A Grounded Theory Study of Truth-Telling in Cancer: Perceptions of White British and British South Asian Community Workers

by
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Abstract

Truth-telling about life-threatening cancer illness is a controversial matter. Few studies have explored attitudes towards truth telling among people from migrant communities living in cultures different to their own. The purpose of this grounded theory study was to explore the perceptions of white British and British south Asian community workers within the Metropolitan Borough of Walsall as to the factors that influence truth telling. In-depth, focused interviews were carried out with a sample of 20 key informants. A theoretical model was developed which describes the factors that lead to an imperative for family to act as gatekeepers of information exchange. The model describes the strategies used and the narrower and broader contexts in which they take place. The implications for practice are discussed and directions for further research are highlighted.

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Introduction

Truth telling about a life-threatening cancer diagnosis and prognosis is a significant concern of bioethics (Vanderpool and Weiss 1987). The relationship between truth telling and culture has been the subject of increasing attention in the literature (Bennett 1999; Anderlik, et al, 2000). There is substantial evidence to show that most western European and north American patients want to be told the truth about cancer (Cassileth, et al, 1980; Newell, et al, 1987; Blanchard, et al, 1988; Meredith, et al, 1996) and doctors over a number of years have been changing their practice to reflect these expectations (Novack, et al, 1979; Turner 1998; Thomsen, et al, 1993).

There is also significant evidence from other parts of the world to suggest that many patients do not want cancer information disclosure and the usual practice is for doctors to disclose such information to the patient's family (Cortes and Olarte 1994; Rigatos 1997; Ghamvamzadeh and Bahar 1997; Uchitomi and Yamawaki 1997).

Less clear are attitudes towards truth telling among cultural groups who

have migrated to other recipient countries. A small number of studies have investigated attitudes towards truth telling among people from various cultural groups in the United States (Orona, et al, 1994; Blackhall, et al, 1995; Carresse and Rhodes 1995) and in Australia (Huang, et al, 1999). These studies suggest that there are significant differences in attitudes towards truth telling between people from minority groups and those of the particular recipient culture.

In Britain there is a lack of studies exploring attitudes toward truth telling among black/minority ethnic communities. This is particularly surprising with regard to Indian, Pakistani and Bangladeshi communities (collectively south Asian) since they constitute 47% of the four million people from black/minority ethnic communities living in Britain (Stationery Office 2001).

The Cancer Information Strategy (NHS Executive 2000) requires practitioners to provide '*culturally sensitive information*' to people from south Asian communities. If health care is to be delivered in a culturally sensitive way, then there is a need for a greater understanding of cross-cultural differences among indigenous and migrant populations (Butow,

et al, 1997).

The purpose of this grounded theory study is to explore the perceptions of white British and British south Asian community workers within the English Metropolitan Borough of Walsall as to what factors may influence the withholding or disclosure of cancer information. Put another way, the central question is: What theory explains why cancer information is withheld from some patients and disclosed to other patients? The study aims to discover important categories of meaning, highlighting similarities and differences, between the perceptions of workers from these two cultural groups. It is hoped that the study will result in the development of theory, which is able to offer insight and understanding about how far cultural factors may influence decisions to withhold or disclose information.

Defining terms

A number of terms are used in the present study and require further definition.

Although not synonymous, the terms *cancer information* and *truth telling* will be used interchangeably in the present study. The former refers to information in one or more of the following areas: diagnosis, that is giving a label to an individual's illness, the nature of any proposed treatment, the most likely side-effects and outcomes of such treatments and the prognosis, that is how long an individual may expect to live. The latter involves cancer information disclosure but it also involves communication of what is 'perceived truth' and not something which can be absolute, fixed, waiting to be identified and then disclosed (Surbone 1997). Therefore, as Galeazzi (1997) suggests, "truth has no autonomous existence; it is a relationship between a portion of reality and its statement" (p40) and it is usually the doctor who has to "...make true an unpleasant portion of reality" (p41).

