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Dying from cancer in developed and developing countries: lessons from two qualitative interview studies of patients and their carers

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Abstract

Objective To describe the experiences of illness and needs and use of services in two groups of patients with incurable cancer, one in a developed country and the other in a developing country.

Design Scotland: longitudinal study with qualitative interviews. Kenya: cross sectional study with qualitative interviews.

Settings Lothian region, Scotland, and Meru District, Kenya.

Participants Scotland: 20 patients with inoperable lung cancer and their carers. Kenya: 24 patients with common advanced cancers and their main informal carers.

Main outcome measures Descriptions of experiences, needs, and available services.

Results 67 interviews were conducted in Scotland and 46 in Kenya. The emotional pain of facing death was the prime concern of Scottish patients and their carers, while physical pain and financial worries dominated the lives of Kenyan patients and their carers. In Scotland, free health and social services (including financial assistance) were available, but sometimes underused. In Kenya, analgesia, essential equipment, suitable food, and assistance in care were often inaccessible and unaffordable, resulting in considerable unmet physical needs. Kenyan patients thought that their psychological, social, and spiritual needs were met by their families, local community, and religious groups. Some Scottish patients thought that such non-physical needs went unmet.

Conclusions In patients living in developed and developing countries there are differences not only in resources available for patients dying from cancer but also in their lived experience of illness. The expression of needs and how they are met in different cultural contexts can inform local assessment of needs and provide insights for initiatives in holistic cancer care.

Introduction

Every year an estimated five million people in developing countries die from cancer, but little is known about their end of life care.¹ With few notable exceptions, such as Hospice Uganda,² health care for the dying has a low priority compared with preventive and curative

services. Global opioid consumption for pain relief confirms that palliative care is currently available only for the rich nations.³ We generated qualitative data from two research studies of the needs of patients with incurable cancer and determined whether services meet their needs in Scotland and Kenya.

In Lothian region, Scotland, people have access to health care free at the point of delivery and a comprehensive social security system. Running water, adequate food, and a reliable supply of electricity are taken for granted. In Meru South, a district on the eastern slopes of Mount Kenya, many people live in absolute poverty (on less than £0.62 (\$1, €1) a day). All health facilities—government, church, or private—charge fees for their service. The main health service provider is Chogoria Hospital, a 300 bed Presbyterian Church hospital that also manages 24 rural clinics.⁴ The cost of admission to hospital is equivalent to several months' wages of an unskilled labourer. The population is mostly Christian (Catholic, Protestant, and African Independent), but many people hold these beliefs alongside those of traditional African religions.^{5,6} There are traditional cultural restrictions on care giving, and there remains a fear of death occurring at home.

Methods

We used qualitative approaches and patient centred methods to obtain accounts sensitively without upsetting participants with advanced illnesses.⁷

In Scotland, as part of a larger study,⁸ 20 patients with inoperable lung cancer were recruited to represent the local demography of lung cancer with respect to age, sex, and methods of treatment. In Kenya, also as part of a larger study,⁹ 24 patients were recruited to reflect various locally common cancers, such as gastric, cervical, skin, and breast cancer; lung cancer is rare.¹⁰ Participants were purposively sampled to give an even mix of those receiving care at home and those receiving most of their care in hospital.

In Scotland, we tape recorded in-depth interviews at three monthly intervals for up to a year with patients and their main informal carers in the patient's homes. In Kenya a local nurse conducted single semi-structured interviews with patients and carers in the local language, Kimeru. She wrote notes in Kimeru

and translated them into English, retaining Kimeru phrases for key concepts.

Analysis

We analysed results throughout the fieldwork to allow emergent themes to be fed back into the data collection. These themes and the research questions formed the basis of the coding strategies. At both sites transcripts and field notes were checked and coded by two experienced researchers. In Kenya, aware of the role of language in determining as well as describing social constructs, a multidisciplinary, bilingual advisory group, assisted by the nurse interviewer, discussed evolving themes and key Kimeru phrases.¹¹

In Scotland a multidisciplinary steering group also met regularly to discuss evolving themes and contribute to data synthesis and interpretation.

