

### Qualitative Research in Palliative Care

Art Frank, reflecting on his experience of serious illness, writes “Care begins when difference is recognised. There is no ‘right thing to say to a cancer patient,’ because the ‘cancer patient’ as a generic entity does not exist.”<sup>[1]</sup>

This insight underpins the contribution of qualitative research to health care and to other spheres of social inquiry. This contribution derives from the interest in the subjective, personal, and particular experience, perspective, or history. The primacy of the subjective is treasured by qualitative researchers in preference to the aggregating, objectifying, numerically based methods of quantitative research.

Qualitative research encompasses a wide range of research approaches and methodologies. These are primarily concerned with exploring the way in which people make sense of their world. It is inductive, drawing out what is observed, rather than deductive, testing hypotheses; it is concerned with the interpretation of observations rather than measurement; and is involved with identifying interactions and how people construct their social worlds, rather than manipulating or modifying those worlds. It seeks to answer questions that explore processes or the meanings of events or other elements of the social world.

There are many methods for data collection in qualitative research such as exploratory interviews, focus groups, and ethnographic approaches of participant observation and field notes. Texts of various types are commonly used, from those arising from transcribed interviews, or spontaneous language observed in field work, to written texts in newspapers, diaries, correspondence, policies, and organizational records. Data are not limited to texts, however, with imagery such as photos or videos, and observations of social interactions, providing rich streams of data. Data may be analyzed in multiple ways, broadly grouped as experiential (grounded theory, narrative analysis, and phenomenology) or discursive (conversational analysis and discourse analysis). Qualitative methods have multiple applications. For example, this methodology is often used to evaluate the impact of programs or changes in services and to obtain the perspectives of consumers before instituting

new services. It may also be used to generate new hypotheses for quantitative evaluation.

The diversity of methods within qualitative research has added to the difficulty of establishing agreement on the quality and validity of this research paradigm. Quality appraisal checklists and frameworks have been developed. While some recoil from such evaluation, seeing such frameworks and checklists as a positivist contamination of the naturalist paradigm, most qualitative researchers embrace the assistance of such frameworks in both publishing and evaluating qualitative research. These frameworks address issues such as the sampling process used in the study; ethical concerns and how they were handled; evidence of reflexivity by the researcher demonstrating an awareness of the co-construction of the experiences emerging in the study; discussion of triangulation in the interpretation of results which describes the way the researchers have approached analysis of their data through more than one lens; and the overall sense and validity of the interpretations.

Since the emergence of qualitative research some 100 years ago, when the notion of an objective world “out there” began to be questioned, there has been considerable debate over the contributions and claims of both quantitative and qualitative research methods according to different epistemologies or understandings of what constitutes knowledge. To this present day era of evidence-based medicine, these tensions remain. However, the increasing acceptance of so-called mixed method research in recent years, in which qualitative and quantitative methods are employed in a single study, has provided a conduit for more fruitful exchange of respective epistemologies, skills, and insights for proponents of both research paradigms. While some would argue that method and epistemology are inseparable, making such combinations as immiscible as oil and water, others advocate that the question rather than the epistemology, dictates the method and that there is complementarity and strength in combining methods. An example of successful blending of the two methodologies to provide a more comprehensive account of a particular phenomenon than would be gained by either method alone is a study of doctors’

emotional reactions to the recent death of a patient, which was reported in a series of papers from 2003 to 2008. This study used a cross-sectional design, in which doctors were selected through the random selection of index cases of recent deaths of patients in their care. Recruited doctors told the story of the patient death through semi-structured interviews. They then completed a series of questionnaires, providing the quantitative data for the study. The authors reported the two types of data in different papers, perhaps because the reporting of qualitative data usually requires more words, which may not sit well with journals more familiar with pithy, tabulated, numerical reports.<sup>[2-4]</sup>

For me, embarking on a PhD study using a qualitative methodology, namely narrative inquiry and analysis, has been a return to the source. Reading Kleinman's illness narratives as a young doctor was one of the most exciting discoveries made along the way of medical education. Years of administrative and clinical practice took the shine off that discovery at times. Returning to the interpretive mindset and the subjective world of patient experience through qualitative research has been refreshing and validating of the original impulse of patient care. Palliative medicine tries to hold the tension between scientific, quantitatively derived evidence-based knowledge, and the patient experience, perhaps better than many other fields of medical practice. However, in the current juggernaut of clinical trials funded by pharmaceutical companies and governments, in the seduction of seeking collegial esteem of nonpalliative care colleagues, and conceding perhaps to the desire to justify ourselves and our speciality, we have been tilling the soil of quantitative knowledge vigorously over recent years, perhaps to the detriment of remaining comfortable with, and committed to, the importance of the subjective experience of our patients.

In conclusion, I would argue that palliative medicine is eminently suited to qualitative methods of research, as subjective experience is given pride of place in our work, from symptom control to the complexities of advance care planning and establishing patient priorities and values.

Many of us in palliative care have been influenced by the scholarship of Eric Cassell. He has single-mindedly focused on the issue of suffering, and the inherently person-centered nature of this experience. In his focus, he has adhered to the advice of the great William Osler: "A little field well-tilled! How much more may come from it that from a large one with its surface only scratched!"<sup>[5]</sup>

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