Theories in health care and research

Theories and studying the care of dying people

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This is the last in a series of six articles on the importance of theories and values in health research

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The quality of care for dying people is often investigated by interviews with dying people, or with carers before or after the death. Conventionally the respondent's account is treated as a resource for learning about previous events. Analysis is concerned with veracity, bias, and the validity of such data. This article describes a project in which the initial analysis of interviews took this approach. Subsequently, the analysis shifted towards a view of the interview as a topic, primarily concerned with events during the interview. This article also shows how theories of language and self identity led the researchers to a questioning of accepted views about the needs of dying people and their carers.

Studying the quality of care for dying people

The study concerned events in the final year of life of a nationally representative sample of 639 adults who died in 1987.[1] [2] Surviving relatives and others who knew the people who died were interviewed to discover their perceptions of the quality of health care. To investigate bias, relatives' accounts were compared with those of healthcare staff about the symptoms of the people who died, the number of admissions to hospital, the incidence of various procedures, the effectiveness of pain relief, and other aspects of care. A smaller parallel study compared reports given by some people with terminal illness with reports from their relatives after their death.[1]

Truth, language, and human essentials

Validity or concern with the truthfulness of research data is common in health services research. The nature of truth and how to get at it is also debated by philosophers of science and social theorists. Much of the debate revolves around the status of language: can it be understood as reporting an underlying reality, or does language continually construct new realities? Traditionally, science has taken the former view. The latter view seems dangerous, implying that scientific attempts at objectivity are doomed to failure. If reality is contained in such a changeable thing as language, we live in a world of uncertainty, where validity cannot be judged by an appeal to external reality, because all such appeals are made through language.

Unsurprisingly, the scientist wishes to set aside such unresolved considerations when proceeding with the comparatively mundane business of research—otherwise the desire to get on with something useful is undermined. In the past 20 years, however, social science methods that start from the second position—that language constructs realities—have been developed. They take investigation of people's use of language as a legitimate topic for scientific inquiry. Speech and its written version, text, are investigated as forms of action and means for people to advance their

Summary points

Examination of the language used in research interviews can lead to useful insights, conventionally dismissed as "bias"

Bereaved people use research interviews to defend their moral reputations and to understand distressing deaths

People seek to make dying meaningful by drawing on (or resisting) cultural scripts, among which is the psychological ideal of "aware dying" promoted in Anglo-American health care

One does not have to resolve philosophical debates about the truth status of interview data, or the existence of universal human qualities, to adopt this analytic stance

interests in social interaction. The way people use language to construct meaning is studied in discourse analysis; conversation analysis, focusing on exchanges between people such as doctors and patients, also shows how people construct meaning.[3]

Associated with these developments has been a climate of radical doubt about some previous certainties about human nature. Anthropologists have shown, through cross cultural analysis, the immense mutability of human beings. Qualities believed to be universally human—driven by biologically grounded human needs—have been exposed by such work to be specific to different cultures (for example, reactions to pain[4] and to death and bereavement). It is a fashion for postmodernists to be enthusiastically "anti-essentialist," denying that there are universal human characteristics. Nevertheless, the deliberate attempt to examine one's own culture as if it is anthropologically strange can lead to valuable insights.

Reading the interview as a topic

The interviews on the project about the final year of life contained both fixed choice and open ended questions inviting respondents to tell their story in their own words. Additionally, interviewers made detailed notes of the respondents' talk, and with the aid of a computer programme (ETHNOGRAPH) these qualitative data were analysed.

