonia must be present; in addition, five of nine minor criteria must also be met almost daily by the subject. The minor criteria are: depressed mood nearly every day, decreased interest or pleasure in almost all activities, change in weight or appetite, lack of restful sleep, restlessness or slowed movement, decreased energy, feelings of worthlessness or guilt, lack of concentration, and suicidality. For a diagnosis, symptoms cannot be better explained by bereavement or a physiologic response to a substance. Some subjects may have symptoms of depression to varying degrees. Women generally are at higher risk for developing MDD in their lifetime.¹¹ Cultural differences in presentation and patient recognition of symptoms must be accounted for when diagnosing this mood disorder. Complete diagnostic criteria for MDD can be found in Appendix A.

Generalized Anxiety Disorder

GAD is characterized by excessive anxiety and worry occurring for at least 6 months, without a specific focus or trigger for the anxiety.¹¹ The excess worry is a burden to the individual, is uncontrollable, and interferes with daily tasks. In addition, at least three other symptoms must be present during the six month period defining the disorder.

These symptoms are: restlessness, easy fatigability, lack of concentration, irritability, muscle tension, and lack of restful sleep. The symptoms must not be better identified by another anxiety disorder or occur exclusively during an episode of Post-traumatic Stress Disorder (PTSD; see later section on PTSD), nor can they be a physiologic effect of a substance. Complete diagnostic criteria for GAD can be found in Appendix B.

Though the symptoms must be recognized as independent of another anxiety disorder, GAD frequently co-occurs with other disorders, including mood disorders (e.g. MDD), other anxiety disorders (e.g. panic disorder), and with other stress-related conditions (e.g. irritable bowel syndrome).¹¹ As with MDD, women make up the majority of those diagnosed.¹¹

Post-Traumatic Stress Disorder

PTSD is a well-recognized cluster of symptoms occurring as a result of exposure to a traumatic event causing serious injury or death to oneself or another person.¹¹ The disorder is characterized by a fear-provoking event, which is re-experienced by one or more of the following means: recurrent thoughts or dreams, acting as though the event was ongoing, and psychological distress or physiological reaction at exposure to cues

related to the event. Additionally, subjects avoid stimuli related to the trauma and have a diminished responsiveness to normal activities. Finally, subjects have heightened arousal following the event. The different classes of symptoms all cause significant impairment to daily living and must have a duration of longer than 1 month to meet criteria.

Symptoms of PTSD often are expressed within 3 months of the inciting event, though delayed onset may occur. PTSD is associated with increased rates of other anxiety disorders and mood disorders.¹¹ Complete diagnostic criteria can be found in Appendix C.

Psychiatric Symptoms in Select Populations

From a sociodemographic perspective, certain characteristics decrease the likelihood of an individual being affected significantly by a psychiatric disorder.² These characteristics include male gender, Hispanic or non-Hispanic black, being married, having a college education, having a high income, and residing in a rural area. Consistent associations have been demonstrated between mental disorders and disadvantaged social status: female gender, unmarried, and low socioeconomic status.¹²

Interestingly, the prevalence of symptoms of anxiety and depression has been observed at much higher rates in family members of ICU patients, with rates of anxiety and depression, as measured by number of symptoms, exceeding 70% and 50% respectively.¹³⁻¹⁵ In a recent study of the prevalence of symptoms of anxiety and depression, next-of-kin (NOK) were asked to complete the Hospital Anxiety and Depression Scale (HADS) in the first few days of their loved one's hospitalization in the

ICU.¹⁴ The goals of the study were to establish prevalence rates of anxiety and depression symptoms and identify risk factors for developing the symptoms, such as access to medical information. Seventy-three percent of all NOK had symptoms of anxiety and 35% of all NOK had symptoms of depression. When compared to all next-of-kin, spouses had significantly higher rates of anxiety, and were more likely to have symptoms of anxiety or depression. Compared to NOK of survivors, NOK of patients who died in the ICU had significantly higher rates of depressive symptoms. The longer the patient had been in the ICU did not decrease the prevalence of anxiety or depression in NOK.

A limited Spanish study using the Clinical Analysis Questionnaire (CAQ) to measure psychopathological aspects of personality (i.e. agitation, apathy-withdrawal) in family members of trauma patients in the ICU found that more than 50% of family members showed symptoms of depression. Women had higher scores on the CAQ, indicating deviation from normal in almost all areas evaluated by the scales of the questionnaire.¹⁵ Compared to men surveyed in the ICU, women were found to be more anxious, have lower energy, and express feelings of guilt and suicidal depression. When both men and women were compared to the control group of adults without hospitalized relatives, women were in fact more vulnerable to symptoms of anxiety or depression, but more than 50% of all family members of the patients in this ICU showed symptoms of depression. Though the majority of patients in this study were trauma victims and were receiving mechanical ventilation, the prevalence of depressive symptoms in their NOK is consistent with rates reported in non-trauma ICUs.^{13, 14}

PTSD has recently been identified as a disorder for which family members of ICU patients are uniquely at risk, especially if PTSD is also noted in the patient.^{16,17} Using the Impact of Event Scale, which evaluates the severity of PTSD symptoms, Azoulay et al. found 33% of family members of ICU patients to have moderate to major risk for PTSD.¹⁸ A main risk factor for PTSD symptoms was participation in end-of-life decisions. Of the patients who died in the ICU, over 50% of their family members experienced symptoms of PTSD; of the patients who survived, over a quarter of their family members had similar symptoms.

A proposed hypothesis for the increased prevalence of psychiatric illness in family members of ICU patients is the relatively stressful circumstances NOK encounter with a loved one in the ICU, especially if that NOK must assume the role of primary decision-maker.¹⁹ Spouses, a subgroup of NOK identified to have an increased rate of psychiatric symptoms,¹⁴ often assume this role and inherit the burden of making decisions regarding the patient's care. The primary decision-maker must then make choices about the patient's care using information presented in terms that may be unfamiliar. Additionally, the psychological stress of choosing to withdraw or withhold care compounds the ICU experience^{13,20} and the day-to-day changes in both the stability of the patient and the expectations for recovery heightens the intensity of the situation.¹³ In a society such as the United States that promotes patient autonomy and participation in the decision-making process,²¹ the difficulties a family member faces as a surrogate decision-maker must be identified. The NOK's level of comfort with the assumed autonomy must be established for optimal participation to occur.²² Barriers to the decision-making process

may include inadequate communication or poor relationships with the healthcare team caring for the patient.²³ These barriers intensify an already stressful situation for primary decision-makers, a subgroup of NOK largely comprised of spouses, who have a higher risk of psychiatric symptoms.¹⁴

Incomplete information received from providers in the ICU has been associated with higher rates of psychiatric symptoms in family members.¹⁸ Therefore, families need to be provided with clear information delivered in a compassionate way by an ICU provider when asked to participate as a surrogate decision-maker for the patient.²⁴ The psychological burden the NOK face when assuming this role is clear and the consequences of poor communication with the healthcare team can be severe.

Adequate communication is facilitated by both continuity of care and increased time spent on cultivating the relationship between NOK and healthcare providers. As demonstrated in the study by Johnson et al, “communication by the same provider was important when measuring the ability of an ICU to meet family needs.”²⁵ Continuity of care with various providers of the team improved both communication and satisfaction. As a result of improved communication with providers, NOK would be likely to receive more complete information and rates of psychiatric symptoms could decrease.

Siegel et al.²¹ demonstrated that 34% of NOK contacted 3-12 months after the death of their loved one in the ICU met criteria for at least one major psychiatric illness. Of those with psychiatric disease, 27% had MDD and 10% had GAD. Among this population,

certain variables were associated with psychiatric illness including spousal relationship to the patient, those who identified additional major stressors in their life, patients whose illness was present for less than 5 years, and NOK who did not find their physician to be comforting. Interestingly, the study noted that only 17% of their subjects had a history of psychiatric care before the patient's death in the ICU, and approximately half of those subjects had a current psychiatric illness.

Just as psychiatric disorders go unrecognized by providers in the general population, NOK's psychiatric symptoms may also go unrecognized. The literature on the NOK of ICU patients suggests the NOK are uniquely at risk for psychiatric symptoms on screening.^{13-15, 18} Although there has been limited confirmation that the presence of psychiatric symptoms is indicative of a true psychiatric disorder, given the circumstances in the ICU, NOK may have an actual prevalence of disorders that is higher than the prevalence seen in the general population.

Detecting Individuals with Psychiatric Symptoms

Many screening tools exist for the identification of psychiatric illness, including depressive disorders and anxiety disorders. The majority of these tools have been used in both inpatient and outpatient settings. The most widely used screening tools are those that are valid when compared to more comprehensive diagnostic tools and are easy to administer as either self-report or using concise, provider-administered questionnaires. Each tool has its individual merits and weaknesses; however all are sensitive enough to recognize the psychiatric symptoms suggestive of psychiatric illness.

Structured Clinical Interview for DSM-IV

The Structured Clinical Interview for DSM (SCID) was initially designed to facilitate diagnostic interviews. Organized by modules, the interviewer may ask questions regarding the presence or absence of symptoms for Axis I disorders (e.g. anxiety disorders, mood disorders), evaluating current and lifetime occurrence.²⁶ The SCID requires the interviewer to be trained in administration and a systematic approach must be used to interpret the subject's responses. The presence or absence of symptoms is then noted by the interviewer and a distinct DSM-IV-TR diagnosis may be given. The SCID is effective in distinguishing mood disorders from anxiety disorders, for example, MDD from GAD.²⁷ The SCID may suggest the presence of subclinical disease, but does not provide information about the severity of the symptoms with respect to a clinical diagnosis.

Hospital Anxiety and Depression Scale

The HADS was developed as a self-assessment mood scale, specifically for use in non-psychiatric hospital clinic populations.²⁸ Although the original intent was for outpatients, it has gained widespread use because it is an effective screening tool in many populations, has been repeatedly validated, and is easy and inexpensive to administer.^{29,30} The original design was formulated to be a quick screening tool focusing on two common psychiatric symptoms, anxiety and depression. Scoring of the HADS was found to be most effective in detecting probable presence of a disorder with scores greater than 10, with scores ranging from 8-10 suggesting possible cases. Additionally, as a result of these subscales, progression or presence of clinically significant symptoms could be

monitored, as the scale reflects the subject's general current mood, including symptoms during the week prior to administration.

Though originally designed for outpatients in hospital-based clinics, it has been used with success in the primary care setting as a screening tool for anxiety and depression, as well as a screening tool for emotional distress.^{6, 28, 29, 31} Recently, the HADS has been integrated into studies evaluating symptoms of anxiety and depression in the family members of ICU patients, given its ease of administration and concise assessment of symptoms.^{13, 14} The HADS is both consistent in its findings and measures similar variables as compared to other screening questionnaires for depression, as identified by the DSM-IV-TR criteria.

Beck Depression Inventory

First designed in 1961, the Beck Depression Inventory (BDI)³² is a self-report inventory that assesses the *severity* of depressive symptoms. The BDI is able to differentiate depression from anxiety, as well as discriminate subtypes of depression.^{33, 34} It has been redesigned a number of times to improve the consistency of the symptoms assessed with those listed in the diagnostic criteria in the DSM-IV.³⁵ Its strong internal consistency, ability to measure many facets of depression, and sensitivity to change make the BDI ideal for assessing the intensity of depression.³³ Though controversy exists regarding day-to-day instability of the results of this self-report inventory, it remains one of the most widely used inventories of its kind.³³

Beck Anxiety Inventory

The Beck Anxiety Inventory (BAI)³⁶ was originally designed as a self-report tool to measure the severity of anxiety with symptoms distinct from those of depression.³⁷ Its high internal consistency (in terms of all the variables assessing anxiety symptoms) and high correlation with other validated measurements has been demonstrated; however, it is unable to classify symptoms into the broader category of belonging to anxiety or mood disorders.^{37, 38}

Comparison of the SCID to the HADS

The SCID is a comprehensive tool to diagnosis DSM-IV-TR disorders, but is time-intensive and must be administered by a trained individual. The SCID is not easily nor quickly administered, two traits desired in a screening tool that can be applied in the clinical setting. The HADS, which is easily *and* quickly administered, is ideal as a screening tool, but when compared to the SCID diagnostic tool for depression, the HADS symptom review focuses on general characteristics of depression, rather than addressing other distinct symptoms such as suicidality.²⁸ Use of the HADS as a screening tool is best when followed by a clinical interview, with a two-stage screening enabling identification of up to 98% of patients with major depressive disorders.⁶

Though higher HADS scores have been associated with a greater likelihood of syndromic depression or anxiety, the scores do not always correspond with a clinical diagnosis per the SCID criteria.³¹ A small number of patients with clinically recognized anxiety or depressive disorders receive a normal HADS screen, perhaps because the HADS reviews

symptoms only over the course of the past week.³¹ However, the ability of the HADS to classify symptom presence or absence in the general population has been recognized,²⁹ with only one study asserting that the HADS is a poor depression screening tool, with poor agreement between the HADS and the SCID.³⁹ The authors of this study suggested that their findings may have been because a significant number of their subjects were low literacy individuals and the HADS requires high literacy levels of the subject for interpretation.³⁹ Overall, the HADS appears to be an effective tool to screen for psychiatric illness, however, as with other screening tools, the results may vary in certain subgroups of the general population and its effectiveness as a screening tool in the ICU is unknown.

