Relevance of Canadian health care evaluation project [CANHELP] Questionnaire in Assessment of Satisfaction of End of Life Care Provided in Patients and Families Receiving Home Based Palliative Care: A pilot Study

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Abstract

Introduction

Good Palliative care provision should culminate with a high quality end of life care. Canadian Health Care Evaluation Project (CANHELP) questionnaire is a means to assess patient and family satisfaction of end-of-life care (EOL) provided.

Aims

Study the relevance of CANHELP questionnaire in patients and families enrolled under home based palliative care. To identify unmet needs of end of life care and use this data to bridge the gaps in care provision.

Methods

A cross-sectional study conducted in patients and their families who are enrolled for home based palliative care with Palliative Medicine Department, Tata Memorial Centre. CANHELP questionnaire is a 1-5 Like scale assessing satisfaction of End of Life Care provided with 38 patient centered questions and 40 family centered questions.

Results

Both patients and their caregivers gave highest importance to illness management (patient mean 67.63 sd 2.67, caregiver mean 45.83, sd 7.56) and expressed highest satisfaction (patient mean 58.58 sd 5.61, caregiver mean 40.33 sd 5.55) with same. Significant differences were found in importance and satisfaction regarding illness management (p<0.001), benefit of communication and decision-making (p<0.001), well-being (p<0.001) and general satisfaction of care received [p<0.001] between patients and their families. There are communication gaps regarding discussions about the use of life sustaining technologies, comfortable talking with relative about his/ her illness, dying, and death and discussions with relative during the past month about wishes for future care in the event he or she is unable to make those decisions which needs to be improved.

Conclusion

CANHELP questionnaire is relevant to patients and their families in assessing satisfaction of end of life care services provided.

Keywords: Home based palliative care; CANHELP questionnaire; End of life care.
societal medical skills as specialist care is accessed the patients at
door step [16,17].

The Department of Palliative Medicine is running home
based palliative care program team for last ten years with a
multidisciplinary team comprising of doctors, nurses, social
workers and volunteers/ counselors. In addition to control of
physical symptoms, the team concentrates on psycho-social and
emotional support too. In some cases, the visits have helped to
change the attitude of families towards the patients, for example,
allaying fear of contagion; and attitude of neighbors towards the
patient and so on. In spite of problems like long distances involved
and bad condition of roads, the experience of this team shows that
a home care system is essential for delivery of effective Palliative
care in Mumbai.

The aim of this study was to learn the relevance of CANHELP
questionnaire for patients and families provided with home based
palliative care. This would help us to identify unmet needs of care
provided at end-of-life. Gaps in service provision can then be used
as targets for service improvement.

Methods
A cross-sectional study was conducted to assess patient and family
satisfaction of end of life care provided through home based
palliative care

Inclusion criteria
1. Age > 18 years.
2. Patients who are registered with the Department of Palliative
Medicine and enrolled under home based palliative care program.
3. Patient and families who have agreed to be part of the study and
have signed the informed consent form.

Exclusion criteria
1. Patients who are not registered with the Department of Palliative
Medicine.
2. Patient residing beyond the geographic territory of home based
palliative care.
3. ECOG 04 and above.
4. Physician predicted survival less than four weeks.

Study setting and intervention
Mumbai based patients and their families registered with Palliative
Medicine Department accessing home based palliative care services
were selected for this study. Subjects were enrolled after they have
filled up the informed consent form. The questionnaire was served
to 29 patients and their families from September to November
2012 after taking informed consent in their preferred language.
The questionnaires were filled by patient and caregiver themselves.
The investigator was present to assist them in case they face any
difficulty. Data analysis was done by using SPSS version 20 [18].
The questionnaire was translated in local languages [Hindi and
Marathi] for indigenous population. This questionnaire was not
validated separately as the purpose of the study was to evaluate the
relevance of CANHELP questionnaire in assessment of satisfaction
of End of Life Care.