Results

In Scotland we recruited 11 men and nine women and conducted 67 interviews (43 with patients and 24 with carers). The average age of patients was 66 years (range 48-87 years), 15 lived with a spouse, and 16 received active treatment. In Kenya, 14 men and 10 women with an average age of 57 years (range 41-80 years) were each interviewed once. We also carried out 18 interviews with carers: spouses, sons and daughters, siblings, parents, and a clansman. Quotes from selected participants are given here; full details can be found on bmj.com.

The mean World Health Organization performance status at first interview was 2.0 in Scotland and 3.3 in Kenya (from 0=unrestricted activity to 4=complete disability).¹² The box compares the two groups.

Living with cancer in Scotland

Patients and their carers in Scotland were predominantly concerned about the prospect of death. "The doctor told me that you're actually on borrowed time with cancer ... They're hoping to shrink this cancer in the right lung, but you're more or less a time bomb" (patient 1). Patients struggled to maintain a normal life while swinging, often in the same day, from hope to despair. They tried to remain positive, but frustration and anger were evident. "Sometimes I just want to throw the best china at the kitchen wall, but then you just have to grit your teeth and get through it. The only thing is to try and lead an ordinary day" (patient 3).

Patients often felt unable to share their distress with family, friends, or professionals. "I just keep that to myself. And then I think, just get up girl and show them different; different, determined, positive. And then other times I just sort of weep into it. You can only do so much" (patient 1).

Only occasionally did religion provide comfort. "Some days we'll receive prayer cards, signed by the priests. I like that. It shows they're caring. I like to know that I've got all these people praying for me—even people I've never met" (patient 4).

During radiotherapy and chemotherapy, regular hospital visits dominated the lives of both patients and carers, giving support and hope. However, patients also had to deal with treatment side effects.

Patients worried about how carers would cope. "I feel more for my wife and family. It's strange. You hear people saying that, and I never thought it was true, but you do worry more about what's going to happen to them" (patient 6). Carers worried about upsetting the patient and about how they would know what to do when death did occur. "Sometimes I wonder, Is this the end? and then I think, What will it be like, you know? How will I know? And will I know? And what will happen? And I just don't know ... the next time the hospice nurse comes, I'll ask her. So I get myself all braced up to ask her, but when she actually comes, I just can't do it. Perhaps I don't really want to know" (carer of patient 6).

Living with cancer in Kenya

In Kenya, pain dominated the experience of living with cancer. "There are times when the pain is so severe that I feel like hanging myself in the house to die" (patient 7). "I want to go to sleep and wake up dead because the disease may take a long time, and I will have to suffer a long time" (patient 8). Many patients could afford neither analgesia nor basic essentials for care. "There is no money in the family, because of the many times I attended dispensaries and did not get well" (patient 10). Some patients tried to hide their illness from their families because "they would be disturbed as this disease needs money" (patient 12). All worried about finding the money to attend outpatient consultations, pay hospital bills, and buy medicines.

Degrading material circumstances were sometimes evident. "There were faeces on her body, urine stinging

Outline comparison between the two groups of patients

Scotland

- Main issue is the prospect of death
- Pain is unusual
- Anger in the face of illness
- "Just keep it to myself"
- Spiritual needs evident
- Diagnosis brought active treatment, then a period of watching and waiting
- Patients concerned about how carer will cope in the future
- Support from hospital and primary care team
- Specialist palliative care services available in hospital and hospice and at home
- Cancer a national priority in Scotland

Kenya

- Main issue is physical suffering, especially pain
- Analgesia unaffordable
- Acceptance rather than anger
- Acceptance of community support
- Patients comforted and inspired by belief in God
- Diagnosis signalled waiting for death
- Patients concerned about being a physical and financial burden to their family
- Lack of medical support, treatment options, equipment, and basic necessities
- Specialist palliative care services not available in the community
- Cancer not a national priority in Kenya

her wounds. No one in the family felt able to wash her. Her daughter was overwhelmed by the smell and look of the wounds" (fieldnotes concerning patient 11).

Patients were accepting of their prognosis and the inevitability of death. "There is nothing that being angry can achieve" (patient 12). "Do the maize and beans ask the harvester where they are going to be stored?" (patient 14). All believed the time of death was not theirs to control, and religious beliefs often provided comfort and peace. A diagnosis of cancer brought an end to searching for a cure and signalled a time of preparation and waiting rather than intensive treatment. "I must simply wait until God calls me home, there is no chance of getting better, so all I have to do is to wait until the home calling" (patient 11).

