

**Audit of Communication, CarE Planning, and
DocumenTation:
A multicenter, prospective study**

The ACCEPT Study

Family Member Questionnaire

Hospital or Acute Care Setting

SHORT VERSION (Self-Administered)

Date

____-____-____
DD MMM YYYY

Section 1: About Your Relative's Health Care Before Hospitalization

1. Have you heard about Advance Care Planning?

Yes No

Advance Care Planning is thinking about your future health care treatment decisions and what your wishes are for end of life care. It is also about talking with your close family, friends, and health care providers (like your doctor) so they know your thoughts and wishes if you are not able to speak and make decisions yourself. It also involves naming someone to make medical decisions for you if you are not able to speak for yourself.

2. Before being in the hospital, have you ever thought about what kinds of treatments you would want, or not want for your relative, if your relative's health got worse? For example, have you thought about the use of cardiopulmonary resuscitation (CPR), breathing machines, dialysis, Intensive Care Unit (ICU) admission, etc.

Yes No

Many people have gone to a lawyer and completed a power of attorney for financial and property matters or last will and testament. The following questions pertain to what planning your relative has done as it relates to their future health care only and not financial matters.

3. a) Has your relative written down their wishes about the medical treatments they would want (or not want) in the event that your relative is unable to speak for themselves? For example, does your relative have an advance care plan, advance directive or living will, or another written document .

Yes No Unsure

4. Has your relative named someone, in writing, to be their substitute decision maker for medical treatment decisions? (eg. Power of Attorney for Person Care, Personal Directive, Representation Agreement)

- Yes No

5. At this point in time, if life supports were needed to keep your relative alive, which option would you prefer for your relative's care? Please check (✓) one.

-
- Use machines and all possible measures including resuscitation (CPR) with a focus on keeping them alive at all costs.
-
- Use machines and all possible measures with a focus on keeping them alive but if their heart stops, no resuscitation.
-
- Use machines only in the short term to see if they will get better but if their illness is prolonged, change focus to comfort measures only. If their heart stops, no resuscitation (CPR).
-
- Use full medical care to prolong their life but if their heart or their breathing stops, no resuscitation (CPR) or breathing machines.
-
- Use comfort measures only with a focus on improving their quality of life and comfort. Allow natural death and no artificial prolongation of life and no resuscitation.
-
- Unsure
-

Section 2: Goals of Care during Current Hospitalization

The following questions are about the treatments your relative would want, or not want the doctors to provide should your relative’s health get worse to the point of being life threatening during THIS HOSPITALIZATION. For example, some patients may want life-sustaining treatments but others may not. By life sustaining treatments, we mean the use of cardiopulmonary resuscitation (CPR), breathing machines, dialysis, Intensive Care Unit (ICU) admission, etc. **Please note that some of these questions may not be applicable to you because we are interviewing many people who may have problems that are more life-threatening than your relative’s.**

		How important is this care issue to you?				
		Not at all Important	Not Very Important	Somewhat Important	Very Important	Extremely Important
Since your relative’s admission, has a member of the health care team						
1. asked you if your relative had prior discussions or written documents about the use of life-sustaining treatments.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. offered to arrange a time when you and/or your family can meet with the doctor to discuss the treatment options and plans.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. provided you with printed information about goals of care discussions to read before you meet with the doctor.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4. asked you what is important to you as you consider health care decisions at this stage of your relative’s life (i.e., values, spiritual beliefs, other practices).	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
5. asked you if you had any questions or needed things clarified about your relative’s overall goals of care.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
6. asked you what treatments you prefer your relative (the patient) to have or not have if your relative develops a life-threatening illness.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
7. offered you an opportunity to discuss with members of the health care team what would happen if your relative (the patient) lost their ability to consent to care.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

		How important is this care issue to you?				
		Not at all Important	Not Very Important	Somewhat Important	Very Important	Extremely Important
Since your relative's admission, has a member of the health care team						
8. informed you that your relative may change their mind about their decisions about goals of care.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
9. talked to you about a prognosis or indicated in some way that your relative has limited time left to live.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
10. talked to you about the outcomes, benefits, and burdens (or risks) of life-sustaining medical treatments.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
11. given you the opportunity to express your fears or discuss what concerns you.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
12. offered you support from members of the health care team (e.g. spiritual care, social work, clinical nurse specialist) as needed.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
13. talked to you about outcomes, benefits, and burdens of focusing on quality of life and comfort care as the goal of your relative's treatment (e.g. treating symptoms like pain without trying to cure or control the underlying illness).	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
14. helped you access legal documents to communicate your relative's Advanced Care Plans.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Section 3: CANHELP Lite

The following questions include items that are considered important in terms of quality of care for people who have serious, life threatening illnesses. Please think about the health care that your relative has received **during the past month (this includes the time before and during this hospital visit)** from doctors, nurses, and other health care professionals. For each question you will be asked to choose a number between 1 and 5 to indicate how satisfied you are with that particular aspect of care -- the higher the number, the more satisfied you are. If you choose option #1 **“Not at all Satisfied”**, for example, you will be indicating that this aspect of the care you or your relative received did not meet any of your expectations of high quality care. At the other end of the scale, your choice of option #5 **“Completely Satisfied”** will indicate that this aspect of the care you or your relative received met or exceeded your expectations of quality care.

All answers are confidential and will not be shown to doctors or other health care professionals who are responsible for your care. There are no right or wrong answers. Completely honest answers are most helpful! Please note that some questions may not be relevant to your situation, because we are interviewing people who may have more serious health issues than your relative’s.