Anthropologists have identified how people use ritual to repair the damage that a death causes to social cohesion.[5] Death threatens the orderly continuation of social life, especially in societies heavily dependent on the personal qualities of important individuals. Additionally, at a personal level the death of a loved person can disrupt a basic sense of security about

being in the world. Rituals soon after a death serve initially to separate close mourners from normal social life; later rituals draw the mourning period to an end and reintegrate mourners, when fear of the malevolence of the dead is reduced. This is often the moment when it is considered safe to distribute the goods of the dead person. Protecting social order and re-establishing optimism about continuing in life can therefore be important functions of ritual. In repairing the fractured world of the mourner the words of funeral laments can be understood as "concrete procedures for the maintenance of reality in the face of death."[6]

Influenced by these ideas, I began to read the interviews as potential examples of such reality maintenance and reintegration. Additionally, I was influenced by work on the way many interviewees seek to portray their actions in a moral light.[7] They were concerned about their moral reputations, as well as trying to repair the distress and disruption caused by the death. The accounts about people who died alone, particularly when at home, were very upsetting for relatives and carers to contemplate and often posed threats to interviewees' reputations as responsible people.

A few examples from the research may give a flavour.[8 9] People's moral reputations seemed to be at stake when the interviewer asked whether they had attended the death. Those who had not attended would often emphasise their distress about this, and their strenuous efforts to arrive in time: "I'd got there in five minutes … must have driven 80 miles an hour; we set off as soon as they rang up and said he was comatose." Others made angry accusations against nursing or medical staff:

"When I arrived the nurse said she had only just left mother and I could go straight up. When I went into the room she was dead.… The nurse said she had only been gone five minutes, but mother's hand and arm were quite cold. I was so upset … I feel they didn't take as much care as they could have done. I'm sure she had died on her own and no one had been in to see her for ages."

Some instances contradicted this general picture. The few people who said that they had not wanted to be present when someone close to them had died gave reasons which preserved their reputations. Thus one man explained that he was absent from his father's deathbed because his wife had early dementia and required his constant presence.

Moral reputations were also at stake over respondents' participation in decisions to place their elderly relatives in institutional care.[10] The disruption of security and fracturing of reality described by anthropologists was particularly evident in deaths alone at home. These were often discovered unexpectedly, and accounts could then be vivid, sometimes involving a detective-like search for clues about the last moments of the deceased:

"It must have been sudden. There was half a bottle of whisky and a small glass. The little glass was on the floor but she hadn't managed a drink. The cork was off the bottle as though she was about to have a drink. She wasn't a drinker. I think she was cold as the fire was switched on high. Her hair was scorched at the back."

Such stories showed a desire for reassurance about the last moments of the deceased which is often addressed by doctors comforting relatives of people who have suddenly died (as in "he wouldn't have felt any pain").

Here, the interview is not used to discover, for example, why people died alone, or even whether the person "really" died alone, or what their relatives "really" felt at the time of death. Instead, the reading focuses on how the interview is used to convey ideals about family obligations and to reconstruct a sense of security fractured by death.

Theories of self identity and cultural scripts

Theories differ about how self identity is formed. Some theories emphasise universal, essential truths about human identity influenced, for example, by genetics or developmental psychology. Other theories consider how individuals construct their identity by telling and retelling narratives about themselves. Such personal narratives can draw on "cultural scripts" offered by systems of expertise, such as medicine, psychotherapy, or religion. The scripts help the narrators to make sense of events, relationships, and their sense of self. Individuals who wish to understand how to die well can draw on a number of such scripts as materials with which to organise their coherent personal story. Some people feel that dying threatens them with the eventual obliteration of self identity, so this is a particularly fertile topic for examining how personal narratives are, nevertheless, sustained in order to give dying some meaning. The issue of whether some scripts address fundamental human needs better than others is temporarily suspended when this analytical stance is adopted.

Psychological wisdom regarding the process of dying from a terminal disease is influenced by Elisabeth Kubler-Ross's stage model of dying.[11] This involves movement from initial denial and numbness, through bargaining and depression, towards final acceptance of the fact that one is dying. Influenced by this model, Anglo-American doctors tend now to be more willing to tell patients directly about their terminal disease. Psychological expertise has developed to help healthcare staff to do this sensitively. (Somewhat paradoxically, this approach contains the view that staff may need to recognise that some people "need" to

People use ritual to repair the damage to social cohesion caused by death

maintain a state of denial.) Modern individuals' trust in authority and tradition to supply answers to troubling questions, such as those posed by illness or death, is declining.[12] A host of experts, including doctors, offers competing advice on how to live, and the individual is forced to choose between them. When deciding, for example, whether to have an operation, or whether to visit the general practitioner or a practitioner of alternative medicine, many people intensively gather information, assess the risks of various courses of action, and ultimately make a leap of faith based on trust.