Cultural factors refer to any aspect of behaviour or thinking which distinguishes one group from another. This thinking or behaviour may be seen as an "...inherited 'lens' of shared concepts and rules of meaning, through which members of a group or society perceive the world they live in, and which guides their behaviour in their daily lives, and influences their emotional reactions to it (Helman 1990 p18). Cultural

values are enduring ideals or belief systems to which a person or society is committed (Ludwick and Silva 2000).

Bhopal, et al, (1991) suggest the term 'Asian' is often used in a misleading way. They suggest that in scientific writing it is important to define how it is being used. For the purposes of the present study, *white British* refers to those people indigenous to Britain and *British south Asian* refers to people resident in Britain who originate from India, Pakistan and Bangladesh. It is also important to acknowledge that there is considerable diversity among British south Asians (Rait and Burns 1997).

The present study has been written in the *first* person. The use of 'I' in the text is consistent with the qualitative nature of the research and my involvement in the research process (Norton 1999). Webb (1992) strongly emphasises that using the *third* person in writing is inconsistent with an interpretivist approach.

How the research question evolved

The research question essentially evolved as a result of my experience as a clinical nurse specialist working within the palliative care setting. It was in this context that I witnessed doctors of all grades regularly making decisions to disclose cancer information to family members without reference to the wishes of the patient. Given current trends within professional practice, I felt confronted by an *ethical conflict* defined as occurring "when a person group or society is uncertain about what to do when faced with competing moral choices" (Silva 1990 p2). The competing choices seemed to be either to tell patients the truth in line with the expectations of an individual autonomy model or to collude in withholding truth as requested by family. Having worked with a model which emphasises the importance of truth telling to patients, I felt more comfortable with cancer information being disclosed to the patient and engaging the patient on that basis. However, I was aware that in the context of a multi-cultural society, adherence to a single model might be inappropriate. This point is well illustrated by Kanitsaki's (1998) study which showed that Italian, Chinese and Greek Australians often perceived nurses "who attempted to discuss with them death and dying

and were negative, insensitive and transmitted to them a sense of hopelessness" (p39). In addition, nurses who were open about death and dying were interpreted as giving up on them, producing fears that they would stop caring. In addressing the ethical dilemma, I did not wish to appear ethnocentric in attitude and culturally insensitive in my practice. The above represents a summary of my own views and perceptions at the outset of the present study. Gonzalez (1997) highlights a case for research in this area:

Cultural differences often create misunderstandings, misinterpretation, and conflict in health care and sometimes results in inferior care. In order to bridge the gap between health-care systems and the population it serves, there is a need to address issues of communication (p213).

Chapter 2

Literature Review

The literature review was based on a number of sources. Medline (1993 to present) and CINAHL (1982 to present) on-line database searches were carried out using a variety of Medical Subject Headings (MeSH) and freetext procedures. Although the majority of the references were identified using this tool, many were not. Other sources include the reference list of published papers, general Internet search-engines and those provided by professional colleagues.

When a grounded theory approach is used, there is some debate as to whether it is appropriate to carry out a literature search at the beginning. Many proponents of grounded theory method discourage this on the basis that the emergent theory will be more likely to be grounded in the data (Cutcliffe 2000). On the other hand, others point out that it is the literature review which assists in identifying the gaps in knowledge and helps to provide a rationale for the proposed research (Hutchinson 1993; Creswell 1998). Using Strauss and Corbin's (1998) approach to grounded theory, the second review of the literature is to be woven into

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the emerging theory towards the end of the study (Cutcliffe 2000).

Strauss and Corbin (1998) point out that there is a danger of 'analytical paralysis' when researchers become too steeped in literature at an early stage. Therefore where a literature review is carried out at the beginning, it seems clear that a balance must be struck between the initial and subsequent literature reviews. I have found that conducting an early literature review has enabled gaps and biases in existing knowledge to be identified. Accordingly, this part of the literature review aims to describe these gaps and biases in more detail. Appropriate literature will also be presented in the results section to support or controvert findings. Strauss and Corbin (1998) suggest this allows for "...extending, validating and refining knowledge in the field" (p52).

