CHEST Online Supplement

Emotional Experiences and Coping Strategies of Family Members of Critically Ill Patients

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e-Appendix 1: Family Distress in the ICU Interview Guide

Thank you for taking the time to speak with me today. My name is _____, and I am from the University of Michigan. We are doing this study to understand what people worry about when their family member is in the ICU. We feel that is very important to speak to family members directly to hear about your experiences and worries in the ICU so we can improve the ICU experience.

During this interview, we will be talking about your experiences and thoughts while your family member was in the ICU. I know that some of these things may be difficult to talk about. Some people find talking about their experiences to be helpful. We are most interested to hear about your own personal experiences, opinions, and views, so please know that your views are very valuable to us, and we are here to learn from you. I have a list of topics that I would like to discuss, but feel free to bring up any topics that you feel are related to our discussion. Also, I want to let you know that your participation in this interview is completely voluntary, so if you want me to stop at any time or don't feel comfortable answering a question, please let me know.

Our interview will last no more than one hour. We will be discussing your experiences while your family member was in the ICU. There are no right answers to these questions. There is a spectrum to how people feel, and it is normal to feel conflicted. The answers to these questions will not be discussed with any person caring for your family member. Since I'm not a part of the medical team taking care of your family member, you can feel free to be open about both good and bad experiences that you have had with your medical team.

Anything you say will be kept confidential. I would like to record our discussion so that the rest of the research team can also hear your views exactly so we don't miss anything you say. Only our research team will listen to the recording. To protect your and your family member's confidentiality, we will take out any names that are spoken when we transcribe the tape. The information you give will only be used for this research project to improve communication in the ICU. I want to emphasize that we will <u>never</u> discuss anything that you say with anyone involved in your family member's care. Do you have any questions or concerns? Is it OK to record the discussion?

[Turn on recorder]

In this interview, I'm going to ask you questions about your experiences while [patient] has been in the ICU.

1. Why was [patient] hospitalized in the ICU?

2. How long has [patient] been in the ICU?

3. Before all of this happened with [patient], what kinds of knowledge or experiences did you have with the ICU?

   *Probes
   - TV/movies, personal, family members

4. This time period must be really hard, and I know that you've had a lot to think about. Can you tell us about some of the things that you've been thinking about while [patient] has been in the ICU?

   *Probes
   - What's been going through your mind?

   - What concerns have you had…
     - about [patient]'s…
       - survival
       - pain or discomfort
       - making decisions for [patient]
       - future health, mental, or physical problems
     - about the hospital's or the ICU's…
       - quality of communication
       - the ICU team
       - facilities
     - about your family, in terms of…
       - conflicts between family members during this time
       - how decisions are being made within your family
       - who's taking care of children or elders
     - about finances, in terms of…
       - the costs of medical care
       - the loss of income, for you or for [patient]
       - how to provide any future caregiving for [patient]
     - about yourself, in terms of…
       - keeping yourself healthy or making sure you don't get sick to take care of your family
       - grief for [patient]
       - trying to understand what's going on with [patient]

   - What types of things are you afraid of during this time?

5. What do you expect to happen to [patient] while [he / she] is in the ICU?

6. What do you expect to happen to [patient] after [he / she] leaves the ICU?
7. Who have you talked to about any of these worries?
   *Probes
   - What did you talk about?
   - Why did you talk to them?
   - What providers have you talked to?

Closing: Sometimes, we like to follow up with you in the future with more questions. Would it be ok to contact you in the future?

Thank you so much for taking the time to talk with me today. I realize this is a hard time for you and that you're going through a lot. We really appreciate your time and energy, and hopefully, our project will be able to help other people who are going through similar things in the future.