Although the cultural norm among this ethnic group is for the extended family to care for their ill, patients often thought they were becoming a physical and financial burden to their family. "Money is being spent on me instead of school fees" (patient 16). Carers described being burdened by the difficulty of caring, their lack of medical knowledge, the lack of drugs in the home, and their fear of not knowing what to do when the patient deteriorated. If the patient died they were anxious about handling the body and either preserving it until the time of the funeral or arranging and paying for transport to a mortuary.

Health care in Scotland

Patients had access to support and effective analgesia at home. "There's a district nurse from the new surgery who comes in every two weeks, just to maintain contact. She's lovely and, in fact, she knows other members of our family and so we've been very lucky with her. She's a really nice person and easy to get on with" (patient 17).

Help with mobility, equipment, and financial benefits were usually available, as were carers' support, sitting services, and some respite care. Specialist palliative care services were available and cancer charities and voluntary agencies offered many services.

Health care in Kenya

Medical, nursing, or social services were not available in rural homes in Kenya. Volunteers with training in palliative care were not available locally. Opioids were available only to hospitals with a specific prescribing licence. Cancer patients were invited to report back to the hospital for review while they were physically able. Radiotherapy was costly and available only in cities, and there was a long delay. The work of attending those who were vomiting, incontinent, or who had offensive wounds strained patient-family relationships. Most homes had neither running water, indoor toilets, electricity, nor easy access to gloves or dressings. Specific local cultural traditions prohibited sons and daughters from seeing their parents naked.

While physical needs were better met in hospital than at home, patients thought that there was less emotional and spiritual support in hospital. "No one takes me out for sunshine" said patient 19, who longed for home, "At home I can see my hut and my garden."

In the community, voluntary groups such as church fellowships helped patients by visiting regularly, singing and praying for the person, and giving essential gifts such as food or soap. Patients valued these visits. The husband of patient 8 explained, "She remains firm by the church praying for her, then she

What is already known on this topic?

Cancer treatment is a priority and is well developed in the United Kingdom

There is an increasing burden on inadequately funded health services in developing countries

What this study adds

The experience of dying from cancer in Scotland contrasts starkly with that experienced in Kenya

Inequalities in provision of palliative care persist between developed and developing countries

Despite the availability of resources in the United Kingdom, people still have major areas of unmet needs

Consideration of patients' experiences and provision of care in contrasting cultural settings can highlight gaps in frameworks of cancer care

turns to prayer and finds herself relieved of the pain and falls asleep." Patients described how this support encouraged them to feel part of the community despite their illness and helped them retain a sense of value and meaning in their lives.

Discussion

We found that people dying of cancer in Scotland have good access to health care but may still experience distress on an emotional level. In Kenya, people were at peace with themselves and more resigned to death but experience more physical distress. The details of our findings may not be generalisable as there are geographic, social, and cultural issues around death and dying specific to every ethnic group. There may also be differences between the needs and beliefs of rural and urban patients in each country, and some of our data may reflect this. Yet sufficient similarities exist between the Kenyan participants and those of other peoples in sub-Saharan Africa and between the Scottish patients and the United Kingdom to make our comparisons of more general interest.

The Meru study, like others,¹³⁻¹⁵ suggests that in Kenya the community with its networks of health and church volunteers has the capacity to care for patients at home but lacks adequate resources. In Scotland the resources are available but the community may no longer have the capacity, or the confidence, to care for dying people and to cope with death.

Care at the end of life is a major problem for global public health.¹ In Africa, flexible methods of essential drug dispensing, distribution, and payment should be developed, which recognise poverty in patients. There is now an opportunity and an imperative to assist developing countries.¹⁶ Western medicine can learn from developing countries to empower patients, families, and communities to accommodate the distress of the dying.

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- 1 Singer PA, Bowman KW. Quality care at the end of life. *BMJ* 2002;324:1291-2.
- 2 Ramsay S. Raising the profile of palliative care for Africa. *Lancet* 2001;358:734.
- 3 Olweny C. Ethics of palliative care medicine: palliative care for the rich nations only! *J Palliat Care* 1994;10:17-22.
- 4 De Boer CN, McNeil M. Hospital outreach community-based health care: the case of Chogoria, Kenya. *Soc Sci Med* 1989;28:1007-17.
- 5 Isichei E. *A history of Christianity in Africa*. London: SPCK, 1995.