There is significant evidence that most patients in western Europe and north America want to be told the truth about cancer diagnosis and prognosis. Studies carried out since the 1980's, primarily using survey questionnaire face-to-face patient interviews and participant observation designs, demonstrated that the majority of north American patients (over 90%) wanted information about prognosis as well as diagnosis. Many of these patients also expected to participate in decisions concerning their

treatment (Cassileth, et al, 1980; Newell, et al, 1987; Blanchard, et al, 1988).

The same trend has been demonstrated by a number of British studies. Meredith, et al, (1996) in a major study involving semi-structured interviews with 250 cancer patients within a regional cancer centre in Glasgow, suggested that the majority of respondents (96%) had a need or an absolute need to know if they had cancer. Over three quarters (79%) of respondents wanted as much information as possible. Specifically, 91% of respondents wanted to know about side effects of treatment and 91% about the chance of cure.

These findings were confirmed by a larger multi-centred quantitative study involving an apparently heterogeneous sample of 2331 patients attending 34 hospitals throughout the UK (Jenkins, et al, 2001). The study suggested that 87% of respondents wanted all possible information, both good and bad news. In addition, 98% preferred to know whether their illness was cancer.

A qualitative study involving 75 cancer patients and 10 of their carers

organised in focus groups, concluded that nearly all participants wanted

as much information as possible. Information about their cancer,

treatment options, the likelihood of treatment success and possible side

effects were considered particularly important (National Cancer Alliance

1996).

In Western Europe and North America there has been a corresponding

shift towards truth telling by doctors over the past 30 years (Novack, et

al, 1979; Turner 1998; Thomsen, et al, 1993). Bioethical approaches to

truth telling are influenced by the Western principle of individual

autonomy in which the patient is responsible for making decisions

regarding health and to participate in therapeutic decision-making

(Surbone 1997; Turner 1998). The model is probably at its most

advanced in the United States where it has become a 'moral absolute' in

which truth telling has become part of an accepted dogma (Pellegrino

1992).

Studies carried out in other parts of the world suggest that a significant

number of patients do not want cancer information to be disclosed to

them. A Spanish study (Cortes and Olarte 1994), involving semi-

structured interviews with 97 hospitalised cancer patients, showed that 42% of uninformed patients wanted to know little or no cancer information. Similar findings have been demonstrated in other countries (Liberati, et al, 1985) and Greece (Dalla-Vorgia, et al, 1992; Rigatos 1997).

In many cultures, the patient is firmly situated in a family that assumes responsibility for decision-making on his/her behalf. Doctors tend to disclose cancer information to the family rather than the patient (Ghavamzedah and Bahar 1997; Malik and Qureshi 1997; Younge, et al, 1997; Pellegrino 1998). Full disclosure appears to violate these norms (Anderlik, et al, 2000).

What is not known is how cultural groups who have migrated to other recipient countries different to their own perceive issues around truth telling.

There is evidence from a small number of studies that people from minority ethnic communities resident in Western countries tend to reflect attitudes about truth telling akin to those of their 'home' cultures.

Blackhall, et al, (1995) conducted a survey study involving 800 people, aged over 65 years, attending 31 senior citizen centres in Los Angeles County, California. When asked whether a patient should be told the truth about the diagnosis of metastatic cancer, (cancer that has spread beyond its original site), there were significant differences in the responses given. Korean Americans (47%) were less likely than African Americans (89%) and European Americans (87%) to believe that a patient should be told such a diagnosis. Similarly, Korean Americans (35%) were less likely than African Americans (63%) and European Americans (69%) to believe that a patient should be informed of a terminal prognosis. Mexican Americans tended to fall between African Americans and Korean Americans with 65% supporting truth telling of diagnosis and 48% disclosure of a terminal prognosis.