Addressing the Psychiatric Needs of Next-of-Kin

Various screening and diagnostic tools are available to assess symptoms in NOK, however their use both during and after the ICU experience is limited. NOK have unique risk factors for psychiatric symptoms during the ICU experience; however, when patients survive, stressors and symptoms do not end with discharge. Caregivers experience heightened levels of anxiety upon patient discharge to home, with caregiver burden contributing to anxiety in NOK.^{17, 20, 40, 41} The burden on the caregiver stems not only from physical and financial demands,^{40, 41} but also from the psychological impact of a life-altering ICU experience and the demands of the recovery period.⁴²

Though any recovery period can be stressful, the unique stressors present during and after an ICU admission may make NOK who are caregivers of ICU patients more likely to

have symptoms of anxiety and depression during the recovery period. Young et al. found at 3 months after discharge of ICU or elective surgery patients, relatives (compared to patients) were more likely to have a HADS score suggestive of a clinical diagnosis of anxiety or depression. The rates of both possible and probable diagnosis were greatest in relatives of ICU patients compared to relatives of elective cardiac surgical patients, with a significantly higher number of depressive symptoms seen in ICU NOK.⁴²

In analyzing themes from open-ended questions, relatives of ICU patients found the ICU experience to be more devastating when compared with the relatives of patients undergoing an elective procedure. The authors propose the greater devastation in ICU relatives may be due to differences in the predictability of hospitalization events, amnesia in ICU patients leading to lack of shared memories with relatives, understanding and potential conflict in relationships, and differing sedation and psychotropic drugs.⁴²

Family members at risk for developing psychiatric illness as a consequence of the ICU experience may benefit from being identified prior to leaving the ICU. However, there is little awareness of the fact that NOK have unique risks for developing a psychiatric illness. The scope of the problem must be assessed to determine if psychiatric symptoms present in the ICU are predictive of a psychiatric disorder using a rigorous diagnostic tool. NOK with psychiatric symptoms may benefit from being identified in order to facilitate a better relationship with the team and an easier experience for the NOK with regard to their responsibilities as a primary decision-maker. A brief evaluation for psychiatric symptoms could help identify those NOK who are likely to develop a

psychiatric disorder in association with the ICU experience and potentially benefit from an intervention.

Previous studies have been able to use the HADS as a screening tool for NOK in the ICU. The sensitivity and specificity of the HADS for predicting disease when compared to the SCID is variable in non-ICU populations.^{6,31,39} There has not yet been a study determining if a positive HADS screen for psychiatric symptoms in NOK of ICU patients is predictive of psychiatric disease, as indicated by a validated diagnostic tool such as the SCID. The predictive value of the HADS in identifying NOK who will have symptoms of anxiety and depression months after the ICU experience also remains to be determined.

STATEMENT OF PURPOSE

This study was designed to determine if psychiatric screening tools could be used to predict NOK likely to have psychiatric illness as a consequence of the ICU experience. We hypothesized that the HADS would be predictive of a diagnosis of MDD, GAD, and/or PTSD using the SCID in the NOK of ICU patients. We also hypothesized that a positive HADS screen in the ICU would be predictive of those at risk for psychiatric diagnoses of MDD, GAD, and/or PTSD eight months or more following their loved ones' ICU stay. We sought to confirm certain risk factors for developing syndromic psychiatric illness in NOK, regardless of patient outcome, including: 1) spousal relationship to patient, 2) patient age, and 3) failure to find healthcare team as a source of comfort. We also hoped to identify risk factors for psychiatric illness specific to conditions NOK experience in the ICU.

METHODS

Study Development

This study was conducted by Janelle K. Moulder (JKM) and Mark D. Siegel, M.D. (MDS). The study aims and design were developed by JKM and MDS. Patient identification, data collection, database development, and data analysis was conducted by JKM with the support of MDS. Drs. William Sledge and Paul Desan of the Department of Psychiatry served as consultants for the integration of psychiatric interviewing tools into this study. The thesis was written by JKM with the support and guidance of MDS.

Study Approval

The study received the approval of the Human Investigation Committee (HIC) of Yale University School of Medicine (Protocol # 0605001432).

Subject Enrollment

The study was conducted at Yale-New Haven Hospital (YNHH); subjects were NOK of medical ICU patients. The medical ICU patients could reside in the medical ICU or board in other subspecialty ICUs, such as cardio-thoracic, cardiac, and neuroscience. Subjects were enrolled between July 2006 and November 2006, with subject telephone follow-up occurring 8-14 months after the initial interview between March 2007 and March 2008. Eligible participants were self-reported or documented NOK of ICU patients. ICU patients were first identified through review of the ICU census and discussion with ICU staff, after which potential subjects (the NOK) were approached and

asked to participate in the research study. In order to maximize the number of subjects enrolled, each new admission was logged onto a master sheet by JKM, with the admission date as well as the date the NOK would become eligible to participate in the study (i.e. 2 days after admission). Potential subjects were approached with information about the study prior to the eligibility period, and if interested, a date and time was established to conduct the interview. In order to maximize interviewer availability and subject enrollment, JKM would be in the ICU during peak visiting hours, late morning through the evening, at a minimum of 6 days per week during the summer months of the study.

Eligible subjects were NOK of patients admitted to the medical ICU service; only one NOK per patient was sought. To be eligible, NOK had to be at least 18 years of age and speak English or Spanish fluently. Patients had to be in the ICU for at least 2 days but not more than 7 days at the time of enrollment (these parameters were adopted from the literature).^{13, 14} Exclusion criteria for participants were:

1. Unwilling to participate in ICU interview or 6 month follow-up interview
2. Not fluent in English or Spanish
3. No home telephone
4. Prior participation in this study
5. Current, symptomatic major psychiatric illness that would impair their ability to participate or make it potentially dangerous for them to participate in this study, as assessed by self-reporting or report from other family member.

Nine participants were interviewed as part of the project pilot in an effort to modify question sets, data collection sheets and optimize the time spent on each interview. No major revisions occurred to the questions sets or data collection sheets as a result.

Questions regarding the ICU experience were revised for clarity. The data from these participants were not included in the final analysis because more questions were asked regarding demographics and the ICU experience in the final population.

Data Collection

All forms, such as the information sheet, HIPAA authorization forms, informed consent forms, and Short Portable Mental Status (SPMS) questionnaire, were translated from English to Spanish by a fluent Spanish speaker (JKM) when a validated Spanish version was not available. The Spanish translation of the forms was translated back to English by a second native speaker to assure accurate translation. Both the SCID and HADS are available in a validated Spanish version. JKM received training for administration of the SCID by Marion Michalski, MA a researcher who has used the SCID extensively for cancer patient research and has trained multiple researchers in using the SCID. JKM received training for scoring the SCID by Dr. Paul Desan.

Subjects willing to participate were then evaluated for their capacity to participate using the SPMS evaluation. SPMS is a short, 10-item questionnaire that assesses cognitive impairment and whose scoring accounts for differences in education level.⁴³ Interviews were conducted in a private meeting area in the ICU, such as the waiting room or family conference room. Demographic information was obtained for the NOK and the patient,

including age, gender, and race. NOKs were asked to identify the patient's illness, its chronicity, and any other comorbidities. Additionally, the following information was collected:

1. The relationship of the NOK to the patient
2. NOK's contact with the patient's outpatient primary care physician
3. Desire of NOK to receive counseling by social worker or their own therapist
4. Previous/current history of mental illness in the NOK, as reported by the NOK.

Subjects were asked to rate statements regarding their own experience in the ICU.

Categories addressed by these statements included healthcare team compassion, support, skill, coordination and professionalism; healthcare team communication and information delivery; NOK's perception of the *patient's* ICU experience; number of hours NOK spent visiting per day and current stressors for NOK (see Appendix D for full list of statements). The statements were rated using the following scale: almost all the time, most of the time, some of the time, none of the time, with the option to refuse to answer, respond with "I don't know," or that the statement was not applicable. Next, the SCID was administered to evaluate for lifetime and current MDD, GAD, and PTSD. Finally, the NOK completed the HADS independently, unless vision was impaired, in which case the questionnaire was read aloud and the interviewer recorded the answers.

Follow up with all participants occurred via telephone 8 to 14 months after the initial interview in the ICU. At this time, the SPMS was administered again to assure the

subject's capacity to participate. Information regarding perception of the ICU experience was again collected, in addition to administration of the SCID for current MDD, GAD, and PTSD. The Beck Depression Inventory-II (BDI-II) and the Beck Anxiety Inventory (BAI) were administered to assess the degree of psychiatric symptomatology. Finally, participants were asked whether they sought or were seeking therapy for psychological distress with interventions such as medication, clinical therapy, faith-mediated healing, or support groups. They were asked to comment on whether receiving any form of therapy or support improved, worsened or had no effect on their mental health. Finally, the subjects were asked to rate their experience in participating in this study.

If a patient was readmitted to the ICU during the interval between the first ICU interview and earliest possible follow-up interview 6 months later, data from their NOK's initial admission were used. All NOK of ICU patients met with social workers during the admission, but were offered additional meetings with social work if interested. If subjects had a score above the threshold for a possible psychiatric diagnosis based on symptom report (using the SCID and/or HADS), the ICU social worker was alerted, even if a social work meeting had already occurred. If subjects became tired or obviously distressed by the interview, the interview was postponed or terminated, based on the subject's request and/or the discretion of the interviewer. Only 1 subject terminated the interview due to distress; this occurred during the follow-up interview. Interviews in the ICU were occasionally postponed and restarted at a later time in order for NOK to attend family meetings or to leave for the day. This occurred with seven subjects during the course of the initial interview. During the follow-up interview that occurred 8-14 months

after their NOK's ICU admission, four subjects with a score above threshold for a possible psychiatric diagnosis based on symptom report (using the SCID, HADS, BAI, and/or BDI) were referred to their primary care physician immediately. The research team did not offer psychiatric care to study participants.

Data Processing and Analysis

All portions of the SCID (MDD, GAD, PTSD) were scored using criteria for diagnosis from the DSM-IV-TR,¹¹ with diagnosis being either present or absent. HADS was scored as positive if responses for either depression-focused questions or anxiety-focused questions totaled 8 points or greater, which has been shown to select for those with at least a possible diagnosis.²⁹ The Beck Inventories (i.e. BAI, BDI) were scored using established criteria.^{32,36} The BAI with total scores of 0-21 indicate minimal anxiety, scores of 22-35 indicate moderate anxiety, and scores over 36 indicate severe anxiety. The BDI with total scores of 0-13 indicate minimal depression, scores of 14-19 indicate mild depression, scores of 20-28 indicate moderate depression, and scores of 29-63 indicate severe depression.