"Aware death"

It became clear that many of our respondents were drawing on a cultural script of "aware death", such as that offered by Kubler-Ross, in order to understand the personal experience of dying.[13] Doctors' ways of delivering bad news were scrutinised particularly closely: caring, compassionate approaches were sharply distinguished from blunt, unfeeling deliveries. Respondents would often then describe a heroic journey for themselves and the dying person, struggling against the wish to deny, fighting the disease, and an eventual growing acceptance that could result in poignant accounts of moments of death, as a mother describing her daughter's death:

"Her death was so lovely. She looked better that day; the growth was not so awful. She knew she was dying. I was glad she could indicate by putting up her arms and showing she wanted me to put my arm round her."

The rewards of an aware death like this were a sense of having been emotionally close to the dying person, of having had the opportunity to review relationships, reconcile any continuing enmities, and to say goodbye. At both a practical and an emotional level, many unresolved affairs of life were often then felt to have been settled.

There were others, however, whose deaths could not have been "written into" this script, even had they wanted this. This applied, for example, to sudden deaths in accidents. Additionally, people who were mentally confused could not participate: "It wouldn't have registered. You couldn't tell her anything; she was too confused." The script was evidently most appropriate for those with a terminal disease.

Keeping a secret

A few people resisted this way of understanding dying, preferring an alternative that was less easily sanctioned by healthcare staff. They desired to remain oblivious to the problem of death, so that the dying person was protected from anxiety and fear. Sometimes this involved a considerable burden for the respondent, who had to keep the secret and fend off others' attempts to write the person into the script of aware dying:

"[The hospital] sent terminal care nurses—but they were just girls. Their one mission in life was to get him to talk about dying.... We had to stop the terminal care nurses.... [One of them] said, "Don't you ever talk to each other?" ... [They were] superfluous to our needs. They were very nice but we just didn't want them to do what they wanted to do ... the doctor running the terminal care nursing—continual bombardment about talking about death. Ugh! ... Absolutely useless."

This rival script of unaware dying now tends to have less support in professional Anglo-American health care, and more support in Japan[14] and some parts of Italy.[15] In these cultures there may be less widespread questioning of the authority of medicine. Additionally, the care of the self may be more easily given over to others when an ideology of individualism is less common. In such cultures, for a doctor to tell a patient that he or she is dying is often seen as an abdication of responsibility. The doctor's and relatives' duty is rather to protect patients from such information by shouldering the burden of awareness.

Conclusion

To adopt the analytic stance described here, it is not necessary to take sides or to resolve philosophical debates about objectivity or the universality of human need. Positivist theories, which take language to be a resource for discovering reality and see the purpose of science as being to identify and relieve universal human needs, are perfectly plausible. Constructionist theories, which explore how language is used to generate versions of reality and which suspend belief in the existence of universal human qualities, can provide equally useful insights. These theories can help to show our own society as strange, encouraging a deeper understanding of the values implicit in everyday medical practice and greater sensitivity to variety in the human condition.

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Correction

Implementing research findings in developing countries

An error during editing and checking has changed the sense of one section of this article by Paul Garner et al (22 August, pp 531-5). On page 532, the statement that "it is precisely these services that governments and international donors such as the United Kingdom's health and population aid programme are attempting to improve through targeted activities" was intended as a general comment and was not particularly directed at this programme. In fact, the Department for International Development UK is particularly good at working closely with partners in poor countries to promote uptake of evidence by policymakers and practitioners, within the wider context of efforts to ensure that healthcare systems are more responsive to the needs and interests of poor people.