

Experiences from Collaborative Research between the Department of Palliative Medicine at RWTH Aachen University (Germany) and the Trivandrum Institute of Palliative Sciences (India)

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Short Communication

This is a short report on nearly seven years of collaborative research between the Department of Palliative Medicine at the RWTH Aachen University Hospital and the Trivandrum Institute of Palliative Sciences (TIPS). It started in February 2008 when Prof Frank Elsner and Norbert Krumm attended the impressive 15th International Conference of the Indian Association of Palliative Care in Kochi, Kerala. With a number of ideas for potential collaboration we travelled on to Trivandrum, intending to establish a partnership between our institution and the TIPS. The first most memorable moment was when we were sitting on white plastic chairs in a consulting room at the TIPS, and noticed a little piece of paper pinned on the wall with just one word: LISTEN! Perhaps this simple message purveys what has become the central tenet in conducting our research among patients and patients' families in need of a palliative care approach.

The primary aim of the meeting at the TIPS was to establish a research collaboration between both centres. We shared and discussed our ideas and learned that especially knowledge of psychosocial problems among terminally ill patients in Kerala (India) was limited and that only few studies existed on these issues in India. Thus, a proposal for a first project was to explore the psychosocial and spiritual problems of terminally ill patients in Kerala, India.

Listening, as mentioned before, appeared to be the most appropriate method to gain deeper insight into patients' perceptions and ideas with respect to their serious illnesses. As a result, we chose to conduct semi-structured interviews with patients for our first combined study in Kerala. This was done in line with expert opinion that suggests that palliative care research should be conducted using a qualitative approach and should carefully explore attitudes and concepts among vulnerable populations.

The first study resulting out of interviews conducted in 2010 has already been published in 2012 in *Future Oncology* under the title *Psychosocial and spiritual problems of terminally ill patients in Kerala*. This study used a semi-structured qualitative interview approach to encourage patients to speak openly about their psychosocial problems. Additionally, biographical data, level of education, income, diagnosis, duration of illness, number of caregivers and hours provided by primary caregivers, as well as a numerical rating scale to evaluate distress caused by the interview was gathered. Inclusion criteria for the study were defined as follows: being cognitively unimpaired, older than 18 years of age, able to speak the local language - either Malayalam or English - and being able to give informed consent. A simultaneous verbal translation into English was voice-recorded by a professional translator and subsequently transcribed. Transcripts were

analyzed with a systematic qualitative content analysis tool, aimed at identifying emerging themes. A total of 37 interviews (22 female patients and 15 male with an average age of 56.5 years) were conducted over a period of three months. After analysis, central topics addressed by patients emerged, including emotions, faith, family, and financial problems. From these topics several prospective conclusions could be drawn by the authors. Findings suggest that psychosocial and spiritual problems are an important issue for terminally ill patients. Nevertheless we could also conclude that many problems are a result of financial troubles as the majority of the patients in the underlying investigation live at or below the Indian poverty line. Some of the problems are also a consequence of tradition and culture. Solutions for an improvement must coincide especially in accord with tradition and culture. The major goal within the coming years must be to address the financial problems in order to reduce a relevant part of the burden which terminally ill patients have to face.

This study has given insight into the burden of life-threatening conditions patients and their families must face every day. Although acknowledging that this burden is multi-dimensional in its origin, financial problems as a social dimension of life-threatening diseases do have a central impact on fears and anxiety. This may underline the need for a public health approach in providing palliative care.

To expand on the findings of this study, further studies have been and will be initiated. Our common aims are to gain a deeper understanding of phenomena such as: coping strategies of terminally-ill patients in South-India when having to deal with pain, patients' associations regarding analgesic medication and routes of application, and an analysis of the experiences and workload of home care staff members in defined settings in Kerala.

Research conducted so far has been coordinated on-site by German medical students working on their doctoral theses. Training in qualitative methodology at the TIPS has been provided by Dr Martina Pestinger (psychologist) as well as by Dr Tania Pastrana (sociologist and physician) of the Department of Palliative Medicine of RWTH Aachen University Hospital. Furthermore, conducting our research projects would not have been possible without all the wonderful local partners at the participating institutions such as the interpreters, social workers, nurses and physicians with a special acknowledgement of Prof Rajagopal, head of TIPS, and most importantly, the participants of the studies.

Listening to both patients and palliative care staff members is a unique opportunity to learn face to face about sensitive issues such as coping with advanced disease, stress and existential experiences.

Projects

Elsner F, Schmidt J, Rajagopal MR, Radbruch L, Pestinger, M (2012) Psychosocial and spiritual problems of terminally ill patients in Kerala, India. *Future Oncology* 20 (11): 1183-1191.

Sarah Behnsen: Coping strategies of terminally-ill patients in South-India dealing with pain.

Luise Fiedler: Analysis of patients' associations regarding analgesic medication and routes of administration in a palliative care setting in Kerala, India.

Reena Rick: Experiences among palliative care workers in Kerala, India.