Microsoft Excel (Microsoft Office 2004) and Statistical Package for Social Sciences (SPSS, version 15) were used for data analysis. Patient and NOK characteristics are shown as percentages or the median and interquartile range, as appropriate. Ordinal data, such as the responses to questions regarding the ICU experience, are shown as median and interquartile ranges. Data collected on the decision to sleep in the ICU was changed to a dichotomous variable, where responses of "almost every day", "most every day",

and “some of the days” were grouped together as yes and “rarely” was grouped as no. Fisher’s exact test was used to determine associations between dichotomous variables. The Mann-Whitney test was used to analyze continuous variables. All data were analyzed using two-tailed tests; a p value of less than 0.05 was used as a threshold for statistical significance.

RESULTS

Subject Enrollment

Two hundred forty-eight MICU patients were admitted during the initial interview period. One hundred thirty-one patients were transferred from ICU prior to spending 48 hours in the unit (See Figure 1). The NOK of 24 were disqualified because the patient did not survive the first 48 hours, was a MICU boarder and not critically ill, or because the patient or NOK did not meet study inclusion criteria. Forty-nine patients did not have NOK present during visiting hours during the study period. Of the remaining 44 eligible NOK, 34 agreed to participate in the study. Reasons for refusal among the remaining 10 included the psychiatric nature of the study (n=3), the length of the interview (n=2), inability to complete the interview (n=1), and inability to keep the interview appointment time (n=4).

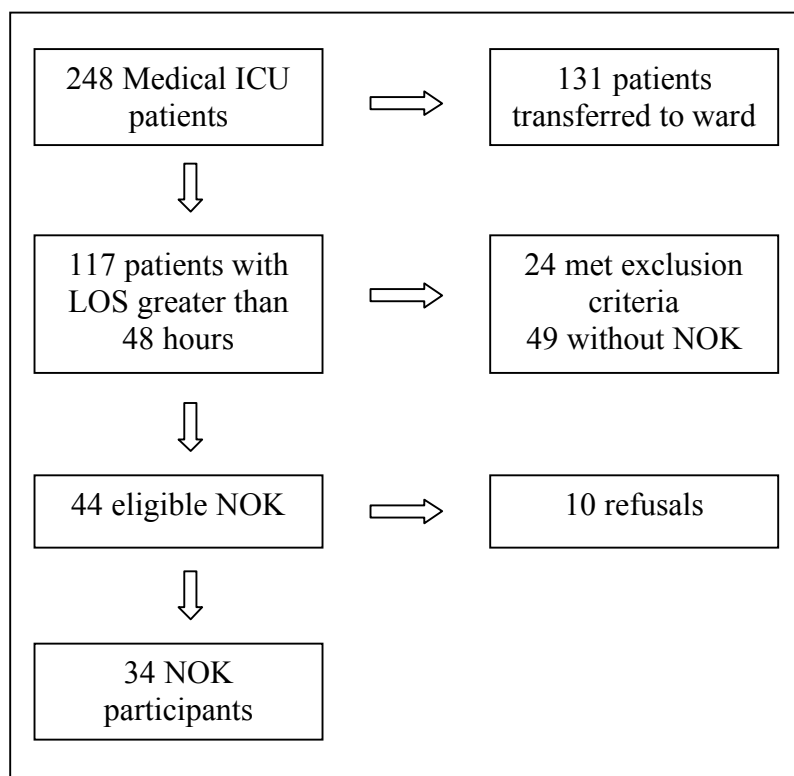


Figure 1. Flow Diagram of Subject Enrollment

Of the 34 subjects initially enrolled, 16 completed the follow-up interview. One participant partially completed the interview and another declined to participate because she said she still found the ICU experience too distressing. Of the remaining 16, 4 telephone numbers were inaccurate, 1 participant had expired, 3 were not willing to participate in the telephone interview, 2 did not remember the original interview and declined to participate in the follow-up interview, and 6 were unreachable after repeated calls (during weekday, weekend, daytime and evening hours).

Patient Characteristics

Patient characteristics are shown in Table 1. The most common admitting condition was cardiopulmonary in nature (38%), followed by genitourinary (18%), gastrointestinal (18%), infectious disease (15%), hematologic (9%), and neurologic/psychiatric illness (9%). The NOK of 71% of patients felt these conditions were acute. The NOK of 56% of patients reported another comorbid condition. Of those with comorbid conditions, the median duration of the secondary condition prior to the ICU admission was 3 years (IQR 1 – 10 years). Fifteen patients died during their hospitalization, with one patient dying after discharge from the hospital. Of the five patients readmitted to the hospital between the first and follow-up interview, none expired.

Table 1. Patient Characteristics

Patient Characteristics	n = 34
Median age, years (IQR)	63 (48-81)
Male, n (%)	18 (53)
Median time in ICU at time of interview, hours (IQR)	80 (72-103)
Previous hospital admissions, n (%)	31 (91)
Previous ICU admissions, n (%)	16 (47)
Median length of hospital stay (LOS), days (IQR)	20.5 (9-31)
Mechanical ventilation, n (%)	26 (77)
Readmission after discharge, n (%)	6 (18)
Death during study period, n (%)	16 (47)

IQR: interquartile range

Next-of-Kin Characteristics

Characteristics of NOK are shown in Table 2. More than half of NOK interpreted their loved one's status as improving during the ICU stay. All but one NOK identified themselves as the primary decision maker regarding the patient's care; the one exception was when the patient had a power of attorney other than a family member. Of the 33 primary decision makers, 17 identified other NOK who were jointly involved in decisions though not available to participate in the study. Forty-one percent of NOK identified themselves as having symptoms of anxiety or depression and 32% reported a history of psychiatric illness. Less than half of the NOK had contacted the patient's primary care provider. When offered the counsel of a social worker, 25 (74%) subjects declined, 3 (9%) accepted, and 6 (18%) were already receiving counsel at the time of the interview. Of the 26 subjects who reported having additional stressors present in their life, 7 (21%) reported work-related stressors, six subjects (18%) reported family-related stressors, four subjects (12%) did not disclose the additional stressor in their life, and 9 (27%) reported multiple stressors. No financial stressors were reported.

Table 2. Next-of-Kin Characteristics

Next-of-Kin Characteristics	n = 34
Median age, years (IQR)	54 (45.5-61)
Male, n (%)	12 (35)
Non-white, n (%)	7 (21)
Non-US native, n (%)	3 (9)
Primary Language, n (%)	
English	31 (91)

Spanish	2 (6)
Other ^A	1 (3)
Education level, n (%)	
Some high school	5 (15)
High School Graduate	7 (21)
Some College	9 (26)
College Graduate	5 (15)
Graduate School	8 (24)
Religion, n (%)	
Protestant	8 (24)
Catholic	14 (41)
Jewish	1 (3)
Other	11 (32)
Relationship to patient, n (%)	
Spouse/Domestic Partner	13 (38)
Parent	7 (21)
Child	9 (26)
Other	5 (15)
Considers self as primary caregiver to patient, n (%)	10 (29)
Interpretation of patient's condition, n (%)	
Deteriorating	7 (21)
Exacerbating underlying condition	1 (3)
No change to status	3 (9)
Improving	18 (53)
Multiple changes	5 (15)
Median time spent visiting per day, hours (IQR)	6 (3-9)
Contacted primary MD, n (%)	15 (44)
Previous psychiatric history, n (%)	11 (32)

Previous psychiatric treatment, n (%)	
For depression	5 (15)
For anxiety	10 (29)
For PTSD	4 (12)
Current psychiatric symptoms, n (%)	14 (41)
Receiving psychiatric treatment currently, n (%)	5 (15)
Additional stressors, n (%)	26 (77)

^A Though primary language was Laotian, subject had lived in the United States more than half of her life and was fluent in English as well.

IQR: interquartile range

Next-of-Kin Perception of ICU Experience

Subjects' perception of the healthcare team is listed in Table 3. During the ICU admission, 50% of the NOK were able to identify one main physician in charge of their loved one's care. When asked to rate the statement "Overall, the healthcare team was supportive," 30 subjects (88%) felt that the staff was supportive most or all of the time. Ninety-one percent of the subjects felt the team was compassionate and 88% found the team comforting all or most of the time. Eighty-eight percent felt that the healthcare team spent adequate time with the patient. Seventy-seven percent felt there was an appropriate environment for meetings with staff; 82% felt there was an appropriate environment for family meetings. Twenty-four percent were concerned about the possibility of medical errors all or most of the time. One hundred percent of subjects felt that the team was very skillful (on a scale of 1-4, where one was the most skilled and four was the least skilled). Most felt that the team worked together effectively (97%), was professional (100%), provided skillful care (100%), and provided well-coordinated care (100%) most or all of the time. Only 53% felt they could identify the role of a specific

team member all or most of the time. When asked to consider if they felt the information received was easy to understand and if enough information was received, 82% felt this was the case all or most of the time. Eighty-eight percent felt they understood the patient's prognosis all or most of the time, and 85% agreed with the attending physician regarding the patient's care all or most of the time. Eighty-five percent felt they received consistent information from different members of the healthcare team all or most of the time. Ninety-seven percent of the subjects reported visiting the ICU daily all or most of the time their loved one was in the unit. Of all the subjects, 28 (82%) never spent a night in the ICU, only 1 subject slept overnight every night, and 5 of the subjects spent some nights sleeping in the ICU waiting area. Complete statements used for evaluating the NOK's ICU experience are listed in Appendix D.

Table 3. Perception of ICU Experience by Next-of-Kin

Compassion, Support Received from Team^A	Median (IQR)^{B,C}
Team is compassionate	1 (1-1)
Team is comforting	1 (1-2)
Adequate time spent with patient	1 (1-1)
Appropriate environment for meetings with staff	1 (1-1)
Appropriate environment for family meetings	1 (1-2)
Overall, the team is supportive	1 (1-1)
Skill, Professionalism, and Coordination of Team	Median (IQR)
Concern about possible medical errors	4 (3-4)
Level of skill of the team ^D	1 (1-1)
Team is cohesive	1 (1-1)
Team is professional	1 (1-1)

Team provides skillful care	1 (1-1)
Team provides well-coordinated care	1 (1-1)
Clarity, Consistency of Information from Team	Median (IQR)
NOK knows specific role of team members	2 (1-3)
Information received is easy to understand	1 (1-2)
Enough information is received	1 (1-2)
NOK understands patient illness/prognosis	1 (1-1)
NOK agrees with MD regarding patient care	1 (1-1)
NOK receives consistent information from team members	1 (1-2)

^A Team is understood to be doctors, nurses, physicians' assistants, social workers, and broadly as "anyone involved in the patient's care."

^B Responses for statements included "almost all the time" (score = 1), "most of the time (score = 2), "some of the time" (score = 3), and "none of the time" (score = 4).

^C Responses of "I don't know" or "not applicable" were excluded from analysis.

^D Rated on a scale, from most skilled (score = 1), to least skilled (score = 4).

IQR: interquartile range

Only 56% NOK felt they could assess the patient's level of confidence in their care; all reported that the patient was confident they were receiving good quality of care all or most of the time. The remaining subjects thought that their loved one's capacity was too impaired to judge the quality of their care themselves. All 34 subjects agreed that they felt the patient was receiving good quality of care all or most of the time. When asked if patient discomfort (if any) was adequately treated, 97% NOK felt this was true all or most of the time.

Psychiatric Assessment of Next-of-Kin during ICU Interview

The number of subjects reaching clinical thresholds for a psychiatric diagnosis on the SCID is depicted in Figure 2. Of the 34 subjects, 8 (24%) had a current psychiatric

illness during the patient's ICU admission. Seven subjects (21%) met criteria for current MDD; one (3%) met criteria for GAD. One of the subjects with current MDD had a concurrent diagnosis of PTSD, and had a history of MDD and PTSD.