Tool
The Canadian Health Care Evaluation Project [CANHELP]
questionnaire
The CANHELP (Canadian Health Care Evaluation Project)
questionnaire was designed to evaluate satisfaction of care in
older patients with life threatening illnesses, and their family
members. It has domains like: characteristics of the doctors and
nurses [8 items], illness management (7 items), health service
characteristics (4 items), communication and decision-making
(11 items), relationships with others [4 items], and spirituality
and meaning questions (3 items). Before rating the domain
specific items, respondents were asked to rate their overall level of
satisfaction with the care they had received in the past month. It
consists of two versions, one for patients and another for family
caregivers. It is a 5 point Likert scale with 1 = not at all satisfied, 2
= not very satisfied, 3 = somewhat satisfied, 4 = very satisfied and
5 = completely satisfied. CANHELP questionnaire correlates with
other established measures of satisfaction with quality of care at the
end of life, has good internal consistency (Cronbach α > 0.70) and
can be grouped into valid subscales. Web link for the questionnaire:
www.thecarenet.ca/canhelp.

There was no availability of prior information for understanding
the feasibility of these questionnaires in Indian patients. So we
evaluated the importance of each question in the CANHELP
questionnaire on a scale of 1 = not at all important, 2 = not very
important, 3 = somewhat important, 4 = very important and 5 =
completely important.

The study was conducted at 5% significance level. No formal
sample size and power estimation was done as there was no prior
information for feasibility of these questionnaires in the Indian
patients. As per the observations made at the Palliative Care
Clinic, at least 100 patients are seen on home care every year,
so we estimated a minimum of 20 patients to achieve statistical
significance, however we enrolled 29 patients for this pilot project.

Data Collection and Analysis
Data was collected and entered in SPSS version 20 data sheet.
Descriptive statistics were used to describe the main study results
(e.g., mean, median value with lower and upper value ranges) for
individual questions as well groups previously assigned by the
investigators [14]. Test for normalcy was applied for each data
distribution. Comparison of means were done by using T-test for
independent samples and Wilcoxon rank-sum test for parametric
and nonparametric data respectively. The significant differences
were noted. Missing data were reported as such, rather than using any specific statistical techniques to counteract for it. We also made a note of the questions which the subjects did not answer. We assumed that those were the questions which were difficult to understand or be answered by the subjects. Schematic bar diagrams were constructed for the individual datasets.

**Results**

Highest importance was given to illness management [patient mean score 67.63 standard deviation [SD] 2.67, caregiver mean score 45.83, SD 7.56] by both the groups. Highest satisfaction [patient mean score 58.58 SD 5.61, caregiver mean score 40.33 SD 5.55] was reported with same.

In other words, the patients and their families feel that they can contribute more towards their own involvement and decision of care process at the end of life (Figures 1 and 2). Significant differences were found in importance and satisfaction regarding illness management (p<0.001), benefit of communication and decision-making (p<0.001), well-being (p<0.001) and general
Table I: demographic profile of the participants

| Gender | Count |
|--------|-------|
| Male   | 13    |
| Female | 16    |

Table II: patient satisfaction with care domains

| Domain                  | Mean       | Std. Deviation | Range | Minimum | Maximum |
|-------------------------|------------|----------------|-------|---------|---------|
| Overall satisfaction    | 4.7931     | .41225         | 1.00  | 4.00    | 5.00    |
| Relationship with doctor| 17.4074    | 1.98570        | 8.00  | 12.00   | 20.00   |
| Illness management      | 58.5833    | 5.60990        | 22.00 | 48.00   | 70.00   |
| Communication with care team | 22.6071 | 2.64350        | 8.00  | 17.00   | 25.00   |
| Self decision making ability | 14.1765 | 4.78586        | 13.00 | 7.00    | 20.00   |
| Role of family in care  | 22.9583    | 4.16485        | 19.00 | 11.00   | 30.00   |
| Self wellbeing          | 14.9615    | 3.43489        | 11.00 | 9.00    | 20.00   |