e-Table 1: Final Codebook

Title	Description
1 Expectations/Reality	Broad theme concerning concurrence or mismatch between family members' expectations about the ICU experience and the reality they encounter. In particular, watch for and code phenomena that suggest potential interventions in this area.
2 Accommodation/Advocacy	Broad theme concerning family members accommodating themselves to staff and/or the circumstances of the ICU; family member empowerment/disempowerment/advocacy; issues of control, uncertainty, hope, and optimism. In particular, watch for and code phenomena that suggest potential interventions in this area.
3 Coping and Emotional experience	Broad theme concerning family members' emotional experiences in the ICU, stress, and coping strategies.
Participant	Parent code to group child codes that apply to participant. No need to apply it without specific child codes.
1 Absence at critical events	Discussion of participant's presence/absence at critical events for the patient; include fear of being absent at critical events. Exclude absence at opportunities to communicate with staff that are not critical events for the patient; instead code as Communication with staff.
2 Advice to others/Advocacy	Code for discussion of participant's advice to others, as well as discussion of the issue of patient or family member advocacy, whether in relation to this patient or in general. Also code this for discussion of family member strategizing about how best to advocate or communicate.
1 Comprehension/Understanding	Relates to a basic, rational level of understanding, distinct from "sense-making" or emotional confusion/clarity. Include discussion of difficulty understanding doctors and thoughts about prognostication. Consider alternatively "Sense-making of how this happened". Do not code for general communication with staff--code Communicating with staff instead.
2 Control	Discussion of participant's thoughts or feelings about control or lack of control in the situation, for example, with respect to predictability, decisions, or capacity to help. Consider co-coding with Decision-making codes or Patient/Trajectory codes.
3 Coping strategies	Code for strategies such as acceptance, avoidance, emotional containment, emotional release, reasoning/rationalizing, solitude, step at a time. Include self-reassurance, such as reminding oneself that staff are competent. Consider co-coding with PR Faith or Ease/Comfort/Relief, when applicable. Co-code with Taking care of self when the strategy is for both physical and mental/emotional care, such as taking time away from the hospital.
3 Outside therapy	Code when the participant has, seeks, or talks about therapy/counseling outside the hospital as a coping strategy for themselves or other family members of concern.

3 Emotional experience	Code as parent for any of the child codes. Also code for any emotional experience not captured by any of the child codes, such as emotional exhaustion, lack of emotion, etc.
3 Anger/Frustration	Expressions ranging from impatience to frustration to anger, whether explicitly identified as such by the participant or only implied by context, language, tone, etc.
3 Ease/Comfort/Relief	Discussion of experiences that bring participant ease, comfort, or relief from negative emotions; expressions of feeling ease or comfort. Consider co-coding with Coping strategies if relevant.
3 Fear/Anxiety	Fear or anxiety, though not anxiety in the sense of mere stress.
3 Guilt	Expressions related to guilt or shame. Consider co-coding with Decision-making, if applicable.
3 Loneliness	Expression of present or anticipated loneliness of participant. Co-code with Thoughts of the future, if applicable.
3 Sadness/Grief/Depression	Expressions ranging from mild sadness to grief (including mention of major life losses) to clinical depression. If impacting participant's mental state as well as emotional state, co-code with PR Mental state.
3 Shock/Trauma	Shock, trauma.
3 Stress	Code for general stress, for stressful emotions not otherwise specified, for discussion of emotional rollercoaster (extreme ups and downs). Co-code with Worst stressors when applicable. Do not code when other child codes more precisely capture the emotion, such as Anger, Fear, Sadness, or Shock.
3 PR Faith	Discussion of participant's faith (not patient's). Consider co-coding with Coping strategies when appropriate.
1,2 PR Goals for patient's ICU care	Participant's goals for the patient's care in ICU. Must be specific goals (e.g., "get off the vent by tomorrow"), not general or vague (e.g., recovery, get better).
2 Hope/Optimism	Expressions of hope or optimism, or discussion of hope or optimism. Include discussion of the participant's need for optimism or hopefulness from providers.
2 PR Involvement in care	Discussion of participant being involved in specific patient care activities in ICU. Exclude decision making and communication involvement; code with appropriate Decision making and Hospital codes instead.
3 PR Mental state	Discussion of participant's mental state, distinct from emotional state, e.g. difficulty cognizing, concentrating, keeping track of time, etc.
1 Prior experience as a caregiver	Discussion of participant's past experiences as a caregiver, whether with the patient or with others. Exclude professional caregiver experience, for example, as a nurse or other provider.
1 PR Prior experience with PT's medical problems	Code when participant discusses experience with any of the patient's current or past medical problems, prior to this ICU encounter.
1 PR Prior ICU experience/expectations	Participant's prior experience with ICU, whether with this patient, themselves, or with someone else; also, whether in real life or via TV, movies, books, etc. In addition, discussion of what the ICU was expected to be like prior to the current experience. Co-code with PT Prior ICU experience if the experience pertains to this patient.