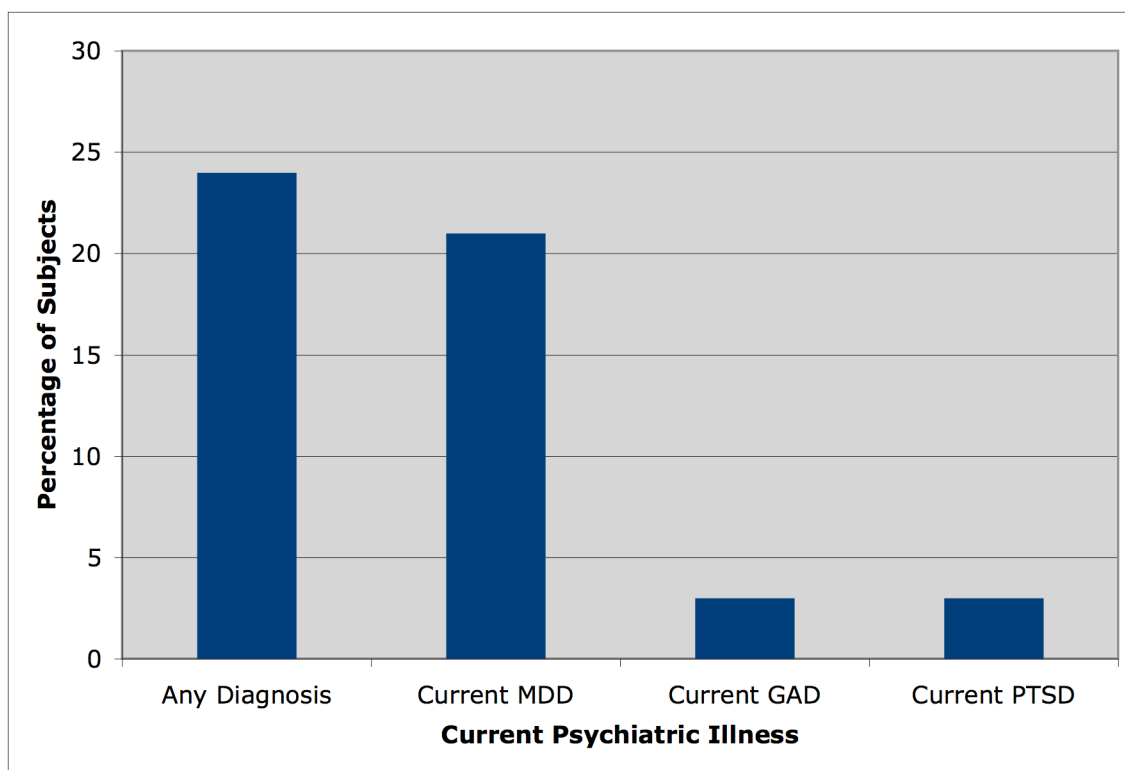


Figure 2. Percentage of All Subjects with Psychiatric Diagnosis on SCID.

The number of subjects reaching thresholds for possible anxiety or depression based on HADS screening is depicted in Figure 3. Of the 34 subjects, 19 (56%) reached the threshold for either anxiety or depression on the HADS. Eight (24%) met HADS anxiety screen thresholds, 4 (12%) met HADS depression screen thresholds, and 7 (21%) met HADS thresholds for both anxiety and depression.

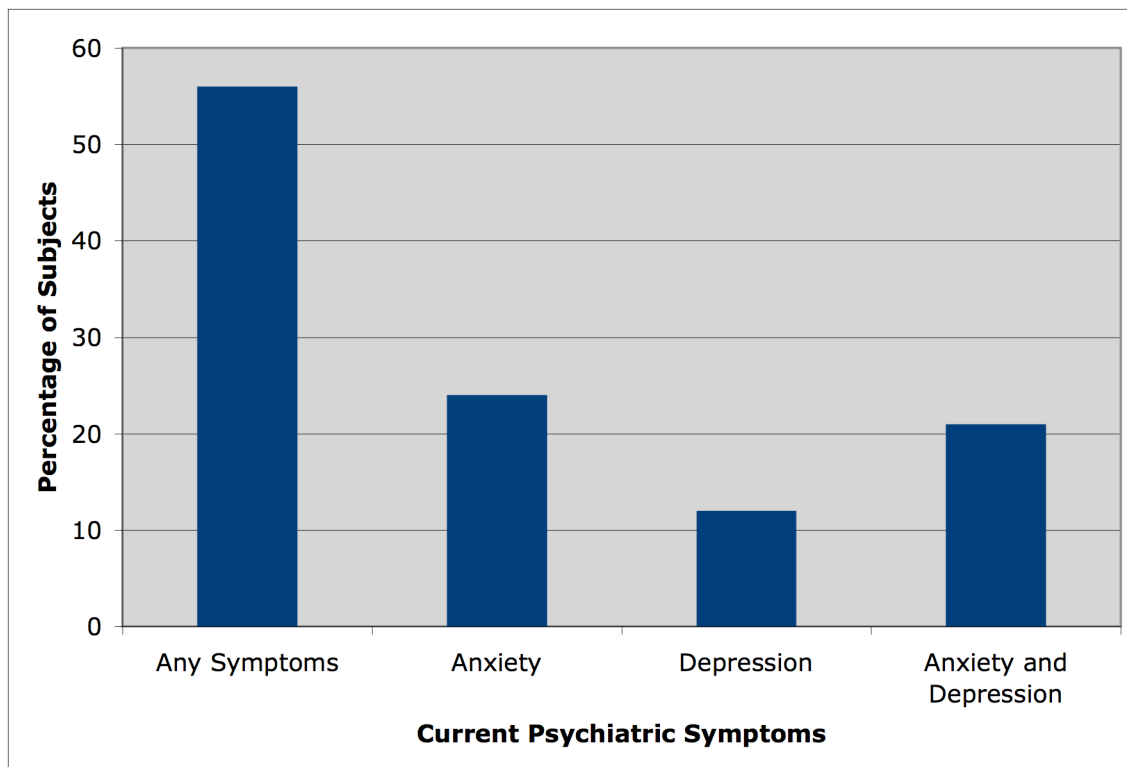


Figure 3. Percentage of All Subjects with Possible Psychiatric Illness on HADS

All subjects with a SCID diagnosis had a positive HADS. Of the 7 subjects with current MDD, 3 (43%) had a positive HADS for anxiety, 1 (14%) had a positive HADS for depression, and 3 of the 7 subjects (43%) had a positive HADS for anxiety and depression. The subject with MDD and PTSD is included among those with a positive HADS for anxiety and depression. The one subject with GAD had a positive HADS for both anxiety and depression.

The HADS had 100% sensitivity and 58% specificity when using criteria for a possible psychiatric disorder (anxiety or depression subscale, score > 8). Using more stringent

criteria (anxiety or depression subscale, score > 10), the HADS had 75% sensitivity and 73% specificity.

Psychiatric Assessment in Next-of-Kin during Follow-Up Interview

Seventeen of the subjects were available for a follow-up telephone interview and 16 completed the interview in its entirety. The one participant that opted to discontinue the interview did so after reviewing the statements of the ICU experience, the SCID and the BAI; the BDI and HADS were omitted by subject choice. The SCID was remarkable for a diagnosis of MDD and the BAI was notable for low anxiety level. This participant's spouse had died in the ICU.

Of the subjects, 12 (70.6%) reported the presence of one of the following life stressors: 4 (23.5%) multiple, 3 (17.6%) family-related, 3 (17.6%) patient-related, 1 (5.8%) work-related and 1 (5.8%) financial.

Of the 8 subjects who had a SCID diagnosis during the ICU admission, 4 completed the follow-up interview. Three of the four subjects who had an original diagnosis of MDD had a SCID diagnosis at follow-up. One subject with a SCID diagnosis in the ICU did not have a SCID diagnosis on follow-up, but did have a positive HADS screen for depression. This was the only positive HADS screen of all subjects who completed a follow-up interview.

Four subjects (23.5%) had a SCID diagnosis on the repeat assessment of current symptoms: 3 met criteria for MDD and 1 for both PTSD and GAD. Of the 4 subjects with a SCID diagnosis at follow-up, 3 had a previous diagnosis of MDD during the hospitalization. The subject without a previous diagnosis had a new diagnosis of MDD. Notably, the 3 NOK with an MDD diagnosis at follow-up had lost their loved one during the study period. The limited number of subjects who completed a follow-up interview precludes statistical analysis of these findings. Follow-up psychiatric assessment outcomes for NOK with a current SCID diagnosis during the ICU interview are displayed in Table 4. Subjects without a SCID diagnosis during the ICU interview are displayed in Table 5.

Table 4. Next-of-Kin with SCID diagnosis in ICU and Psychiatric Assessment Outcomes at Follow-up

Subject	Kinship	ICU SCID	ICU HADS	Follow-up SCID	Follow-up HADS	Patient Outcome
1	Spouse	MDD	Anxiety	PTSD, GAD	none	Alive
5	Spouse	MDD PTSD	Anxiety Depression	none	Depression	Expired
6	Other	MDD	Anxiety	MDD	none	Expired
15	Spouse	MDD	Depression	MDD	incomplete	Expired

Table 5. Next-of-Kin without SCID diagnosis in ICU and Psychiatric Assessment Outcomes at Follow-up

Subject	Kinship	ICU HADS	Follow-up SCID	Follow-up HADS	Patient Outcome
2	Spouse	Anxiety	none	none	Alive
3	Child	Anxiety	none	none	Expired
4	Child	Anxiety	none	none	Expired
7	Child	Depression	none	none	Alive
8	Child	none	none	none	Expired
9	Child	Depression	none	none	Alive
10	Other	none	none	none	Expired
11	Spouse	none	none	none	Expired
12	Parent	none	none	none	Alive
13	Parent	none	MDD	none	Expired
14	Other	none	none	none	Alive
16	Spouse	none	none	none	Alive
17	Spouse	Anxiety, Depression	none	none	Expired

Decision of Next-of-Kin to Sleep in the ICU

Six subjects chose to sleep in the ICU during their loved one's admission. None of the six subjects reported a history of psychiatric illness. Two of the subjects reported having current symptoms. Of the 6 subjects, 1 met criteria for MDD and 1 for GAD. Four of the 6 subjects had a positive HADS: 1 subject was positive for anxiety, 1 for depression, and 2 for both. Four of the six NOK's loved one had been admitted to the hospital and the ICU previously. Though the number of subjects who reported having slept in the ICU is

small, the decision to sleep in the ICU is an association we chose to explore in further detail with regard to specific aspects of the ICU experience.

Interestingly, subjects that reported having slept in the ICU at some point during the admission were less likely to find the healthcare team compassionate (median score 2 (IQR 1-3) vs. median score 1 (IQR 1-1), $p = 0.004$; Figure 4a) or comforting (median score 2 (IQR 2-2) vs. median score 1 (IQR 1-1), $p = 0.002$; Figure 4b). Exploring this finding further, we found that these subjects were less likely to believe the healthcare team spent adequate time with the patient (median score 2 (IQR 2-2) vs. median score 1 (IQR 1-3), $p = 0.026$; Figure 4c) or that there was an appropriate environment for meetings with staff (median score 2 (IQR 1-3) vs. median score 1 (IQR 1-2), $p = 0.041$; Figure 4d). These NOK also found the team to be less professional (median score 1 (IQR 1-2) vs. median score 1 (IQR 1-1), $p = 0.022$; Figure 4e). There was a trend towards the NOK that slept in the ICU finding the team overall less supportive (median score 2 (IQR 1-3) vs. median score 1 (IQR 1-1), $p = 0.056$; Figure 4f). Notably, NOK who slept in the ICU were not more likely to be concerned about medical errors (median score 3.5 (IQR 3-4) vs. median score 4 (IQR 3-4), $p = 0.899$) nor were they more likely to think the team was less skillful (median score 1 (IQR 1-2) vs. median score 1 (IQR 1-1), $p = 0.274$).

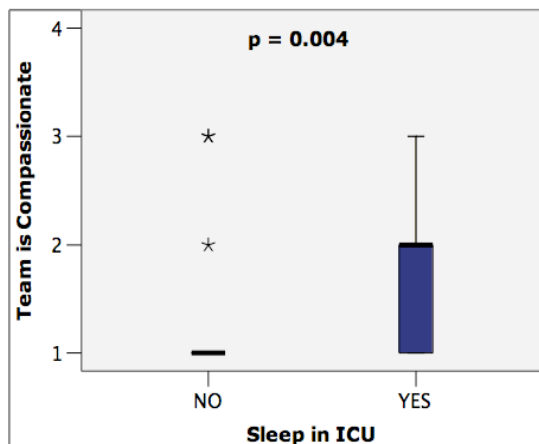


Figure 4a.

