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Care Transition Experiences

Project Title: Developing an in-depth understanding of patient and caregiver engagement across care transitions from hospital: protocol for a qualitative study exploring experiences

PATIENT INTERVIEW GUIDE

Thank you again for taking the time to connect today. As a reminder, this interview is aimed at helping us understand how you (and your caregiver) were involved in your care, or participated in your care, at *[insert hospital/unit location]* and during your move from *[hospital/unit]* to *[new(current) location]*. Throughout this interview, we will have you think back and recall specific details about your care and transition through the health care system.

A. General Questions

1. Tell me a little bit about yourself... (question to get participant comfortable).
2. Can you describe for me why you were hospitalized?
3. Do you have anyone caring for you in your day to day life (family/friend caregiver)?

If yes to Q3: Prior to this stay at the hospital, how did they support you? During your hospital stay, how have they been involved?

B. Pre-Transition – Stay at [Hospital Location] and Preparation for Transition

4. When you first arrived to *[insert inpatient unit]*, what happened?
5. Within the first 24hrs of your stay, did anyone speak to you about what your care preferences were, or about your goals of care while you were going to be in the hospital? By goals of care, I mean, did your care team ask you about your values and goals, and what you wanted to achieve during your stay.
 - If yes, what did this conversation look like?
 - If no, would you have wanted someone to ask about your goals? Why?
6. Follow up: Were care providers/staff (e.g. food services/environmental services like laundry/cleaning) open to hearing your preferences for care and flexible in meeting your requests/needs? Tell me more about that.
7. In general, how did you feel about your involvement with your day-to-day care while you were on *[insert inpatient unit]*?
8. Tell me about your experience making decisions about your care in hospital. For example, making decisions about your day-to-day care, discussing how prepared you felt to move to *[insert next location – rehab, home, LTC]*
9. *If patient has active family caregiver, ask:* How was your caregiver involved in these discussions about your care planning?

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C. During Transition (within 48hrs of Transition)

10. Transitions between hospital and healthcare services involve lots of planning and discussion. As you started to prepare for your transition to *[insert current location where patient is]*, what kinds of discussions took place with your healthcare team?
11. Can you walk me through what happened on the day that you moved from *[insert last location]* to *[insert current location]*?
12. In the days leading up to your discharge from the hospital when you had a question about your care, how did you go about finding an answer?
13. What materials/information/resources about the transition and the next steps in your care were provided to you before your discharge?

D. Post-Transition (after the transition to new location occurred, reflection on transition process)

14. What challenges did you experience in the days following your transition to *[insert present location]*? What went well?
15. When you arrived, did you feel like you had an adequate understanding of your care moving forward? What about now? If different: what changed?
16. As you left *[insert hospital]* did you have any outstanding or ‘burning questions’?
17. As you left *[insert hospital]* did you have any pressing concerns or worries? How were they addressed?
 - If they weren’t addressed, why do you think they weren’t addressed? (e.g., patient did not voice concerns, HCP would not listen, etc.) How would you have liked them to be addressed?
18. Upon reflection, moving from *[hospital]* to *[current location]*:
 - a) Who was the most helpful person in your care transition process?
 - b) What was the best part of your care transition process? What was the most challenging part of your care transition process?
 - c) If you could give advice to someone going through the same care transition process, what would you tell them?

E. Concluding Question

19. Is there anything else that you feel is important for us to know to understand your experiences?

Modify questions for subsequent transitions in care interviews (e.g. rehabilitation unit to home)

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CAREGIVER INTERVIEW GUIDE

Thank you again for taking the time to connect today. As a reminder, this interview is aimed at helping us understand how you were involved in the care of [insert patient name], at [insert hospital/unit location] and during your move from [hospital/unit] to [new(current) location]. Throughout this interview, we will have you think back and recall specific details about your care and transition through the health care system

A: General Questions

1. Tell me a little bit about yourself...
 - Probe: How long have you been involved in caring for [name of patient]?
2. Prior to this stay at the hospital, how did you support [name of patient] *Examples: day to day support with ADLs, casual support with groceries, transportation, etc.?*
3. During their hospital stay, how have you been involved?

B: Pre-Transition- Stay at [Hospital Location] and Preparation for Transition

4. When [name of patient] first arrived to [insert unit] what happened?
5. When [name of patient] was first admitted, did the health care team ask you for any information or input about [name of patient]?
 - If yes: What did that conversation look like? If no: Would you have wanted someone to ask you?
6. Were your needs or preferences as a caregiver asked about or discussed by [name of patient]'s healthcare provider(s)?
7. *How were you* involved in decision making and discussions about care planning for [name of patient] while they were in [hospital location]?