1 Sense-making of how this happened	Code when participant discusses ways of making sense, or emotional struggles with making sense, of the circumstances and complexities of patient's illness, such as coincidental timing of multiple unrelated illnesses, unexplained trajectory, failed treatments, coming to grips with what's going on with the patient, etc. For a participant's more purely cognitive/rational understanding, code Comprehension/Understanding.
3 Taking care of self	Discussion of physical self-care such as sleeping, eating, exercising, resting, etc. Co-code with Coping strategies when the care is for both physical and mental/emotional care, such as taking time away from the hospital or eating meals with family.
3 PR Time amount in ICU	Amount of time participant is spending in the ICU, whether in total days, days per week, or hours per day. Exclude how that time is spent (code PR Activities in the ICU) and patient time amount in ICU (code PT Time amount in ICU). Consider co-coding with Other obligations.
2 Waiting	Discussion of waiting, whether short-term or long-term, such as waiting for providers, waiting for a room transfer, waiting for tests or procedures, waiting for patient trajectory to change, waiting for family members, etc.
1 What it's like seeing PT sick	Code when participant describes their subjective experience of seeing the patient sick. This is distinct from Patient/Physical appearance, which concerns the objective appearance of the patient. Okay to co-code when applicable.
3 Worst stressors	Code for answers to questions such as, "what's been the most stressful part of all of this?" or "apart from your loved one's illness, what's been the most stressful thing?" Co-code with Stress.
Patient	Parent code to group child codes that apply to patient. No need to apply it without specific child codes.
1 Capacity to communicate	Discussion of patient's capacity to communicate or quality of their communication.
1 Complications during ICU stay	Discussion of unexpected complications arising during the ICU stay.
1,3 PT Mortality	Discussion of the possibility or likelihood of the patient's death. Consider coding Mortality/Life is precious if the participant expresses thoughts about mortality generally, apart from patient's death. Consider co-coding with End of life decisions when applicable.
1 Pain/Discomfort	Discussion of patient's pain, discomfort, pain management, discomfort with ventilator, participant's perception of patient's pain, etc. Consider co-coding with participant's Emotional experiences, What it's like seeing PT sick, Sedation, Ventilator, or Complications during ICU stay. Code only for discussion of patient's pain/discomfort in this ICU stay; for prior pain/discomfort, code What PT was like pre-ICU; for post-ICU pain/discomfort, code Functional capacity or Thoughts of the future, as appropriate.
1 Physical appearance	Discussion of patient's objective physical appearance, including direct observation of patient actions such as gagging, coughing, struggling, etc. Consider alternatively or co-coding with Participant/What it's like seeing PT sick, if a more subjective expression is applicable.

1 PT Prior ICU experience	Patient's prior experience in ICUs. Also code with What PT was like pre-ICU. Co-code with PR Prior ICU experience when applicable.
1 Reason for ICU admission	Discussion of onset of critical illness and reason for current ICU admission.
1 Suddenness of critical illness	Code for discussion of the suddenness of onset of the critical illness, in the participant's subjective experience.
1 Restraints	Discussion of physical restraints for patient. Consider co-coding with Pain/discomfort or Sedation.
1 Sedation	Discussion of patient's level of sedation; often relevant to discussion of pain medications, since in the ICU setting they are often sedating. Consider coding with PT Mental state/delirium/emotional state and Pain/Discomfort.
1 Trajectory	Discussion of improvement, recovery, worsening, stability, or instability of trajectory. Consider sub-codes of Rate of Change or Uncertainty of Trajectory, when applicable.
1 Rate of change	Gradualness or rapidity of change in trajectory, whether worsening or improving.
1 Uncertainty of trajectory	Code for discussion of uncertainty of trajectory. Consider co-coding with Decision-making codes, Emotional experience codes, Thoughts of the future, PT Mortality, etc.
1 Ventilator	Code for significant discussion of the ventilator, such as going on or off the ventilator, the perceived role of the ventilator, for example, "keeping the patient alive" versus "breathing for the patient." Consider co-coding with Participant/What it's like to seeing PT sick, if applicable.
1 What PT was like pre-ICU	Includes discussion of patient's past medical history, functional capacity and quality of life prior to this illness, etc. Also consider coding with PT Past experience in ICU.
1,2 What would PT want	Discussion of what participant or others think patient would want. This may be different from what participant thinks is best for patient.
3 Other Family	Parent code to group codes about other family members. Also see Participant/Other obligations/stressors. Apply this code without child codes if none are applicable, but other family is the topic. Family is defined broadly to include unmarried partners, ex-partners, children of partners, very close friends, live-in friends, extended family, step-family, etc. Exclude deceased family.
3 Concern for other family members	Discussion of participant's concern for other family members. Consider co-coding with Other obligations/stressors if participant is also in some way responsible for those family members, e.g., children or elderly family for whom participant cares.
3 Other family support/conflict	Discussion of support from family members or conflict with or among family members. If the topic is the participant supporting other family members, consider coding as Concern for other family members, Other obligations/stressors, or simply Other Family.