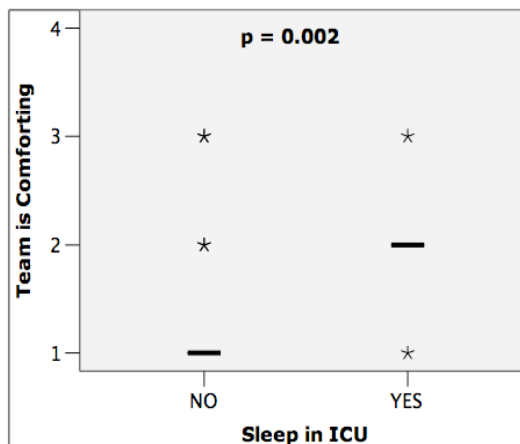


Figure 4b.

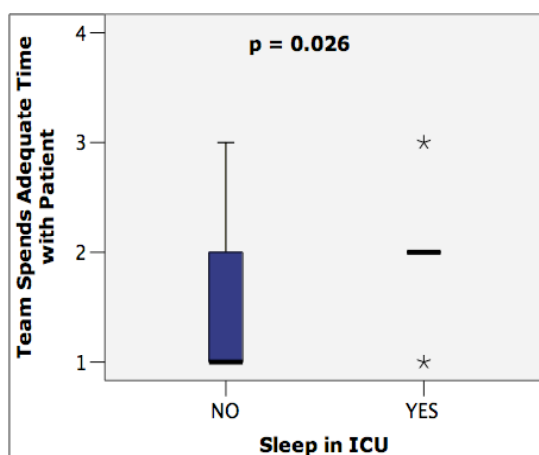


Figure 4c.

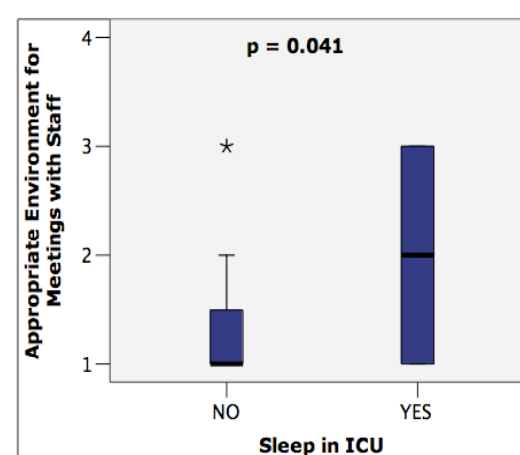


Figure 4d.

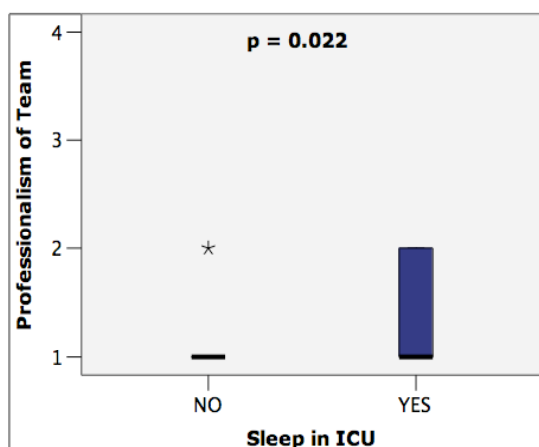


Figure 4e.

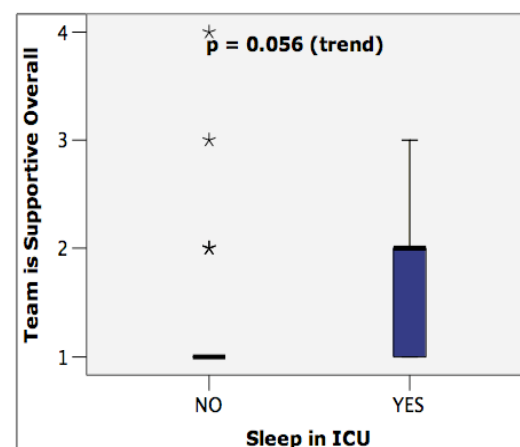


Figure 4f.

Figures 4a-f. Elements of the ICU Experience Rated by Next-of-Kin as Compared to the Next-of-Kin's Desire to Sleep in the ICU. The responses were graded on a scale of 1 to 4, where 1 = "almost all the time", 2 = "most of the time", 3 = "some of the time", and 4 = "none of the time". The median of each group is represented by a solid black bar; the interquartile range is represented by the T bars. Outliers are indicated by a star. Statistical significance of findings is noted on each figure.

Psychiatric History and Assessment Outcomes during the ICU Interview

Subject Report of Psychiatric History and SCID Diagnosis

A current SCID diagnosis was more common in those subjects who had a self-reported history of treatment for depression (5/10 vs. 3/24, $p = 0.031$). A current SCID diagnosis was also more common in those with a self-reported history of treatment for PTSD-like symptoms (3/4 vs. 5/30, $p = 0.033$). A current SCID diagnosis was more common in those with self-report of current psychiatric symptoms (6/14 vs. 2/20, $p = 0.042$). A current SCID diagnosis trended towards being more common in those with a self-reported history of treatment for anxiety (3/5 vs. 5/29, $p = 0.072$). A current SCID diagnosis trended towards more common in those with a history of any diagnosed psychiatric illness (5/11 vs. 3/23, $p = 0.079$).

Subject Report of Psychiatric History and Positive HADS Screen

A positive HADS screen was more common in those subjects who reported current psychiatric symptoms (11/14 vs. 8/20, $p = 0.038$). A trend was towards a positive HADS screen being more common in those receiving treatment for a current psychiatric illness was noted (5/5 vs. 14/29, $p = 0.053$). A positive HADS screen was not more common in those with a self-reported history of treatment for depression (6/10 vs. 13/24, $p = 1.0$), anxiety (3/5 vs. 16/29, $p = 1.0$), or PTSD-like symptoms (3/4 vs. 16/30, $p = 0.613$). A positive HADS screen was not more common in those subjects with a self-reported history of any psychiatric illness (6/11 vs. 13/23, $p = 1.0$).

Patient and Subject Demographics and Psychiatric Assessment Outcomes

Patient and Subject Demographics and Association with SCID Diagnosis

A trend was noted for NOK who had a later interview (relative to how long their loved one had been in the ICU) to have a current SCID diagnosis (median 101 hours (IQR 80-121 hours) vs. median 77.5 hours (IQR 71-84 hours), $p = 0.065$). A current SCID diagnosis was more likely to occur when a loved one's present illness was chronic in nature (5/10 vs. 3/24, $p = 0.031$). The median age for loved ones of NOK who had a SCID diagnosis was similar to those of NOK without a SCID diagnosis (median 60 years (IQR 55-66 years) vs. median 68.5 years (IQR 48-82 years), $p = 0.440$). A SCID diagnosis during their loved one's ICU admission was not more likely in NOK whose loved one was readmitted to the hospital (1/6 vs. 7/28, $p = 1.0$), nor was a SCID diagnosis more common in NOK whose loved one had previously been admitted to the hospital (7/31 vs. 1/3, $p = 1.0$) or the ICU (6/16 vs. 2/18, $p = 0.1$). Though the difference is not statistically significant, the rate of SCID diagnosis was higher in those NOK whose loved one died during the course of the study (6/18 vs. 2/16, $p = 0.233$).

A current SCID diagnosis was more common in spouses than other NOK (6/12 vs. 2/22, $p = 0.013$) and in those NOK who identified themselves as the primary caregiver to the patient at home (6/10 vs. 2/24, $p = 0.003$). A SCID diagnosis was not more common in those who identified themselves as non-native English speakers (1/3 vs. 7/31, $p = 1.0$), nor in those who had an additional referral to social work (4/10 vs. 4/24, $p = 0.195$). Thirty-three (97%) of NOK identified themselves as the patient's primary decision-

maker, which precluded a statistical analysis of whether they were more likely than non-decision-makers to have a current SCID diagnosis.

Patient and Subject Demographics and Association with HADS Assessment

A trend was noted for NOK who had a later interview (relative to how long their loved one had been in the ICU) to have a positive HADS screen (median 95.5 hours (IQR 77-110 hours) vs. median 75 hours (IQR 70-84.5 hours), $p=0.083$). A trend was noted for NOK's with a positive HADS during the ICU admission to be less likely to have their family member readmitted to the hospital (1/6 vs. 7/28, $p = 0.066$). A positive HADS during the ICU admission was not more common in NOK whose loved one had previously been admitted to the hospital (17/31 vs. 2/3, $p = 1.0$) or the ICU (10/16 vs. 9/18, $p = 0.5$). The ages of the patients were similar for NOK with a positive HADS compared to those without (median 60 years (IQR 52.5-79 years) vs. median 72 years (IQR 47.5-80.5 years), $p = 0.591$). The prevalence of chronic illness between groups of NOK with and without a positive HADS were also similar (7/10 vs. 12/24, $p = 0.451$) were similar. A positive HADS during the ICU admission was not more common in NOK whose family member died during the course of this study (11/18 vs. 8/16, $p = 0.73$).

Neither spouses nor primary caregivers for the patient were more likely to have a positive HADS screen (67% vs. 50%, $p = 0.476$; 80% vs. 46%, $p = 0.128$, respectively). The small size of this study may have precluded detecting statistical significance between a primary caregivers and non-caregivers with a positive HADS screen, as a positive HADS

screen is almost twice as common in caregivers. Non-native English speakers were not more likely to have a positive HADS screen on either subscale (2/3 vs. 17/31, $p = 1.0$). Thirty-three (97%) of NOK identified themselves as primary decision-maker for the patient's care, which precluded a statistical analysis of whether they were more likely to have a positive HADS screen.

ICU Experience and Psychiatric Assessment Outcomes in Next-of-Kin

Next-of-Kin Experience and the SCID Assessment

NOK with a current SCID diagnosis were less likely to feel there was an appropriate environment for family meetings (median score 1.5 (IQR 1-3) vs. median score 1 (IQR 1-1), $p = 0.031$; Figure 5). NOK with a current SCID diagnosis did not perceive the healthcare team's level of skill and professionalism, nor the clarity of the information received differently than other NOK (Table 6). NOK gave relatively high marks for all aspects of the ICU experience, which may have precluded finding a difference among those with and without psychiatric illness.

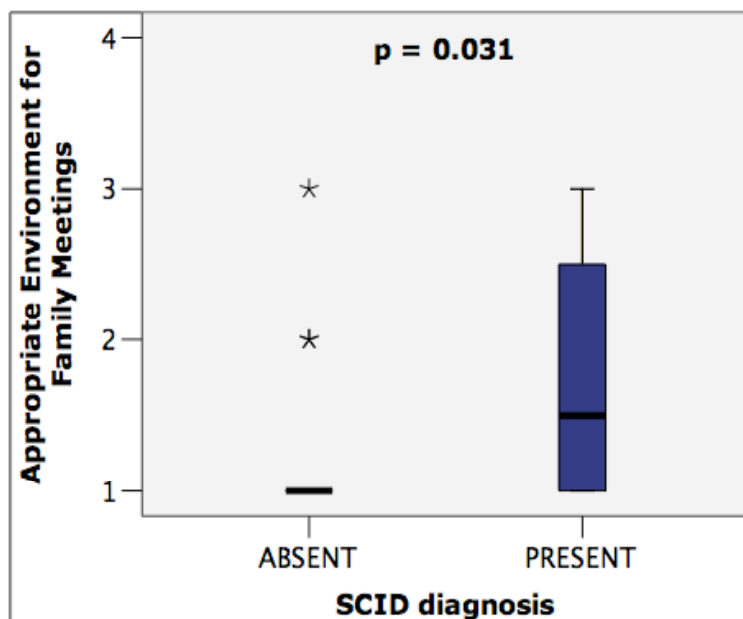


Figure 5. Presence of an Appropriate Environment for Family Meetings Rated by Next-of-Kin as Compared to SCID Diagnosis in Next-of-Kin. Subjects who had a current SCID diagnosis were less likely to feel there was an appropriate environment for family meetings than those who did not have a SCID diagnosis ($p = 0.031$). The responses were graded on a scale of 1 to 4, where 1 = “almost all the time”, 2 = “most of the time”, 3 = “some of the time”, and 4 = “none of the time”. SCID diagnosis includes presence of MDD, GAD, and/or PTSD. The median of each group is represented by a solid black bar; the interquartile range is represented by the T bars. Outliers are indicated by a star.

