Research project of Dr.Shamsudeen Moideen Calicut, India

Community Participation in Long Term and Palliative Care

Background

The Neighbourhood Network in Palliative Care (NNPC) is a community based project in palliative care and long term care in Northern Kerala, India, facilitated by the Institute of Palliative Medicine (IPM) in Calicut, and a WHO demonstration project for Palliative Care. The program looks after patients with incurable illnesses, over 40% of these patients have advanced cancer.

Neighbourhood Network in Palliative Care
The NNPC program is very successful in terms of patients served, number of volunteers and families involved, fund raising, and awareness. It is an attractive model to disseminate both in underdeveloped and developed countries. The information available has the potential to further catalyse the dissemination of the NNPC in other countries.

Research program

Assigned Person
The research fellow is Shamsudeen Moideen (SM), he works for the NNPC as a middle level Palliative Care Physician based at the Institute of Palliative Medicine.

Duration
The research project ran for a period of one year, in 2007.

Working structure
While at the unit in Kerala, SM spent 80% of his professional time on research, 10% on clinical work and 10% on teaching.

- The research fellow (SM) also spent three months in St Gallen in 2007.

The Research project

The research project was based on a qualitative methodology

Background information
Resource poor countries and other developing countries are facing the global epidemic of chronic diseases, like cancer, and the burden of life limiting illnesses is on the rise. Demographics show that the world population is getting older, and over all dependency is shooting up. Geriatric care management is also an issue for the developed world too, how will it be possible to care for the huge number of patients in need of palliative care when the resources are limited?

The changes that the NNPC networks bring to the community are multidimensional e.g. social coherence , social changes, association of people etc., it may not be possible to measure them all. A visible change is the increase in coverage of palliative care and sustainability of these services.

In palliative care, professionals and many volunteers are associated at different levels of activity. The volunteers (4,000- 5,000) are from all walks of life and contribute at least two hours a week of voluntary activity in palliative care. The following research question formed:
"What are the predictors for successful coverage and sustainability of community based palliative care (NNPC) in Northern Kerala ?"

Aims and objectives

This qualitative study explored the community based palliative program (NNPC) in Northern Kerala, India and looked at the active involvement of the community in the care of patients so that a sustainable palliative care program within the community and family empowerment is possible. The attempt was made to assess the predictors of success of this program and consider the possible transferability to other countries making use of the lessons learned from this model.

Methodology
A qualitative research approach was taken, based on grounded theory with interviews from people involved in the program and constant comparison evolving a theory. A total of 28 interviews from six palliative care units were conducted with team discussions.

Why Qualitative Research?

The NNPC activities are the experiences of people in the community ,their outlook of social work and feeling of responsibility for each other. The personal experiences were extracted from the people who actually carry out the work.

In order to transform personal experiences to consensually validated public knowledge, a qualitative approach with an emphasis on description, and involved the active participation from the researcher, study participants and the readers (who eventually evaluate the results) was found to be appropriate.

Participants

Selection of Units by random picking of lots (N=6, i.e.; 10% ,total No. 65)
Units which have been functioning for more than a year are selected
Choice of interviewed persons
From each unit, the interviews performed included: 1 doctor, 1 nurse, 1 volunteer, 1 key person (if not included in other interviews)
Team members associated with the unit either in organizational activities or in patient care activities for at least 6 months were interviewed.

The local ethics committee approved the study.

Interview Guideline

Open ended interviews lasting between thirty to sixty minutes (which could be extended) were conducted with each person. The variable interview length was designed to allow for differing individual's experiences. The interviews were held at the NNPC units, at a time convenient to the participant.

From each unit, the interviews conducted included:

Doctor	1	
Nurse	1	
Volunteer	1	
Key person	1	(if s/he was not included in other interviews)

In the event that the size/development, process and/or structure of the unit suggested that a larger number of persons should be interviewed ,the investigator might add a second day of interviews after clarifying the argument. That would be until saturation of retrieved categories and subcategories showed no more variability among professions, namely saturation was achieved.

Team members who had been associated with the unit either in organizational activities or in patient care activities for at least 6 months were interviewed.

The semi structured questionnaire

The details of the clinic were completed first by the research fellow with the help of person in charge of the clinic, and then the basic information about the interviewee would be written down as in the questionnaire.

Each person interviewed was given adequate privacy, and assured that any personal information given would be treated as confidential.. At the beginning of each interview, the researcher explained to the participant that the aim of the interview was to learn about their experience of community based palliative care and, to find out in their own words, the factors that determine the success of the unit.

Interviewees were asked "What are the reasons why you decided to associate with this palliative care unit?"

S/he were asked to describe briefly how s/he came to be associated with the unit and in their own words to explain the current status of how the unit functions and his/her role in the process. "What is your unit's history and what is its current functioning level?"

Why s/he is doing this work and to ellaborate on that.

S/he was asked to give their own views about the reasons for success of the unit and the other neighbouring NNPC units.
Furthermore, s/he was invited to comment on the issues currently facing the unit and provide suggestions as to how they could be overcome (e.g. attrition and burn out of volunteers, lack of funds, poor accessibility and acceptability).

* Organizational set-up
* Burnout issues of Staff and Volunteers, if any.

