

Topic Guide: Caregiver

How do patients with advanced cancer decide to attend the emergency department, and what influences their decision-making at this time? A qualitative case study

Aim: To investigate the processes by which advanced cancer patients, and their caregivers, decide to attend the emergency department, and; to explore advanced cancer patients', and their caregivers', preferences for an urgent care service.

Introduction:

- Introduce researcher and study purpose.
- Thank participant for taking part.
- Explain that this is an opportunity for the participant to tell the researcher, in their own words, what happened when their family member/ close friend attended the ED, and how the decision to go to the ED came about.

Administrative Tasks:

- Describe the interview process, including the following:
 - o The interview will be audio recorded.
 - o All information from the interview will remain confidential unless there are concerns regarding the safety of the participant, others, and/ or information is disclosed that is required to be reported by law.
 - o Expected interview duration is approximately 60 minutes.
 - o The participant can stop the interview at any time and/ or decline to answer any questions asked.
 - o There are no right or wrong answers.

- Encourage the participant to speak freely throughout the interview. Reassure participant that any names or identifying information disclosed will be removed when the interview is transcribed.
- Make sure the participant understands that the interview is regarding the patient's most recent ED visit: probe participant for the date/ time of patient's most recent ED visit. Check that this is consistent with study records.
 - *If **NOT** consistent, then ensure that the participant is unaware of any more recent ED visits, but, do not disclose any details of the most recent ED visit. ("As far as you know, that was the last time that [inserts patient's name] visited the ED?"). Document the date and time of this ED visit and proceed to interview regarding this episode.*

Check Written Consent Form

----- **START RECORDING** -----

Icebreaker:

- | | |
|---|--|
| | Examples |
| 1. General question aiming to put participant at ease | "Tell me a little bit about yourself and who the key people are in your life" |

Explore Participant's Relationship to Patient:

Topic Areas to be Covered

1. Clarify and explore the participant's relationship to the patient
 - How long have they known each other?
 - Are they family members or friends?
 - Do they live together?

Examples

- "How do you know [insert patient's name]?"**
- "Tell me about your relationship with [insert patient's name]"**

2. Explore the participants role as caregiver
 - How long has the participant been involved in the patient's care?
 - Are they the only caregiver?
 - Do others help with caring? Who?
 3. Explore any particular challenges experienced with being a caregiver
- "How are you involved with [insert patient's name] care?"**
- "Describe to me what a typical day caring for [insert patient's name] consists of?"**
- "How do you find caring for [insert patient's name]?"**
- OR**
- "What do you find most challenging about being a caregiver?"**

ED Attendance:

Topic Areas to be Covered

1. Explore the events surrounding the patient's ED attendance
 - Where was the patient?
 - Where was the participant?
 - Did they participant go to the ED with the patient?

Examples

"I'm interested in knowing more about the time that [insert patient name] came to the ED.

What can you tell me about that day?

OR

Talk me through what happened that day?"

Explore Decision Making:

Topic Areas to be Covered

1. Explore the decision to go to the ED
 - Who made the decision to go to the ED?
 - Who else was involved in making the decision?

Examples

"Explain to me how it was decided that [insert patient's name] should go to the ED."

- Were there differences in opinions?
- How long did it take to make the decision?

2. Explore influencing factors in decision making

- What were the factors?
- What made them important?
- If not mentioned by participant, ask specifically whether any of the following factors influenced decision making:
 - a. **Symptoms** experienced by the patient;
 - b. **Access** to healthcare services (both physical in terms of location of patient to the service and non-physical in terms of the availability of such service);
 - c. **Religion**;
 - d. Previous **end of life discussions or advance care planning**;
 - e. **Previous advice** or guidance provided about healthcare services and utilisation;
 - f. **The set-up at home** (e.g. living alone? Married? Children in the house); and
 - g. **Previous patterns of consulting behaviour and experiences of healthcare services** (including both the ED and elsewhere)

“What things did you weigh-up when deciding that [insert patient’s name] needed to visit the ED?”

“You’ve told me about these important factors that influenced your decision-making [list factors mentioned]. Explain to me why they were important and how they influenced your decision?”

3. Explore hierarchy and relationship between factors mentioned
 - Was there one factor that was the most important?
 - Were there factors that were not so important?
 - Were they related?

“Were any of these factors you’ve mentioned more important than others? In what way?”

“Do you think any of these factors were related to each other? Or are they separate things that you considered individually?”

Experience at ED and reflecting on decision:

Topic Areas to be Covered

1. Explore ED experience further

2. Explore previous healthcare utilisation behaviour
 - Have there been similar situations in the past?
 - Did they act the same or differently?
3. Ask participant to reflect on decision

4. Explore preferences for acute care services
 - Would they prefer care at home or in hospital?
 - Why?

Example Questions

“Tell me a bit about what happened when [insert patient name] arrived at the ED?”

“Has [insert patient name] ever been that unwell before?”

“Looking back now, what are your reflections on the experience and decision that was made?”

OR

“If the same situation arose again, what would you do differently?”

“If [insert patient’s name] needed urgent care again, describe to me what you would consider an ideal service to respond?”

Concluding Interview

1. Remind participant about the study purpose

The purpose of this study is to try and understand how people with cancer, and their family or friends decide to go to the ED. Are there any areas that we haven't talked about that you feel would be important to discuss?"

2. Ask for any final thoughts or comments

"Do you have any questions, final thoughts or comments?"

----- STOP RECORDING -----

----- COMPLETE PARTICIPANT DEMOGRAPHICS FORM -----

Final Tasks:

- Check participant is okay with the interview process and enquire if they would like any additional support at this time. If participant shows any signs of distress refer to Distress Protocol for further action.
- Leave details of the Macmillan Information & Support Centre, based at the Cicely Saunders Institute, King's College Hospital.
- Ask caregiver if they would like a copy of the study findings.
- Thank participant.