Table 6. ICU Experience and SCID Diagnoses in Next-of-Kin

Statement	Current SCID Diagnosis	No Current SCID Diagnosis	p value
Compassion, Support Received from Team^A, Median (IQR)^{B,C}			
Team is compassionate	1 (1-1)	1 (1-1)	0.472
Team is comforting	1 (1-2)	1 (1-1)	0.628
Adequate time is spent with patient	1 (1-1)	1 (1-2)	0.301
Appropriate environment for meetings with staff	2 (1-2.5)	1 (1-1.5)	0.112
Appropriate environment for family meetings	1.5 (1-3)	1 (1-1)	0.031
Overall the team is supportive	1 (1-1)	1 (1-2)	0.445
Skill, Professionalism, and Coordination of Team, Median (IQR)			
NOK concern about possible medical errors	4 (2.5-4)	4 (3-4)	0.927

Level of skill of team ^D	1 (1-1)	1 (1-1)	0.140
Team works together	1 (1-1)	1 (1-1)	0.322
Team is professional	1 (1-1)	1 (1-1)	0.322
Team provides skillful care	1 (1-1)	1 (1-1)	0.322
Team provides well-coordinated care	1 (1-1)	1 (1-1)	0.524
Clarity, Consistency of Information from Team, Median (IQR)			
NOK knows specific role of team members	2 (2-2)	3 (1-4)	0.450
Information received is easy to understand	1 (1-1)	1 (1-2)	0.723
Enough information is received	1 (1-1)	1 (1-2)	0.248
NOK understands patient illness/prognosis	1 (1-1)	1 (1-2)	0.353
NOK agrees with MD regarding patient care	1 (1-1)	1 (1-2)	0.433
NOK receives consistent information from team members	1.5 (1-2)	1 (1-2)	0.426

^A Team is understood to be doctors, nurses, physicians' assistants, social workers, and broadly as "anyone involved in the patient's care."

^B Responses for statements were "almost all the time" (score = 1), "most of the time" (score = 2), "some of the time" (score = 3), and "none of the time" (score = 4).

^C Responses of "I don't know" or "not applicable" were excluded from analysis.

^D Rated on a scale, from most skilled (score = 1), to least skilled (score = 4).

IQR: interquartile range

Next-of-Kin Experience and the HADS Assessment

NOK with a positive HADS screen on either subscale were less likely to feel that the patient's care was well-coordinated compared to NOK without a positive HADS screen (median score 1 (IQR 1-2) vs. median score 1 (IQR 1-1), $p = 0.033$; Figure 6a). NOK with a positive HADS screen on either subscale were also less likely to feel that enough information had been received about patient's treatment and prognosis (median score 1.5 (IQR 1-3) vs. median score 1 (IQR 1-1), $p = 0.026$; Figure 6b) and were less likely to agree with the attending physician regarding the patient's care (median score 1 (IQR 1-3) vs. median score 1 (IQR 1-1), $p = 0.008$; Figure 6c). A trend was noted that NOK with a

positive HADS screen were less likely to agree that adequate time was spent with the patient (median score 1.5 (IQR 1-3) vs. median score 1 (IQR 1-2), $p = 0.054$; Figure 6d). NOK with a positive HADS screen were less likely to feel that the patient's discomfort (if any) was adequately controlled (median score 1 (IQR 1-1.5) vs. median score 1 (IQR 1-1), $p = 0.017$). NOK with a HADS screen were not more likely to perceive the healthcare team's compassion, support, level of skill, nor professionalism, differently than other NOK (Table 7).

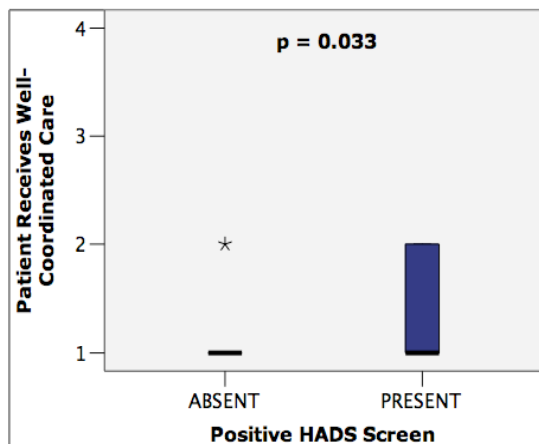


Figure 6a.

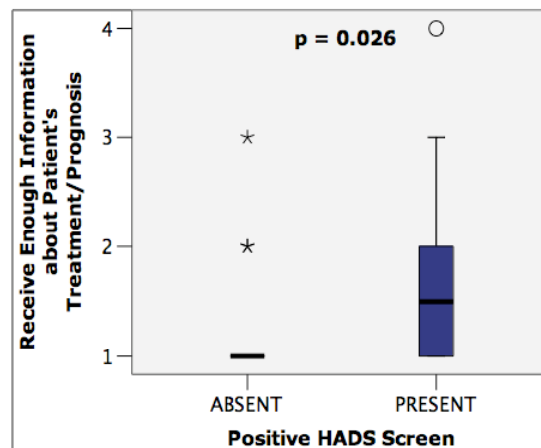


Figure 6b.

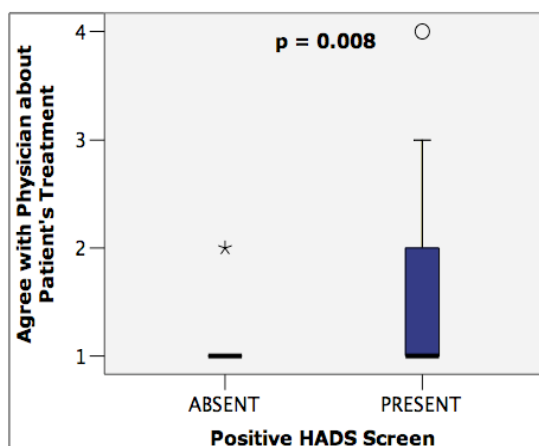


Figure 6c.

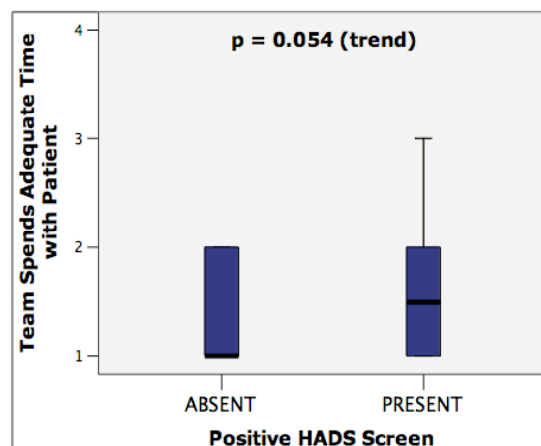


Figure 6d.

Figure 6a-d. Elements of the ICU Experience Rated by Next-of-Kin as Compared to Positive HADS Screen in Next-of-Kin. The responses were graded on a scale of 1 to 4, where 1 = “almost all the time”, 2 = “most of the time”, 3 = “some of the time”, and 4 = “none of the time”. Presence of positive HADS screen was considered to be any subject reaching a score of > 8 on HADS subscales for anxiety, depression, or both. The median of each group is represented by a solid black bar; the interquartile range is represented by the T bars. Outliers are indicated by a star or open circle. Statistical significance of findings is noted on each figure.

Table 7. ICU Experience and Positive HADS Screen in Next-of-Kin

Statement	Any Positive HADS Screen ^A	No Positive HADS Screen	p value
Compassion, Support Received from Team,^B Median (IQR)^{C,D}			
Team is compassionate	1 (1-1)	1 (1-1.5)	0.687
Team is comforting	1 (1-2)	1 (1-1.5)	0.467
Adequate time is spent with patient	1 (1-2)	1.5 (1-3)	0.054
Appropriate environment for meetings with staff	1 (1-2)	1 (1-1)	0.152
Appropriate environment for family meetings	1 (1-1.5)	1 (1-1)	0.361
Overall the team is supportive	1 (1-2)	1 (1-1)	0.249
Skill, Professionalism, and Coordination of Team, Median (IQR)			
NOK concern about possible medical errors	4 (2-4)	4 (3-4)	0.408
Level of skill of team ^E	1 (1-1)	1 (1-1)	0.223
Team works together	1 (1-1)	1 (1-1)	0.754
Team is professional	1 (1-1)	1 (1-1)	0.420
Team provides skillful care	1 (1-1)	1 (1-1)	0.420
Team provides well-coordinated care	1 (1-2)	1 (1-1)	0.033
Clarity, Consistency of Information from Team, Median (IQR)			
NOK knows specific role of team members	3 (2-3.5)	2 (1-3)	0.290
Information received is easy to understand	1 (1-2)	1 (1-1)	0.248
Enough information is received	1.5 (1-3)	1 (1-1)	0.026
NOK understands patient illness/prognosis	1 (1-2)	1 (1-1)	0.113
NOK agrees with MD regarding patient care	1 (1-3)	1 (1-1)	0.008
NOK receives consistent information from team members	1 (1-2.5)	1 (1-1.5)	0.140

^A Any positive HADS screen is considered a score > 8 on either the anxiety or depression subscale.

^B Team is understood to be doctors, nurses, physicians assistants, social workers, and broadly as “anyone involved in the patient’s care.”

^C Responses for statements were “almost all the time” (score = 1), “most of the time (score = 2), “some of the time” (score = 3), and “none of the time” (score = 4).

^D Responses of “I don’t know” or “not applicable” were excluded from analysis.

^E Rated on a scale, from most skilled (score = 1), to least skilled (score = 4).

IQR: interquartile range

DISCUSSION

Main Findings

Psychiatric symptoms were common in NOK, with over half of our population affected. Notably, 32% reported a prior history of psychiatric illness. Though the prevalence was slightly below previously reported rates of psychiatric symptoms in the NOK population of the ICU,^{13-15, 18} our findings confirm that a significant portion of NOK have psychological distress during the ICU experience. The rate of current psychiatric illness of MDD, GAD, and/or PTSD in this population during the ICU stay was 24%. Taken individually, our prevalence of MDD was 21%, which is higher than the previously reported 12-month prevalence of 6.7% in the general population,² and higher than the previously reported lifetime prevalence of 16-17%.^{44, 45} Given the small sample size, and subsequently the small number of NOK with GAD (1 subject) and PTSD (1 subject), we can not accurately determine if the rate of these psychiatric illnesses in our population is consistent with the rates reported for a 12-month period (3% for each disorder) or the previously reported lifetime prevalence of 5-6% for GAD and 7-8% for PTSD.⁴⁵⁻⁴⁷

We found that the HADS was able to predict SCID diagnoses of MDD, GAD, or PTSD using possible (score > 8) and probable (score > 10) criteria on the HADS anxiety and depression subscales. During the ICU admission, over 50% of our subjects had a positive HADS screen, with a positive predictive value of 42%. The HADS is 100% sensitive, with all SCID diagnoses during the ICU experience having a concurrent positive HADS

screen for anxiety, depression, or both. Three of the 4 subjects with a SCID diagnosis on follow-up had a positive HADS during the ICU admission, but did not subsequently.

A number of factors may explain the reason for a negative HADS screen at follow-up in NOK with SCID diagnoses after the ICU experience. Primarily, the HADS assesses central characteristics of anxiety or depression²⁸ (e.g. it does not assess suicidality), which may have differed from the responses of NOK on the SCID. Additionally, the HADS assesses symptoms over the past week, and for some of the diagnoses, the period of experiencing symptoms extends to 3-6 months. Though the subjects may have met SCID criteria for their symptoms, if in the past week the particular set of symptoms assessed by the HADS was not present, then their screen would have been negative. The symptoms assessed by the HADS may explain why HADS subscale scores do not always correlate with a projected SCID diagnosis.^{31,39} Finally, given the size of the study sample at follow-up, it may be by chance that the 4 with a SCID diagnosis at follow-up did not also have a positive HADS. What was suggested from our findings was that the HADS was reliable during the ICU experience in predicting a SCID diagnosis and that having a positive HADS screen during the ICU experience may be predictive of a psychiatric illness after the ICU experience.