The interviewee was questioned about the different functions of the unit namely, and the following check list was used:

1. Clinical support to patients for better symptom control
2. Assisting families in distress
3. Associate timely planning for death and grief.
4. Involving public and new volunteers in activities

5. Fund raising, training programs and awareness programs.
6. Patient and family rehabilitation

S/he was further asked for their views on the socio-economic situation in the area. If s/he did not mention these issues the researcher would prompt the question for their comments. The interview concluded with his/her thoughts on the future plans of the unit and his/her own expectations.

The codes were identified from this and further explored until the interviewee completed their explanations for the code (saturation).

Each unit's interview was audio-taped, transcribed and reviewed before the next unit's interview. Data was analyzed after the interview process.

5.4. <u>Data collection process</u>

Interview with unit 1

Interview process

The printed guide line was the backbone and guide line for each interview
The interviews were conducted in the local language (Malayalam)
The interviews lasted 30-60 minutes.
The interviews were audio-taped.

Transcription

Translation to English

Coding done

Discussed with local research team
Decided not appropriate, not professional, financial issues
Discussed with mentor
Decided to do coding in local language and translate the codes only

Recoding in local language

Conceptualization and discussion with team and mentor

Amendment of interview guidelines

Interview with unit 2 with adapted interview guidelines (IG)

Transcription

Coding

Constant comparison (CC) ;and
Discussion with team one and two and mentor

Amendment 2

Interview with unit 3 using adapted IG and CC

Transcription

Coding

Constant comparison (CC) and
Discussion with team one and two and mentor
Discussion of putative categories and subcategories
Amendment of IG

Interview with unit 4 using adapted IG

Transcription

Coding

Focus group meeting
Constant comparison (CC) and
Discussion with team one and two and mentor
Discussion on categories and subcategories, properties and dimensions
Amendment in IG

Interview with unit 5 using adapted IG

Transcription

Coding

Constant comparison (CC) and
Discussion on saturation with team one and two and mentor
Discussion on categories and subcategories, properties and dimensions
Amendment in IG (NIL)

Interview with unit 6 using adapted IG

Transcription

Coding

Constant comparison (CC) and
Discussion on saturation with team one and two and mentor
Discussion on categories and subcategories, properties and dimensions
Amendment in IG (NIL)

5.5 <u>Data analysis</u>

Transcripts were coded using both open coding and an axial coding process. The coded segments were analyzed by constant comparison .The validity of the results was optimised by the use of the following strategies from the start of the study: methodological coherence, concurrent data collection and analysis, theoretical consideration and development of a comprehensive,

consistent, and logical theory. This method is consistent with the Grounded Theory method (Strauss & Corbin, 1990) as the interview was guided by the emerging theory and data was gathered and analysed concurrently.
The trustworthiness of the results was approved by the interview participants, research team partners and the focus groups.

Dr. Shamsudeen Moideen stayed for 3 months in St.Gallen to:

1) complete the research project started and conducted in Kerala and
2) work as an expert for the community palliative care program in St.Gallen.

Supervision and mentoring

Florian Strasser and Steffen Eychmüller from St. Gallen jointly coordinated activities.

Florian Strasser is a medical oncologist; board certified for palliative medicine, by the American Board of Hospice and Palliative Medice (ABHPM) obtained after a two year clinical and research fellowship at the M.D. Anderson Cancer Centre in Houston, Texas (Eduardo Bruera). He is experienced in both quantitative and qualitative research, and leads the palliative care research group for the Swiss Society of Palliative Care (SSPC) and Swiss group for cancer research, he is also involved with the European Association for Palliative Care (EAPC) research steering committee and research forum (as Chair).

Steffen Eychmüller is an internal medicine and psychotherapeutic physician, he holds a Master in medical education and is involved with the EAPC education task force. He conducts research activities focused on prognosis and needs including qualitative methods, and is responsible for the national survey of needs. As Co-President of the SSPC he will support the dissemination process of NNPC at the Swiss community level.

Prof. Thomas Cerny as Director of medical oncology supported the close collaboration.

A Academic Work

1. Completion of the manuscript **"systematic literature review of community palliative care in developing countries"**.
Based on the poster presented at the EAPC conference in Budapest, a full manuscript will be written by Dr. Shamsudeen, Dr. Strasser and via e-mail contact with the two co-authors in Kerala. In addition, interested researchers from St.Gallen, namely from the group of the CPC, are invited to contribute to this paper if able to contribute substantially.
2. The qualitative research project on **"predictors of success for suitability and coverage of NNPC"** in Kerala will be discussed based on the current results and a decision was made that the project is saturated. This decision was taken 27th June 2007
Dr. Shamsudeen delivered the necessary information, based on the documents he brought from Kerala. He attended the workshop on qualitative methodology in June 2007, in Lausanne with Karen Olson from Canada. He also discussed his project at the Swiss national research day on June 27 2007 in St.Gallen.
He discussed his project status with the CPC research team of the palliative care centre, department interdisciplinary medical services.

b) Since the project is saturated, a full manuscript was written by the end of August 2007, contributing specialists were invited to collaborate on this project.

B Community palliative care project

Dr. Shamsudeen will serve as an external expert to further develop St. Gallen's CPC program with the three project elements in different regions. He will also serve, upon request, as a speaker when such opportunities arise.