Table III: family satisfaction with care domains

| Domain                  | Mean       | Std. Deviation | Range | Minimum | Maximum |
|-------------------------|------------|----------------|-------|---------|---------|
| Overall satisfaction    | 8.5357     | 1.42678        | 5.00  | 5.00    | 10.00   |
| Relationship with doctor| 17.1786    | 2.49523        | 9.00  | 11.00   | 20.00   |
| Illness management      | 40.3333    | 5.54559        | 19.00 | 31.00   | 50.00   |
| Communication with care team | 25.1111 | 2.93956        | 12.00 | 18.00   | 30.00   |
| Role of family in care  | 26.4167    | 5.56708        | 18.00 | 18.00   | 35.00   |
| Self wellbeing          | 23.1429    | 4.02847        | 18.00 | 12.00   | 30.00   |

Table IV: patient importance with questionnaire

| Domain          | SATIS_PI | RL_DOC_PI | ILL_MAN_PI | COMMUN_PI | DEC_MAKIN_PI | ROLE_FAM_PI | WELL_B_PI |
|-----------------|----------|-----------|------------|------------|--------------|-------------|-----------|
| Missing         | 0        | 1         | 5          | 1          | 4            | 1           | 0         |
| Mean            | 4.9655   | 18.7500   | 67.6250    | 24.5357    | 19.1600      | 27.2500     | 17.9655   |
| Std. Deviation  | .18570   | 1.64711   | 2.66723    | 1.03574    | 2.33952      | 3.55512     | 2.47101   |
| Range           | 1.00     | 6.00      | 13.00      | 4.00       | 9.00         | 13.00       | 9.00      |
| Minimum         | 4.00     | 14.00     | 57.00      | 21.00      | 11.00        | 17.00       | 11.00     |
| Maximum         | 5.00     | 20.00     | 70.00      | 25.00      | 20.00        | 30.00       | 20.00     |
### Table V: family importance with questionnaire

|       | SATIS_FI | RL_DOC | ILL_MAN_FI | COMMUN_FI | ROLE_FAM_FI | WELL_B_FI |
|-------|----------|--------|------------|-----------|-------------|-----------|
| Missing | 0        | 0      | 0          | 1         | 8           | 1         |
| Mean   | 9.4483   | 17.8966| 45.8276    | 28.6786   | 31.8095     | 26.0714   |
| Std. Deviation | .98511   | 2.58215| 7.56434    | 2.76290   | 3.74992     | 5.11301   |
| Range  | 4.00     | 10.00  | 36.00      | 13.00     | 14.00       | 20.00     |
| Minimum| 6.00     | 10.00  | 14.00      | 17.00     | 21.00       | 10.00     |
| Maximum| 10.00    | 20.00  | 50.00      | 30.00     | 35.00       | 30.00     |

### Table VI: Independent Samples Test

|                  | t-test for Equality of Means |                  |                  |
|------------------|------------------------------|------------------|------------------|
|                  | Sig. (2-tailed) | Mean Difference | Std. Error Difference |
| SATIS_PS         | Equal variances assumed     | .000             | -3.743            | .276           |
|                  | Equal variances not assumed | .000             | -3.743            | .280           |
| RL_DOC_PS        | Equal variances assumed     | .709             | .229              | .609           |
|                  | Equal variances not assumed | .708             | .229              | .607           |
| ILL_MAN_PS       | Equal variances assumed     | .000             | 18.250            | 1.610          |
|                  | Equal variances not assumed | .000             | 18.250            | 1.610          |
| ROLE_FAM_PS      | Equal variances assumed     | .044             | -3.458            | 1.649          |
|                  | Equal variances not assumed | .074             | -3.458            | 1.818          |
| WELL_B_PS        | Equal variances assumed     | .000             | -8.181            | 1.089          |
|                  | Equal variances not assumed | .000             | -8.181            | 1.108          |