In another qualitative study involving focus groups and telephone interviews with 45 Chinese cancer patients (who were all aware of their diagnosis) in Sydney, Australia, Huang, et al, 1999 showed that the majority of participants believed that they should be told the diagnosis but felt that some other people would not be able to cope and should not be told. Most participants also believed that patients with incurable

cancer should not be told, as it would be too stressful and likely to lead to early death.

Unfortunately, British studies do not appear to have included people from south Asian communities. In the study by Meredith, et al, (1996) this was explicable by the fact that it was conducted in a geographical area in which black/minority ethnic communities comprise only 1.3% of the entire Scottish population (OPCS 1992).

Jenkins, et al, (2001) claimed that their sample was heterogeneous in nature, but this does not seem to have extended to the ethnicity or cultural group of respondents. Moreover, the researchers report that 2331 individuals participated in the study but 350 of these (13%) declined to do so. Among the most common reasons cited for non-participation was lack of English. The researchers do not make explicit how many of these potential participants were of south Asian ethnicity.

Whilst the National Cancer Alliance Study (1996) had been carried out in two of four regions with high black/minority ethnic populations (London and the West Midlands), the study did not include people from these

communities in their sample. The researchers state that the method of sampling used "...did not allow [us] to target specific patient populations that tend to have limited opportunity to voice their opinions, such as ethnic minorities...". (p13). Whilst this qualitative study involving 75 focus groups provides some useful insights concerning the nature of the information that most people seem to want, the failure to purposefully sample people from black/minority ethnic communities weakens its overall impact.

However, the lack of inclusion of people from different minority cultural groups in studies is likely to reflect the practical difficulties of carrying out research involving these groups, especially in the context of a language barrier.

Studies in which the researcher and participants do not speak the same language are fraught with difficulty. In research involving interviews, there are problems in translating the interview data from one language to another (Hatton 1992). As Jones (1987) suggests, the failure to use proper translation procedures may reflect translation errors rather than differences in the people being studied. The use of certain language may

convey different meanings among people from different cultures

(Steeves 1992). Barnes (1996) suggests "when the respondent's culture

differs significantly from the researcher's, it may be necessary for the

researcher to have some personal or professional cultural experience, as

well as experience with the same kind of phenomenon" (p437).

The resources needed to carry out research involving people who speak a

different language are therefore more significant because of the need for

meticulous attention to the words used and subsequent translation

procedures. Very few studies exploring truth-telling issues have been

carried out involving researchers fluent in the language of other cultural

groups. The study by Huang, et al, (1999) referred to above, being a

notable exception. These considerations have guided the present study

towards exploring of the perceptions of English-speaking 'key

informants' rather than cancer patients themselves, many of who will be

likely to be older British south Asians who speak little or no English.

Key informants are so-called because they possess a high degree of

insight, knowledge and experience relevant to the subject area (Gilchrist

1992). Key informants play a significant role in research studies,

especially where it is difficult to gain access to subjects (Sim and Wright 2000). Researchers, however, need to be aware of the potential biases of informants in presenting their data (Maxwell 1996).

Interpreting the evidence on cancer information disclosure preferences is clearly affected by *who* and *what* is asked.

Comparison of studies is made difficult because sample groups range from patients (Cortes and Olarte 1994; Seo, et al, 2001) to lay 'healthy' individuals (Dalla Vorgia, et al, 1992; Blackhall, et al, 1995 and Fielding and Hung 1996). When involving patients, published research reports do not make clear how researchers overcame the ethical problem of asking patients about truth-telling issues when unaware of their own diagnosis. Yet, only involving individuals who are aware of their diagnosis is likely to give a distorted picture because they may answer questions relating to their information disclosure preferences differently to those who have not been so informed. Views on disclosure are likely to be coloured by experience and the informed patient will have the benefit of hindsight and an opportunity to assimilate the implications of their cancer diagnosis. The disadvantage of involving lay individuals is that most will

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