In the subjects with a diagnosis of MDD at follow-up, all had greater than normal severity of symptoms on the BDI. Though the BDI did not indicate clinical levels of depression in any of the patients, this may be explained by the day-to-day instability of the BDI³³ and the small number of subjects at follow-up.

PTSD was not seen extensively in our study population, though PTSD symptoms have been reported in populations who participate in end-of-life discussions and in those whose loved ones die in the ICU.^{17, 18} The lack of confirmatory findings may be because our tools assessed anxiety symptoms (some of which overlap with PTSD) and we used stringent criteria to diagnose PTSD. A PTSD diagnosis requires symptoms to be present for at least 3 months,¹¹ in which case any diagnosis of PTSD during the initial interview would have predated the ICU experience. Additionally, the population of NOK we interviewed may not have been involved in discussions regarding the end-of-life, given that our window for interviews occurred just after 48 hours in the ICU. On follow-up we did identify one subject with PTSD, however a number of factors do not lend support to the symptoms and subsequent diagnosis occurring as a result of the ICU: the subject had a lifetime history of PTSD that was noted in the initial interview, at the time of the initial interview the subject felt the patient's condition was improving and the patient survived the ICU experience, and was doing well at follow-up.

Our study did confirm that spouses are more likely to have a psychiatric illness in the ICU. Additionally, we found that those NOK that are primary caregivers to the patient are also at greater risk. Though it cannot be assumed that most spouses are caregivers, the role that each plays in providing support to a patient with chronic illness is similar. Caregiver burden has primarily been discussed with reference to the psychological and physical demands during the patient's recovery period, but that a psychological burden would exist during the ICU admission seems plausible in certain situations. A caregiver that was providing care for a patient with a chronic illness prior to admission might have

psychological distress related to concerns about prognosis during the ICU admission.

Similarly, spouses are often present during a critical illness (including before admission to an ICU) and could therefore also carry a psychological burden, perhaps related to the possibility of losing a life partner.

Previous studies have shown absence of chronic disease in the patient to be a risk factor for psychiatric symptoms in NOK.¹³ Our findings suggest that those NOK whose loved one had a chronic disease are more likely to have a psychiatric illness on the SCID during the ICU admission. Severity of psychiatric illness has been reported as higher in the parents (i.e. caregivers) of children with a recently diagnosed chronic illness than those involved in an accident.⁴⁸ In those with a positive HADS screen, there was no difference in the acuity of the patient's illness. In light of the fact that the majority of our NOK with a SCID diagnosis had MDD, a possible explanation could be the burden on the caregiver for this prolonged illness. However, given our small sample size, we can neither confirm nor refute the influence of disease chronicity on psychiatric symptoms in NOK. Though many patients had previous hospital admissions (91%) and previous ICU admissions (47%), there was no association with the NOK of these patients having with an increase in psychiatric symptoms or illness during the current admission. It seems reasonable that previous exposure to critical illness of a loved one could exacerbate the experience (and subsequent psychiatric symptoms) on later admissions, however, we were unable to demonstrate this in our small group of subjects.

We did find that the rates of psychiatric illness in NOK whose loved one died was higher than the rate in NOK whose loved one survived. Our small sample size likely limited our ability to detect statistical significance. In our population, almost half of the patients died prior to the follow-up interview, though it is unknown if these deaths occurred later in the patient's ICU admission or shortly after discharge or transfer. Regardless of when the deaths occurred during the study period, NOK may find themselves ill-prepared for coping with their loss. One might expect that in our follow-up interviews, more of the NOK whose loved ones had died would show symptoms of psychiatric illness. However, only one of our subjects whose loved one had died had a positive HADS for depression. One explanation could be the limited number of subjects during follow-up; another explanation could be that studies previously reporting death as a risk factor for psychiatric symptoms were identifying symptoms commonly found during bereavement. After the death of a loved one, bereavement may present with symptoms characteristic of depression, such as insomnia or poor appetite.¹¹ A diagnosis of MDD can be made when the symptoms persist beyond two months after the loss.

Our median patient age was 63 years, which is similar to other patient populations in related studies.^{13,14} Previous studies have identified younger patient age as a risk factor for psychiatric symptoms in NOK, which we did not confirm in this study. One reason for this discrepancy may be that previous reports have included patients of pediatric ICUs.¹³ These findings were also reported in populations that exceeded 300 subjects, and our small study size may have precluded our ability to detect these differences.

Our findings demonstrate that lack of an appropriate environment for family meetings was associated with presence of psychiatric illness. This has previously been associated with an increased risk of anxiety symptoms.¹³ Additionally, we were able to show that NOK who felt they did not receive enough information regarding the patient's illness were more likely to have symptoms of anxiety or depression. Lack of regular meetings to discuss patient care has been associated with an increased risk for anxiety¹³ and incomplete information has been shown to be a risk factor for psychiatric symptoms.¹⁸

Very few NOK reported that they did not find the team as a source of comfort, which may have precluded analysis of this element as a risk factor, as this has previously been reported as associated with a psychiatric diagnosis.²¹ However, we identified a unique association that to our knowledge has not been mentioned in the literature. In this study, NOK who decided to sleep in the ICU were less likely to find the team comforting or compassionate compared to those who did not stay overnight. From the data, it appears that the more time family members spent in the ICU, including sleeping, the less likely they were to find the team as a source of comfort. At least three explanations are plausible: the NOK did not find the healthcare team as a source of comfort and subsequently were less trusting and decided to sleep at the hospital; alternatively, the NOK may have lost trust in the team as a consequence of their experience in the hospital. Given that 4 of the 6 subjects who slept in the ICU had had their loved ones admitted to the hospital and the ICU before, a third explanation could be that their past experience with admissions made them more inclined to stay, either for fear of the severity of the patient's illness, or because they were less trusting based on a past experience. None of

the subjects reported a past psychiatric history, therefore it is unlikely that an underlying anxiety or mood disorder influenced their decision to sleep in the ICU. Further investigation is required to confirm and fully explore the nature of the relationship between desire to sleep in the hospital and the attitudes of NOK regarding the medical team.

Strengths

One of the primary strengths of this study was the inclusion of a validated diagnostic tool to assess psychiatric illness in NOK. Most previous studies of NOK in the ICU have used screening tools, such as the HADS, which is able to identify symptoms related to anxiety or to depression. These screening tools are able to identify those NOK who may be at risk for a psychiatric illness, but are unable to provide a diagnosis. When the HADS is used, additional assessment with a clinical interview is needed to confirm the presence of psychiatric illness. In this study, the use of both screening and diagnostic instruments allowed us to identify the HADS as an effective screening tool to identify NOK in the ICU with a psychiatric illness. Because we used both a screening and a diagnostic tool, we were able to determine the rates of both psychiatric symptoms and psychiatric illness in the NOK ICU population.

A second strength of this study is that the interviewer received formal training to appropriately administer the SCID, assuring that the data reported on diagnosed psychiatric illness were accurate and reliable. Although the HADS, BDI, and BAI are self-report questionnaires, the SCID requires the interviewer to present questions from

each diagnostic module in a non-biased way. Additionally, the interviewer must be mindful not to lead a subject towards over-reporting a symptom's occurrence in order to meet diagnostic criteria (e.g. "feeling depressed or down *most of the day, nearly everyday, for at least 2 weeks,*" for MDD). Finally, scoring of the symptoms and interpretation of the findings from each of the modules must meet the criteria set forth by the DSM-IV in order to yield a diagnosis. The psychiatric diagnoses reported in this study are a result of using stringent standards in both administration and interpretation.

With regard to the ICU follow-up, a length of time was chosen that was sufficient to allow for the diagnosis of illness whose symptoms began during or shortly after the ICU experience. For example, a diagnosis of GAD can occur only after symptoms have been present almost daily for 6 months. One of our follow-up subjects did in fact have this diagnosis, but only after the ICU experience. Although this time frame of development does not imply causality, it does suggest that the ICU experience may have influenced the development of this illness. Had follow-up occurred earlier than 6 months after the ICU interview, this diagnostic finding may have been missed.

A fourth strength of this study is the extended time the interviewer spent with each subject who participated in the study, which allowed collection of a wealth of information regarding the NOK's ICU experience. This information is invaluable towards identifying what elements of the ICU could be improved in order to increase family satisfaction with the ICU experience.

Limitations

The first limitation of this study was the impact our small sample size had on the ability to draw conclusions. One of the barriers to achieving a larger sample size may have been the length of the initial interview as well as the agreement to participate in a follow-up interview. Families were informed that the time commitment for participation to complete each interview in its entirety would take approximately 30 to 45 minutes, depending on their responses (e.g. responding positively to initial criteria on the SCID, thus requiring further assessment of additional symptoms). These two factors may have been a deterrent to those NOK who were interested in participating but could not commit to both time points. A second barrier to increasing subject enrollment was that this was a single interviewer procedure and the time spent interviewing subjects diminished the amount of time that could be spent recruiting more participants. Though the small sample size may have diminished our ability to fully evaluate the significance of many of our findings, we identified some interesting trends worthy of pursuit in future studies. In addition, we were able to confirm the high prevalence of psychiatric disease in the family members of ICU patients, consistent with previous reports. In the future, should a study of this complexity be attempted, more interviewers with more time available to recruit participants would be necessary.

A second limitation of this study was a potentially non-representative subject pool.

Though only 10 eligible subjects declined to participate, there were 49 NOK who were not present during the hours of enrollment that otherwise met initial enrollment criteria. For a variety of reasons, the NOK may not have visited the ICU during hours JKM was

present, for example, if the NOK worked evening shifts and could only visit in the early morning hours, the NOK could only visit on the weekends and was missed during their one visit, or the NOK was not likely to visit because the distance to travel to the medical ICU was too far. In order to limit this potential bias in subject enrollment, a regular schedule was kept during the months of enrollment. Additionally, no discrimination was made between which NOK were approached to participate in the study. Every effort was made to contact and enroll all NOK that were present in the ICU during the hours JKM was present in the unit. To avoid missing NOK during an expected visit, medical ICU staff was able to contact JKM when the NOK arrived using a mobile phone.

During the follow-up period, every effort was made to contact the NOK. The seventeen subjects did not complete the follow-up for a variety of reasons: they were unreachable, they did not recall participating in the initial interview, they were unwilling to complete the follow-up interview. It is possible that those that declined to participate did so because of current psychiatric symptoms that they were unwilling to disclose or which prohibited them from participating in the interview (e.g. unable to answer the phone, unable to express interest in the activity). Of those that could not participate, 10 had a positive HADS screen and 4 had a current SCID diagnosis on the initial interview. Though we are unable to draw any conclusions regarding the psychological factors at play, it is possible that the loss to follow-up was not entirely random.

A third limitation of this study was a potential bias in NOK's responses to the ICU experience. Often, the NOK found the interview session provided an opportunity to

speaking freely about their experiences, (beyond rating the standardized statements). Though the majority of subjects reported favorable encounters with members of the healthcare team, it could be argued that the number of subjects reporting favorable encounters could be artificially high. Despite reassuring participants that their responses would be anonymous, subjects may have felt that the information given to the interviewer would be conveyed to members of the team. If this was the case, subjects' responses may have been biased towards reporting a more favorable experience. To address this concern, future studies should have participants complete the questionnaire on the ICU experience apart from the interviewer, obtaining all demographic information, standardized ICU experience questions, and responses to the HADS, prior to a brief encounter with an interviewer, in which only the SCID would be administered. This would likely significantly decrease the interview time (and perhaps allow more subjects to participate, as a block of 30 to 45 minutes would not be necessary) and would allow more flexibility, in terms of both scheduling the interview as well as the subject's ability to speak more freely about their experiences in the ICU.