### Table VII: Independent Samples Test

|                  | Levene’s Test for Equality of Variances | t-test for Equality of Means |                  |
|------------------|----------------------------------------|-----------------------------|------------------|
|                  | F          | Sig. | t         | df |
| SATIS_PI         | Equal variances assumed     | 34.914 | .000     | -24.081 | 56  |
|                  | Equal variances not assumed | 3.469 | .068     | 1.482   | 55  |
| RL_DOC_PI        | Equal variances assumed     | 6.456 | .014     | 13.424  | 51  |
|                  | Equal variances not assumed | 6.456 | .014     | 14.469  | 36.054 |
| ILL_MAN_PI       | Equal variances assumed     | .013  | .908     | -4.340  | 47  |
|                  | Equal variances not assumed | .013  | .908     | -4.306  | 41.936 |
| ROLE_FAM_PI      | Equal variances assumed     | 1.654 | .204     | -7.662  | 55  |
|                  | Equal variances not assumed | 1.654 | .204     | -7.578  | 38.655 |
satisfaction of care received (p<0.001) between patients and their families. (see tables)

**Discussion**

We have conducted a cross-sectional observational study involving 20 patients and their family caregivers to find out the relevance of the CANHELP Questionnaire in Indian settings. This new instrument has various domains [illness management, communication and decision-making, relationships and well-being] which represent key areas of quality EOL care that can stand alone as significant indicators of end of life care in the subjects. We have shown that the various domains of are relevant to both patient and family members in our study population in India. QOL refers to the holistic notion of ‘well-being’. Whether QOL or quality of care measures should be the primary endpoint of EOL studies will depend on the context and the nature of the study. A major impediment to progress in EOL research has been the failure to define the distinctions between or the boundaries of terminologies [21]. A tool to assess QOL at the EOL go beyond physical, role and social functioning and provides direct attention to the more complete social, psychological, and spiritual wellbeing. Quality of Care at the EOL focuses on patient and family caregiver assessment of satisfaction in key domains of care in real time when interventions targeting specific areas needing improvement can be addressed. For quality of care assessments, there is a clear link between the measurement of key processes of care and subsequent efforts to improve quality of care during the final weeks to months of life [19]. A conceptual framework published by Stewart et al. [20] describes various outcomes [QOL, satisfaction with care] at the EOL, as a function of patient and social variables, and structure and process of care variables.

The strengths of this study was that the rigorously tested psychometrically developed, holistic and patient/family-centered instrument focusing on EOL care in Canada [14] was also relevant to our sample population in India. A further strength of this study was that both the versions for the patient and family member were relevant which enhances the clinical utility of the questionnaires. Often, in situations where the patient is no longer capable of communicating, the caregivers provide the only perspective on the care received at the EOL. Interestingly, the patient and family version of the questionnaires are not exactly the same. They measure differing perspectives on care issues over subscales that best measure each aspect of care. Again, family ratings of satisfaction are an important outcome by themselves [22] which are independent of the patient's assessment of outcome and are quite evident from the results.

The limitations of this study include the fact that the majority of our patients with advanced cancer were residents of Mumbai. Minority group of patients having cognitive, hearing or speech impediments, and surgical patients at the EOL are under-represented in our sample. Although this instrument was relevant in Mumbai, its applicability to other places even within India with dissimilar Diaspora may be limited. In addition, we do not yet know the test–retest reliability and responsiveness of the CANHELP Questionnaire, nor do we know the validity of using the questionnaire without the assistance of research personnel [self-administered]. In spite of being a pilot study, the sample size was small, so study remains underpowered to show a statistically significant effect. Future studies should be tried with bigger samples. Finally, we acknowledge that the CANHELP instruments are lengthy and might pose a challenge to the patient and caregivers who are suffering from serious illness. Future studies should evaluate the relevance of shorter versions of CANHELP questionnaire instead of this longer version.

In short CANHELP questionnaire is relevant to patients and their families regarding satisfaction with the end of life care services and both of them are satisfied with end of life care services provided to them. There is need for further discussions with doctor about the place of care and use of life sustaining technologies in end of life care. By enabling often disempowered, voiceless, and vulnerable patients to share their perspectives comprehensively with us at the EOL, we are in a much better position to improve the quality of EOL care in Mumbai.

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