	1 Not At All	2 Not Very	3 Somewhat	4 Very	5 Completely
Global Questions of Caregiver Satisfaction					
A. <u>In general</u> , how satisfied are you with the quality of care your relative received <i>during the past month</i> ?					
Relationship with the Doctors					
1. How satisfied are you that the doctor(s) took a personal interest in your relative <i>during the past month</i> ?					
2. How satisfied are you that the doctor(s) were available when you or your relative needed them (by phone or in person) <i>during the past month</i> ?					

	Not At All	Not Very	Somewhat	Very	Completely
3. How satisfied are you with the level of trust and confidence you had in the doctor(s) who looked after your relative <i>during the past month</i> ?					
Communication					
4. How satisfied are you that the doctor(s) explained things relating to your relative's illness in a straightforward, <u>honest</u> manner <i>during the past month</i> ?					
5. How satisfied are you that you received <u>consistent</u> information about your relative's condition from all doctors and nurses looking after your relative <i>during the past month</i> ?					
6. How satisfied are you that the doctor(s) <u>listened</u> to what <u>you</u> had to say <i>during the past month</i> ?					
Decision Making					
7. How satisfied are you with discussions <i>during the past month</i> with the doctor(s) about where your relative would be cared for (in hospital, at home, or elsewhere) if your relative were to get worse?					
8. How satisfied are you with discussions <i>during the past month</i> with the doctor(s) about the use of life sustaining technologies (for example: CPR or cardiopulmonary resuscitation, breathing machines, dialysis)?					
9. How satisfied are you with your role <i>during the past month</i> in decision making regarding your relative's medical care?					
10. How satisfied are you with discussions with your relative about wishes for future care in the event he or she is unable to make those decisions?					









Section 4: Tell us more about yourself

1. Age: _____ years
2. Sex (✓) one: Male Female
3. **Legally Appointed Decision Maker**
Have you been appointed as the legal representative for health related decisions for your relative?
 Yes No
4. **Is your relative mentally competent?**
 Yes No
5. **Do you see yourself as:** (✓) one
 Asian/Pacific Islander
 African/Black North American
 Caucasian/White
 East Indian
 Native Canadian
 Other (specify): _____
6. **Besides English (or French if you live in Quebec) do you speak another language on a daily basis?**
 Yes, specify: _____
 No

Section 4: Tell us more about your relative

1. Age: _____ years
2. Sex (✓) one: Male Female
3. In general, how would you rate your relative's health?
 - Excellent
 - Very Good
 - Good
 - Fair
 - Poor
4. Does your relative see themselves as: (✓) one
 - Asian/Pacific Islander
 - African/Black North American
 - Caucasian/White
 - East Indian
 - Native Canadian
 - Other (specify): _____
5. Besides English (or French if your relative lives in Quebec) does your relative speak another language on a daily basis?
 - Yes, specify: _____
 - No
6. Please consider your relative's overall condition 2 weeks before admission to the hospital. How fit or frail were they at that time point?
Please refer to the table on next page.
Check only ONE response only.
If you have trouble deciding between two options, choose the higher functioning level.

2 weeks before admission to the hospital

(✓)	Description	
<input type="checkbox"/>		<p align="center">Very Fit (category 1)</p> <p>People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.</p>
<input type="checkbox"/>		<p align="center">Well (category 2)</p> <p>No active disease symptoms but less fit than people in category 1. Often, they exercise or are very active occasionally, e.g. seasonally. <i>Well</i> older adults share most attributes of the very fit, except for regular, vigorous exercise. Like them, some may complain of memory symptoms, but without objective deficits.</p>
<input type="checkbox"/>		<p align="center">Managing Well (category 3)</p> <p>Medical problems are well controlled, but people in this category are not regularly active beyond routine walking. Those with treated medical problems who exercise are classed in categories 1 or 2.</p>
<input type="checkbox"/>		<p align="center">Vulnerable (category 4)</p> <p>Not dependent on others for daily help, but often symptoms limit activities. A common complaint is being “slowed up” and/ or being tired during the day. Many people in this category rate their health as no better than “fair”. Memory problems, if present, can begin to affect function (e.g. having to look up familiar recipes, misplacing documents) but usually do not meet dementia criteria. Families often note some withdrawal – e.g. needing encouragement to go to social activities.</p>
<input type="checkbox"/>		<p align="center">Mildly Frail (category 5)</p> <p>More evident slowing and individuals help needed in “high” activities of daily living (finances, transportation, heavy housework, medications). Mildly frail people might have difficulty with shopping or walking outside alone, meal preparation, and housework. Often, they will have several illnesses and take multiple medications. This category includes people with mild dementia. Their common symptoms include forgetting the details of a recent event, even though they remember the event itself, asking the same question, or telling the same story several times a day and social withdrawal.</p>
<input type="checkbox"/>		<p align="center">Moderately Frail (category 6)</p> <p>Individuals need help with all outside activities and with keeping house. Inside, they often have problems with stairs and need help with bathing and might need minimal assistance (cuing, standby) with dressing. If a memory problem causes the dependency, often recent memory will be very impaired, even though they seemingly can remember their past life events well.</p>
<input type="checkbox"/>		<p align="center">Severely Frail (category 7)</p> <p>Completely dependent on others for all or most personal activities of daily living, such as dressing and feeding.</p>
<input type="checkbox"/>		<p align="center">Very Severely Frail (category 8)</p> <p>Completely dependent, approaching the end of life. Typically, people in this category could not recover from even a minor illness.</p>

1	0			-				
Site Number					Enrollment Number			

You have reached the end of the questionnaire. Thank you for your participation. Please return your completed questionnaire to the nurse or unit clerk at the front desk.