- 6 Mbiti JS. *African religions and philosophy*. London: Heinemann, 1969.
- 7 Green J, Britten N. Qualitative research and evidence based medicine. *BMJ* 1998;316:1230-3.
- 8 Murray SA, Boyd K, Kendall M, Worth A, Benton TF. Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community. *BMJ* 2002;325:929-2.
- 9 Grant E, Murray SA, Grant A, Brown J. A good death in rural Kenya? Listening to Meru patients and their families talk about care needs at the end of life. *J Palliat Care* (in press).
- 10 Murray JL, Lopez AD. *The global burden of disease*. Boston: Harvard School of Public Health, 1996.
- 11 Lincoln YS, Guba EG. Paradigmatic controversies, contradictions and emerging confluences. In: Denzin N, Lincoln YS, eds. *Handbook of qualitative research*. London: Sage 2000;163-188.
- 12 World Health Organization. *Handbook for representing results of cancer treatment*. Geneva: WHO, 1979.
- 13 Defilippi K. Palliative Care issues in sub-Saharan Africa. *Int J Palliat Nurs* 2000;6:108.
- 14 Westphal VB. *Monograph on six home care programmes in Uganda and Zambia*. Geneva: WHO, 1990.
- 15 Olweny C. Cultural issues in sub-Saharan Africa. In: Doyle D, Hanks G, McDonald N, eds. *Oxford textbook of palliative medicine*. Oxford: Oxford University Press, 1996.
- 16 World Health Organization. *Macroeconomics and health: investing in health for economic development. Report of the commission on macroeconomics and health*. Geneva: WHO, 2001. (Accepted 23 December 2002)

Association between practice size and quality of care of patients with ischaemic heart disease: cross sectional study

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Proportionally fewer inpatients die in hospitals that do more operations than in hospitals that do fewer.¹ Similar associations between outcome and the size of hospitals have been found in other studies. An association between size and outcome may also be important in primary care settings, where most patients with chronic illnesses are managed. If large practices or those that treat more people provide better care, this could have important implications for the organisation of primary care services. We looked for an association in patients with ischaemic heart disease because the management of this disease is an international priority.²

Participants, methods, and results

From September 2000 to May 2001, we identified patients diagnosed as having ischaemic heart disease using paper and computerised medical records in four primary care groups in southwest London (69 general practices; population 382 188). Seven general practices did not take part.³

We recorded patients as hypertensive if their blood pressure was more than 140/85 mm Hg. We classed cholesterol concentrations greater than 5 mmol/l as high and defined patients with a body mass index (weight (kg)/height (m²)) of 30 or greater as obese. We extracted information on treatment with cardiovascular drugs from computerised records. Fifteen practices were unable to supply some data and were excluded from some of the analyses.

We calculated the proportion of patients in each practice whose risk factors were assessed or controlled; who were taking aspirin, statins, β blockers, or angiotensin converting enzyme inhibitors; or who had had revascularisation treatment. To examine the association of practice size and volume of cases with

quality of care, we used a logistic population averaged generalised estimating equation model, adjusted for age and sex, that allowed for clustering within practices.

Practice size varied from 1265 to 13 147 patients (mean 5762). In total, 6888 people had ischaemic heart disease; the number of cases in individual practices varied from 12 to 326 (mean 111) and prevalence varied from 0.45% to 4.37% (mean 1.96%).

Only records of cholesterol concentrations showed an improvement with increasing number of cases of ischaemic heart disease. An increase of 10 in the number of cases was associated with a 6% increase in the odds of recording (table). On average, a practice with 200 patients with ischaemic heart disease would have recorded cholesterol concentrations for 69% of patients registered with the practice compared with 56% in a practice with 100 cases.

Comment

Most aspects of the management of ischaemic heart disease in primary care were not associated with the number of cases managed. We also found no association between practice size and the quality of care. This suggests that the trend in the NHS towards larger general practices by itself has little impact on the quality of chronic disease management in primary care.

Although recent developments in the NHS have cast doubt on the future of smaller practices, both patients and the doctors seem happy with smaller practices. Smaller practices are seen as more accessible and achieve higher levels of patient satisfaction.^{4 5} The NHS should reconsider how it can improve the quality of care provided by general practices, without relying on the presumed benefits of consolidating them into

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