3 Other People	Discussion of people excluding family members (see Other Family) and hospital staff (see Hospital Staff). For example, friends or clergy. Include home health care staff who are not family; do not code them as Hospital Staff. Include discussion of support from other people, conflict with other people, lack of desire to discuss with others, other people visiting/not visiting, lack of understanding from others, social stigma, etc.
Hospital	Parent code to group child codes that apply mainly to hospital. No need to apply it without specific child codes. Child codes are not mutually exclusive.
2,3 Chaplain services	Discussion of experiences with the hospital's chaplain services, or lack thereof. Exclude discussion of external clergy; instead code that Other people.
2 Communication with staff	Includes discussion of informativity, openness to questions, directness of communication, setting/adjusting expectations, etc. Includes positive or negative assessments of staff communication. Consider co-coding with Staff providing support, Negative interactions with staff, or other Hospital child codes.
1 Hospital facilities	Mention of hospital size, signage, parking, accommodations, etc.
2 Negative interactions with staff	Discussion of negative interactions with staff, including pessimistic attitude or communication from hospital staff, complaints, etc. Include negative interactions that happened at outside hospitals. Consider co-coding with Hope/Optimism (e.g., participant's need for hope from staff) when applicable.
1 Opinion of ICU	Discussion of the participant's opinion of the ICU based on the current encounter. Exclude discussion of specific staff or specific incidents, if not generalized to ICU overall. Exclude discussion only of communication issues: code as Communication with staff instead.
1,2 Quality differences	Includes discussion of quality differences between staff, different hospitals, ICU and ER, day and night teams, etc. Do not code for discussion of the mere fact of different hospitals when quality differences between them are not emphasized.
2,3 Social work services	Discussion of experiences with the hospital's social worker or social work services, or lack thereof.
1,2 Spending time with patient	Discussion of amount of time staff spend with patient, e.g. "someone is always coming in."
1,2 Staff changes	Discussion of what it's like when the assigned staff change, e.g., shift changes, rotation, frequency of changes, quality of hand over, etc. Consider co-coding with Quality differences, if applicable.
2,3 Staff providing support	Discussion of general support provided by any hospital staff, whether to patient or participant. Co-code with other Hospital child codes, if applicable.

e-Appendix 2: Reflexivity during qualitative analysis:

Reflexivity and awareness of positionality in qualitative research are important to mitigate the effects of a researcher's background on study methods and analysis.[1,2] When designing and analyzing the study, we fostered reflexive dialogue between multiple investigators with diverse backgrounds (EAH-internal medicine physician with background in bioethics; TSV-pulmonary/critical care physician-researcher; JM-research analyst with sociology and chaplaincy background; AF-psychologist with expertise in decision-making; TJI-pulmonary/critical care physician-researcher with expertise in survivorship after critical illness). Furthermore, during the coding and consensus-building process, the beliefs and values between primary analysts (JM, EC, KL, TSV, EAH) as well as their position in the study setting were actively discussed.

e-Appendix References:

1. Malterud K. Qualitative research: standards, challenges, and guidelines. *Lancet Lond Engl* 2001;358(9280):483–488.
2. Barry CA, Britten N, Barber N, Bradley C, Stevenson F. Using reflexivity to optimize teamwork in qualitative research. *Qual Health Res* 1999;9(1):26–44.