

Appendix 1 (as supplied by the authors): Items from the domains of the Canadian Health Care Evaluation Project (CANHELP) instrument pertinent to end-of-life communication and decision making — relationship with physicians, communication, and decision making

Patient Version

Relationship with the Doctors

2. How satisfied are you that you knew the doctor(s) in charge of your care during the past month?
3. How satisfied are you that your doctor(s) took a personal interest in you during the past month?
4. How satisfied are you that your doctor(s) were available when you needed them (by phone or in person) during the past month?
5. How satisfied are you with the level of trust and confidence you had in the doctor(s) who looked after you during the past month?

Communication

20. How satisfied are you that the doctor(s) explained things relating to your illness in a straightforward, honest manner during the past month?
21. How satisfied are you that the doctor(s) explained things relating to your illness in a way you could understand during the past month?
22. How satisfied are you that you received consistent information about your condition from all doctors and nurses looking after you during the past month?
23. How satisfied are you that the doctor(s) listened to what you had to say during the past month?
24. How satisfied are you that you received updates about your condition, treatments, test results, etc. in a timely manner during the past month?

Decision Making

25. How satisfied are you with discussions during the past month with your doctor(s) about where you would be cared for (in hospital, at home, or elsewhere) if you were to get worse?
26. How satisfied are you with discussions during the past month with your doctor(s) about the use of life sustaining technologies (for example: CPR or cardiopulmonary resuscitation, breathing machines, dialysis)?
27. How satisfied are you that, during the past month, you have come to understand what to expect in the end stage of your illness (for example: in terms of symptoms and comfort measures)?
28. How satisfied are you with your role during the past month in decision making regarding your medical care?

Family Member (Caregiver) Version

Relationship with the Doctors

3. How satisfied are you that you knew the doctor(s) in charge of your relative's care during the past month?
4. How satisfied are you that the doctor(s) took a personal interest in your relative during the past month?
5. How satisfied are you that the doctor(s) were available when you or your relative needed them (by phone or in person) during the past month?

6. How satisfied are you with the level of trust and confidence you had in the doctor(s) who looked after your relative during the past month?

Communication and Decision Making

22. How satisfied are you that the doctor(s) explained things relating to your relative's illness in a straightforward, honest manner during the past month?

23. How satisfied are you that the doctor(s) explained things relating to your relative's illness in a way you could understand during the past month?

24. How satisfied are you that you received consistent information about your relative's condition from all the doctors and nurses looking after him or her during the past month?

25. How satisfied are you that you received updates about your relative's condition, treatments, test results, etc. in a timely manner during the past month?

26. How satisfied are you that the doctor(s) listened to what you had to say during the past month?

27. How satisfied are you with discussions during the past month with the doctor(s) about where your relative would be cared for (in hospital, at home, or elsewhere) if he or she were to get worse?