



A Project of the Palliative Care in the Cross-Cultural Context New Emerging Team (NET) for Equitable and Quality Cancer Care for Culturally Diverse Populations - A CIHR Funded Five Year Grant

"Each of our participating Centres has a different composition of ethnic groups, which we believe may give us insight into specific cultural factors related to QOL."
~ Gillian Fyles

Background

1. Improved Quality of Life (QOL) for patients and families living with a terminal illness is the stated aim of most palliative care programs. Typically, however, symptom outcomes are measured and not other domains that are identified as important contributors to QOL.
2. In 2003, the BC Cancer Agency (BCCA) implemented the Palliative / Patient Outcome Scale (POS) for QOL assessment into their 4 Regional Cancer Centre Pain and Symptom Management / Palliative Care Interdisciplinary Outpatient Clinics (SMCs). We use POS as a QOL tool for clinical audit, as a QOL research database and to address our mandate to improve QOL.
3. In 2004, the BCCA received a Canadian Institutes of Health (CIHR) NET grant to study cross-cultural palliative care. This grant allows us to expand our QOL investigation into the cross-cultural sphere.

Phase One - POS

In 1999, the Palliative/Patient Outcome Scale (POS) was developed and validated by Dr. Irene Higginson and team at Kings College, London, England. This tool includes domains shown to be relevant in the palliative / end of life setting. It has been translated into Urdu, Punjabi, Italian and Portuguese, and validated in Spanish and German.

In 2003 / 2004, a review of 309 historical data sets of POS results from Vancouver and Kelowna BCCA SMCs was conducted to assess (1) overall symptom burden and subscale burden, and (2) the role of demographic and cultural factors in QOL. We used Statscan data as a proxy for ethnicity according to region.

Phase One Results

1. Total POS score median of 15/40.
2. Major issues were pain, patient anxiety, family anxiety: these areas scored a median of 3, 2 and 3, indicating significant distress.
3. Demographics revealed that pts in Vancouver were younger compared to those in Kelowna (statistically significant) and that there was a higher female ratio in the Vancouver patient group (not statistically significant).
4. Only significant difference in POS scores between the Centres was in the information domain. Pts in Kelowna were more satisfied with the amount of information they received than those in Vancouver.
5. Phase I gave us a picture of the major issues, possible demographic influences and expertise in data linkage.

Current Initiative - Phase Two

**Patient Outcomes In Tertiary Palliative Cancer Care:
A Prospective Assessment Of The Cultural Dimensions Of QOL
Using The Kings College London POS**

We propose that:

1. Care provided in specialized palliative care settings improves QOL.
2. There are specific cultural and demographic factors associated with QOL for patients/families in palliative/EOL settings in Canada.
3. POS is an appropriate and sensitive tool to effectively explore and delineate these issues.

Research questions:

1. Do specialized palliative care services make a difference to the QOL of patients/families at end-of-life: ie.do the total POS scores change over time?
2. Do POS scores change in specific domains?
3. Are there cultural indicators such as ethnicity, immigration status, language, etc which are specifically linked to POS scores?
4. Are there predictors/links to other demographic factors, for example, age, gender, marital status, etc, as well as to disease factors such as diagnosis?
5. Which palliative care services are the most effective, and are there linkages to specific ethnic/cultural groups?
6. What are the implications regarding accessibility and utilization of palliative care services?

Methodology

1. Three-year prospective, longitudinal multi-site study.
2. Includes collection of utilization data for the purpose of identifying palliative care services that are most effective for specific ethnic or cultural groups.
3. Conducted in the 4 BC Regional Cancer Centre (RCC) Symptom Management / Palliative Care Outpatient Clinics and the Burnaby Tertiary Hospice Palliative Care Unit. (Burnaby Unit is an 11 bed inpatient hospice – 25% non-English speaking.)
4. During every visit, the patient will complete 4 forms:
 1. POS
 2. Edmonton System Assessment Scale
 3. Additional Demographic Form (only completed on first visit)
 4. Services Utilization Form