Another limitation of this study was the order of the administration of instruments—administration of the SCID, followed by administration of the HADS. To our knowledge, the sequence of administration has not been discussed in the literature; however, it is possible that the sequence may have influenced our results. For example, the administration of the SCID could have increased the subjects' awareness to symptoms they may not have identified as related to psychiatric stressors. Subsequently, subjects may have over-reported the frequency of symptoms during the HADS administration.

However, the HADS is designed to assess core symptoms of anxiety and mood disorders, not necessarily the specific symptoms required for a diagnosis of MDD or GAD. As such, the HADS generalized review of symptoms occurring in the past week may have been impacted minimally by the more specific questions found on the SCID.

Future Directions

One of the interesting findings of this study was the correlation between the decision of NOK to sleep in the ICU and their failure to find the team comforting or compassionate. From the data, it appears that the more time family members spent in the ICU waiting room, including sleeping, the less likely they were to find the team as a source of comfort. Previous investigators have linked failure to find the physician as a source of comfort as negatively impacting the ICU experience and in some cases having a higher association with the presence of a psychiatric illness after the ICU experience.^{20, 21} Although our study did not show that this subgroup was more likely to have psychiatric symptoms or illness by our two initial assessment tools, the small size of this subgroup may have limited our ability to fully explore this association.

The association between NOK's decision to sleep in the ICU and their failure to find the team as a source of comfort warrants further investigation, likely in the form of a survey following the ICU experience. The first aim would be to study a larger population of NOK to validate that the correlation between the decision to sleep in the ICU and the failure to find the team as a source of comfort. The second aim would be to identify specific aspects of the encounter with the team that impact whether the NOK finds a staff

member as a source of comfort (e.g. amount of time spent with patient, amount of time spent with the NOK). The third aim would be to determine if the desire to sleep in the ICU is correlated with psychiatric symptoms using a validated screening tool, because of the previously described association of psychiatric symptoms with a negative ICU experience.^{20, 21}

Another association found in this subgroup of NOK who slept in the ICU was their desire for a more appropriate family meeting environment, which has previously been recognized as a shortcoming of the ICU environment.²⁰ In future studies of NOK in the ICU, it would be prudent to assess the role of sleeping in the ICU with these healthcare team specific factors. With a larger population, one may be able to assess if staying in the ICU is actually more influenced by cultural or religious factors, rather than a perceived need to provide additional care or support for the patient.

What this study was not able to establish definitively is whether a troubling ICU experience contributes to the development of a psychiatric disorder. Associations has been shown previously using brief and non-diagnostic measurements (i.e. HADS) while in the ICU and afterwards,^{14, 42} and the association has been shown after the experience using diagnostic tools,²¹ however, no long-term studies have been able to track this suggested development over time, which might allow exploration of possible causality. Given the small number of participants able to participate in the follow-up interview, it would be difficult to draw any conclusions regarding the development of psychiatric illness as a consequence of the ICU experience. The development of psychiatric illness

as a consequence of the ICU experience should be studied in a fashion that can identify those at risk or with disease in the unit and can track the progression of symptoms or disease over time. This would require the incorporation of a diagnostic tool (i.e. SCID or equivalent) during the ICU admission and at the follow-up interview, with the understanding that some diagnoses require symptoms to have occurred over a certain period of time (e.g. 6 months for a diagnosis of GAD).

With regard to clinical practice, increasing NOK satisfaction with the ICU experience may be protective against the development of psychiatric illness. One study suggested that the family-centered approach for NOK of patients nearing the end of life had an increased level of satisfaction with the ICU experience as compared to those NOK of patients who survived.⁴⁹ The satisfaction measures identified were specifically related to the healthcare team, including communication and support received, both of which have been shown to be important with regard to the presence of psychiatric disorders.^{18,21} Standardizing procedures, such as the amount of time spent with each family, the occurrence of family meetings regardless of whether the patient is near the end of life, consistent methods of relaying information to families through any member of the healthcare team, in addition to a designated primary physician for each ICU case, would not only increase family satisfaction with the ICU experience, but may also protect against developing psychiatric illness.

Conclusion

In conclusion, we found that psychiatric symptoms and diagnosed psychiatric illness is common in a population of the NOK of ICU patients. Psychiatric symptoms were even more common than a diagnosis and can be a significant burden to the NOK, especially those that are caregivers to the patient. Recognizing that our study was small, we found preliminary evidence that the HADS can be used effectively to screen for psychiatric illness in ICU NOK. A larger study is needed to determine if the HADS is able to predict development of psychiatric illness in NOK after the ICU admission, but our findings show that all NOK with a diagnosis at the follow-up interview had a positive HADS screen during the ICU admission. The majority of NOK perceive the relationship and communication between staff and NOK of medical ICU patients at YNHH as satisfactory according to the measures studied, however further investigation is needed to identify the role of the decision to sleep in the ICU and its impact on the perception of the healthcare team. Further work is required to identify interventions that can occur in the ICU decrease the rates of NOK with psychiatric symptoms that develop as a consequence of the ICU experience.

APPENDIX A

Criteria for Major Depressive Disorder taken directly from DSM-IV-TR¹¹

A. Five (or more) of the following symptoms have been present during the same 2-week period and represent a change from previous functioning; at least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure.

Note: Do not include symptoms that are clearly due to a general medical condition, or mood-incongruent delusions or hallucinations.

1. depressed mood most of the day, nearly every day, as indicated by either subjective report (e.g., feels sad or empty) or observation made by others (e.g., appears tearful).

Note: In children and adolescents, can be irritable mood.

2. markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day (as indicated by either subjective account or observation made by others)

3. significant weight loss when not dieting or weight gain (e.g., a change of more than 5% of body weight in a month), or decrease or increase in appetite nearly every day.

Note: In children, consider failure to make expected weight gains.

4. insomnia or hypersomnia nearly every day

5. psychomotor agitation or retardation nearly every day (observable by others, not merely subjective feelings of restlessness or being slowed down)

6. fatigue or loss of energy nearly every day

7. feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self-reproach or guilt about being sick)

8. diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or as observed by others)

9. recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide

B. The symptoms do not meet criteria for a Mixed Episode.

- C. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.
- D. The symptoms are not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition (e.g., hypothyroidism).
- E. The symptoms are not better accounted for by Bereavement, i.e., after the loss of a loved one, the symptoms persist for longer than 2 months or are characterized by marked functional impairment, morbid preoccupation with worthlessness, suicidal ideation, psychotic symptoms, or psychomotor retardation.

APPENDIX B

Criteria for Generalized Anxiety Disorder taken directly from DSM-IV-TR¹¹

1. Excessive anxiety and worry (apprehensive expectation), occurring more days than not for at least 6 months, about a number of events or activities (such as work or school performance).
2. The person finds it difficult to control the worry.
3. The anxiety and worry are associated with three (or more) of the following six symptoms (with at least some symptoms present for more days than not for the past 6 months).
4. **Note:** Only one item is required in children.
 - a. restlessness or feeling keyed up or on edge
 - b. being easily fatigued
 - c. difficulty concentrating or mind going blank
 - d. irritability
 - e. muscle tension
 - f. sleep disturbance (difficulty falling or staying asleep, or restless unsatisfying sleep)
5. The focus of the anxiety and worry is not confined to features of an Axis I disorder, e.g., the anxiety or worry is not about having a Panic Attack (as in Panic Disorder), being embarrassed in public (as in Social Phobia), being contaminated (as in Obsessive-Compulsive Disorder), being away from home or close relatives (as in Separation Anxiety Disorder), gaining weight (as in Anorexia Nervosa), having multiple physical complaints (as in Somatization Disorder), or having a serious illness (as in Hypochondriasis), and the anxiety and worry do not occur exclusively during Posttraumatic Stress Disorder.
6. The anxiety, worry, or physical symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.
7. The disturbance is not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition (e.g., hyperthyroidism) and does not occur exclusively during a Mood Disorder, a Psychotic Disorder, or a Pervasive Developmental Disorder.

APPENDIX C

Criteria for Post-Traumatic Stress Disorder taken directly from DSM-IV-TR¹¹

1. The person has been exposed to a traumatic event in which both of the following were present:
 - a. the person experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others
 - b. the person's response involved intense fear, helplessness, or horror.
Note: In children, this may be expressed instead by disorganized or agitated behavior
2. The traumatic event is persistently re-experienced in one (or more) of the following ways:
 - a. recurrent and intrusive distressing recollections of the event, including images, thoughts, or perceptions. **Note:** In young children, repetitive play may occur in which themes or aspects of the trauma are expressed.
 - b. recurrent distressing dreams of the event. **Note:** In children, there may be frightening dreams without recognizable content.
 - c. acting or feeling as if the traumatic event were recurring (includes a sense of reliving the experience, illusions, hallucinations, and dissociative flashback episodes, including those that occur on awakening or when intoxicated). **Note:** In young children, trauma-specific reenactment may occur.
 - d. intense psychological distress at exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event
 - e. physiological reactivity on exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event
3. Persistent avoidance of stimuli associated with the trauma and numbing of general responsiveness (not present before the trauma), as indicated by three (or more) of the following:
 - a. efforts to avoid thoughts, feelings, or conversations associated with the trauma
 - b. efforts to avoid activities, places, or people that arouse recollections of the trauma
 - c. inability to recall an important aspect of the trauma

- d. markedly diminished interest or participation in significant activities
 - e. feeling of detachment or estrangement from others
 - f. restricted range of affect (e.g., unable to have loving feelings)
 - g. sense of a foreshortened future (e.g., does not expect to have a career, marriage, children, or a normal life span)
4. Persistent symptoms of increased arousal (not present before the trauma), as indicated by two (or more) of the following:
- a. difficulty falling or staying asleep
 - b. irritability or outbursts of anger
 - c. difficulty concentrating
 - d. hypervigilance
 - e. exaggerated startle response
5. Duration of the disturbance (symptoms in Criteria B, C, and D) is more than 1 month.
6. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.

APPENDIX D

Standardized ICU Questionnaire

Compassion/Support

1. There is one main physician who has meeting/s with me, that I can identify (Y/N) _____
2. The healthcare team is compassionate (or “The healthcare team really cares about my loved one’s condition”) _____
3. The healthcare team is comforting to me _____
4. The time the healthcare team spends with my loved one and with explaining things to me is adequate _____
5. There is an appropriate environment for meetings with staff _____
6. There is an appropriate environment for family meetings without staff _____
7. Overall, I have received support from the healthcare team _____

Skill, coordination, professionalism

8. Given the recent media attention regarding medical errors, I find myself concerned about this possibility _____
9. On a scale of 1-4, where 1 is the most skilled and 4 is the least skilled, my loved one’s healthcare team is _____
10. The healthcare team works **together** to treat my loved one _____
11. The staff works professionally _____
12. There are different teams, besides the ICU team, coordinating the care of my loved one (e.g. cardiology and renal) (Y/N) ___
 - a. The ICU team and other specialists work **together** effectively to care for my loved one ___
13. Overall, the care of my loved one has been skillful _____
14. Overall, my loved one’s care has been well-coordinated _____

Clarity, adequacy, consistency

15. I know the specific role of each member of the team _____
16. All information regarding my loved one is explained in a way that is easy to understand _____
17. I receive enough information about my loved one's condition regarding treatment/prognosis _____
18. I understand the nature of my loved one's illness and associated treatment _____
19. The doctor and I agree on my loved one's treatment _____
20. I receive consistent information about my loved one's care from different members of the healthcare team (or "I receive different information about my loved one's care from different members of the healthcare team") _____

Patient perception

21. My loved one is confident s/he is receiving good quality of care, (where quality of care means the level of skill of the team, the level of compassion the team expresses, and also the ability to communicate effectively) _____
22. I feel my loved one's discomfort has been adequately treated _____
23. **I believe** my loved one is receiving good quality of care _____

Other

For questions 25-26, introduce the following scale: 1) Almost every day 2) Most every day 3) Some of the days 4) Rarely

24. I am here _____
25. I sleep here _____
26. When you are here, how many hours/day do you spend here? _____
27. Do you have any additional stressors, beyond your loved one's illness that are weighing on your mind? (Y/N; if yes, what?) _____

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