C: During Transition (within 48hrs of Transition)

1. Transitions between hospital and healthcare services involve lots of planning and discussion. As they started to prepare for [name of patient]'s transition to [insert current location where patient is], what kinds of discussions were you involved in with their healthcare team?
2. Can you walk me through what happened on the day that they moved [name of patient] from [insert last location] to [insert current location]?
3. In the days leading up to discharge, when you had a question about the care of [name of patient], how did you go about finding an answer? OR Can you think of an example

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during the days leading up to discharge when you needed to know something about the care of your partner/friend/relative? (Probe for more than one example)

4. Were you given any information or resources to help support you in your role as a family caregiver? Were you told about any resources or information available in the community?
5. What, if any, education or training did you receive on how to care for [name of patient] in preparation for leaving [*insert last location*]?
6. How were you involved in decisions about discharge planning and future care arrangements? Tell me more about that.... Do you feel you were involved about as much as you wanted to be? (If not...)
7. Did anything make it more difficult to discuss discharge planning and transitions with health care providers or staff? If so, could you talk about those?
8. What steps do you think healthcare providers or staff could take to make it easier to discuss discharge planning and transitions with them?

D: Post-Transition (after the transition to new location occurred, reflection on transition process)

1. What challenges did you experience as a caregiver in the days following [name of patient]'s transition to [*insert present location*]?
2. When they arrived, did you feel like you had an adequate understanding of what would happen moving forward? What about now? If different: what changed?
3. As [name of patient] left [*insert hospital*] did you have any outstanding or 'burning questions'?
 - *Probes for: What were your unanswered questions? Were they answered after discharge, and if so, how?*
4. Upon reflection as a caregiver of someone moving from [hospital] to [current location]:
 - d) Who was the most helpful person in the care transition process?
 - e) What was the best part of the care transition process?
 - f) What was the most challenging part of the care transition process?
 - g) If you could give advice to someone going through the same care transition process with a loved one, what would you tell them?

E: Concluding Questions

Is there anything else that you feel is important for us to know to understand your experiences?

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HEALTH CARE PROVIDER INTERVIEW GUIDE

Thank you again for taking the time to connect today. As a reminder, this interview is aimed at helping us understand the process of care transitions in your organization and how patients and caregivers are involved in these discussions.

A. Introduction

1. Please describe your position here at [*insert location*]?
2. How many years have you been employed in this position?
3. Have you ever worked in other areas at [*insert location*]?
4. Can you walk me through how you feel patients and caregivers are involved in decisions about their care and/or discharge plans? *Probe: do you always involve caregivers?*
5. What does patient and caregiver engagement mean to you?

B. Care Transitions

1. Can you walk me through what a typical transition looks like for your patients? *Probe: what does discharge planning look like? What staff members are involved? How are patients/families involved? What do planning meetings look like? How do you decide where patient is going next (optional depending on patient/journey)*
2. Tell me about the benefits and/or challenges associated with working patients and caregivers during times of transition?
3. Thinking about a patient being discharged to [*insert example discharge location*]; can you walk me through how you prepare the patient/caregiver to ensure they know what to expect next in their care journey?
4. Are you able to provide education/hands-on training to patients/caregivers in preparation for leaving the hospital (e.g. transfers, bathing, dressing, catheterization, medication management, etc.)? Could you say some more about what happens/how that goes?

C. Patient/Family Engagement

1. How do you identify whether your patient is being helped by a caregiver?
2. To what extent are patients and caregivers involved in decision making about their care?
3. What are things that make it easier to involve patients/caregivers in care planning? What are things that make the process of engagement difficult?
4. How do you feel older patients wish to be involved in care planning and decision-making? *Probe: Do you feel some wish to be more or less involved? Does it depend on the situation? How do you go about understanding how a patient wishes to be involved?*

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5. What written educational information/send information electronically do you provide patients/families? What other types of information are available?
6. How do you go about recognizing and assisting caregivers who may seem to be overwhelmed?
7. What process is there to ensure that patients/caregivers understand the information they are being provided, or are informed enough to partake in care decisions/discussion?

D. COVID-19 Impact

1. How do you think the COVID-19 pandemic has changed the process of care transitions?
Probe: Have there been any benefits to the care transition process as a result of the pandemic? Any difficulties?

E. Concluding Questions

Is there anything else that you would like to share or didn't have a chance to say?