Additional Demographic Information Form – to be completed once at start of study by patient

1. Where were you born?
2. If outside Canada, when did you arrive?
3. What is the language usually spoken at home?
4. Are you a visible minority group member?
5. If the above answer is yes, please check which applies:
 - Aboriginal
 - Black
 - South Asian
 - Southeast Asian
 - Chinese
 - Other - please specify
6. What is your marital status?
 - Single/married/separated/
 - Divorced/widowed/common-law
7. What is the highest level of education you obtained?
 - Elementary school
 - Some high school
 - High school diploma
 - Technical/community college
 - Some university
 - Bachelor's degree
 - Degree above a Bachelor's
8. What are your living arrangements?
 - Live on your own
 - with Partner/spouse
 - with Children/grandchildren
 - with Parents
 - with Other relatives
 - with Friends
 - Other- please specify

POS Patient Questionnaire

BC Cancer Agency
CARE & RESEARCH

Patient Outcome Scale
Patient Questionnaire

Patient name: _____ Assessment date: _____
Date of birth: _____ Assessment no: _____

Please answer the following questions by ticking the box next to the answer that is most like you. Your answers will help us to improve your care and the care of others. Thank you.

- Over the past 2 days, have you been affected by pain?
 - 1 Not at all
 - 2 Slightly - but not bothered to be told it
 - 3 Moderately - you notice some activity
 - 4 Severely - activities or concentration markedly affected
 - 5 Chronically - unable to think of anything else
- Over the past 2 days, have other symptoms (e.g. feeling sick, having a cough or constipation) been affecting you?
 - 1 Not at all
 - 2 Slightly
 - 3 Moderately
 - 4 Severely
 - 5 Chronically
- Over the past 2 days, have you been feeling anxious or worried about your illness or treatment?
 - 1 Not at all
 - 2 Occasionally
 - 3 Sometimes - affects my concentration now and then
 - 4 Most of the time - often affects my concentration
 - 5 Can't think of anything else - completely preoccupied by worry and anxiety
- Over the past 2 days, have any of your family or friends been anxious or worried about you?
 - 1 Not at all
 - 2 Occasionally
 - 3 Sometimes - it seems to affect their concentration
 - 4 Most of the time
 - 5 Yes, always preoccupied with worry about me
- Over the past 2 days, how much information have you and your family or friends been given?
 - 1 Full information - always feel free to ask what I want
 - 2 Information given but hard to understand
 - 3 Information given or received but would have had more
 - 4 Very little given and some questions were avoided
 - 5 None at all

- Over the past 2 days, have you been able to share how you are feeling with your family or friends?
 - 1 Yes, as much as I wanted to
 - 2 Most of the time
 - 3 Sometimes
 - 4 Occasionally
 - 5 Not at all
- Over the past 2 days, have you been feeling depressed?
 - 1 Not at all
 - 2 Slightly
 - 3 Moderately
 - 4 Most of the time
 - 5 All the time
- Over the past 2 days, how much time do you feel has been spent on appointments relating to your symptoms (e.g. waiting around for transport or repeating tests)?
 - 1 None at all
 - 2 Up to half a day wasted
 - 3 More than half a day wasted
 - 4 More than half a day wasted
 - 5 More than half a day wasted
- Over the past 2 days, have any practical matters resulting from your illness, either financial or personal, been a problem?
 - 1 Practical problems have been addressed and my affairs are as up to date as I would wish
 - 2 Practical problems are in the process of being addressed
 - 3 Practical problems exist which were not addressed
 - 4 I have had no practical problems
 - 5 I have had no practical problems
- How many of your main problems in the last 2 days?
 - 1 _____
 - 2 _____
 - 3 _____
 - 4 _____
 - 5 _____
- How did you complete this questionnaire?
 - 1 On my own
 - 2 With the help of a friend or relative
 - 3 With help from a member of staff

Future

Subsequent to this study's completion, we plan to move this work into more complex settings; for example, follow patients across care settings in British Columbia and in Nova Scotia.

