

Primary care

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 In developing countries, health services are struggling with population increases,

underfunding, wars, the HIV pandemic, and natural disasters. 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—a measure of success in the acceptance of pain relief for cancer—confirms that palliative care is currently available only for the rich nations, with little or no morphine consumed in half of the world's countries.³ We examined inequalities in end of life care and differences in patients' experiences of living with illness. 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 primary and secondary 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, €0.96) 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 church run 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 so that accounts could be obtained sensitively without upsetting participants with advanced illnesses.⁷

In Scotland, as part of a larger study,⁸ respiratory medicine consultants identified outpatients with inoperable lung cancer, which is the commonest and most lethal cancer in Scotland.⁹ Twenty patients 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,¹⁰ hospital doctors identified 32 adult patients with a life

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bmj.com 2003;326:368

limiting illness who were at different stages of the disease progression. We purposively sampled participants to give an even mix of those being cared for at home and those receiving most of their care in hospital. Twenty four patients with cancer were chosen to reflect various locally common cancers, such as gastric, cervical, skin, and breast cancer; lung cancer is rare.¹¹ All participants gave fully informed consent.

In Scotland, we conducted and tape recorded in-depth interviews at three monthly intervals for up to a year with patients and their main informal carer in the patient's home. In Kenya, guided by staff at the hospital and affiliated nurse training school, we developed a semistructured interview schedule that provided sufficient flexibility to allow respondents to express ideas in their own ways without being bound by preconceived categories of the researchers. A local nurse who was empathetic and experienced in caring for the dying was trained by LG. She conducted single 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. We used the qualitative computer package QSR NVivo and the techniques of narrative analysis.¹² 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 advisory group, assisted by the nurse interviewer, discussed evolving themes and key Kimeru phrases.¹³ This group, most of whom were native speakers of Kimeru who were also fluent in English, included doctors, teachers, nurse trainers, and community health promotion workers, who brought a wide range of research, education, clinical, and local community perspectives to the analysis.

In Scotland the multidisciplinary steering group, which included hospice and hospital based community medicine specialists, a social worker, a nurse, and a general practitioner, regularly discussed the evolving themes and contributed to data synthesis and interpretation.

Results

In Scotland we recruited 20 patients (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 17 were offered and 16 received active treatment.

In Kenya, 24 patients (14 men and 10 women) with an average age of 57 years (range 41-80 years) were each interviewed once. Cancer types included were gastric, cervical, skin, and breast cancer. We also carried out 18 interviews with carers: spouses, sons and daughters, siblings, parents, and a clansman.

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).¹⁴ The box highlights the main differences in the experiences, needs, and service use of 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). "You're wondering if you're going to see tomorrow. When I first was told, that was the first thing that went through my head, How long? When?" ... it's been like going to hell and back" (patient 2).

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).

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

During radiotherapy and chemotherapy, regular hospital visits dominated the lives of both patients and carers, giving support and hope. "The oncology people, I mean, they get to know their patients so well, you know. They, they know them so well, don't they? They're great nurses and departments, eh, specialists... They're so caring" (patient 5). However patients had to deal with treatment side effects. "Yesterday I just wanted to curl up in a ball and die, but I know that's not the cancer. That's the treatment. The treatment makes you feel so bad, and each time the after effects have lasted longer and been worse" (patient 3).

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. The pain was constant and unbearable for many. "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). "I would like to die rather than live as I am living" (patient 9).

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).

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

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. A constant task for many was "searching for money and never getting it" (patient 13).

Patients were accepting of their prognosis and the inevitability of death and were rarely angry at the illness. "There is nothing that being angry can achieve" (patient 12). "Death is a path we all must tread" (patient 7). "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. "We belong to God and he will take us away when he feels it is right, when he wants" (patient 15). Religious beliefs often provided comfort and peace. "God comforts me; my heart calms down when I remember this and I get emotional support" (patient 7).

A diagnosis of cancer brought an end to searching for a cure and signalled a time of preparation and wait-

ing 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). "At home there may be only one person to care for you and the farm, the animals and other things" (patient 12).

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). "They gave me like morphine, you know, a substitute of morphine, I was supposed to take 4, 4 or 5 times a day for pain, but I don't really have any pain, so I don't really take it" (patient 1).

Help with mobility, equipment, and financial benefits were usually available, as were carers' support, sitting services, and some respite care. Specialist palliative care services offered support at home, day care facilities, and hospice admission, which only some people used. "I wouldn't know what I wanted counselling on, why I'd want to phone her up... unless it gets really bad" (patient 5). 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 until they were physically unable to do so. 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. "There are parts of the body that you cannot show to your family members. There are some people who should not touch you" (patient 18).

While physical needs were better met in hospital than at home, patients thought that there was less emotional and spiritual support in hospital. Surrounded by sickness and unable to see their children or their land and animals, patients felt isolated. "In hospital, death and illness surrounded me; the smell of drugs was ever present" (patient 16). "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 cope with their illnesses by visiting regularly, singing and praying for the person, and carrying small 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 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

Patients expressed contrasting needs and received different standards of clinical care in each country. Understanding the needs of patients and carers in different cultural contexts by listening to their experiences can give valuable insights and comparisons that can inform the planning of cancer services in each context.

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. Within both the United Kingdom and sub-Saharan Africa, poverty levels vary, religious beliefs differ, and disease patterns and resources vary. 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. The Kenyan patients were recruited from a Presbyterian Church hospital but reflected the diversity in religious affiliation in the area, with atheism, as in many African countries, being rare. Yet sufficient similarities exist between the situation of our Kenyan participants and those of other peoples in sub-Saharan Africa and between the experiences and needs of our Scottish patients and the United Kingdom generally to make this comparison of more general interest.

We used qualitative methods to gain evidence about the quality of end of life care. This strategy can illustrate and bring alive statistics—for example, although two thirds of the world’s cancer patients live in developing countries, less than 10% of cancer care resources are available to them.^{3 15} We report the voices of patients denied active treatment because of the injustice of global health inequality. However, we also report the voices of some patients in Scotland who, in retrospect, regretted accepting in hope the offer of “active treatment” because of reduced quality of life. Has the professionalisation of palliative care and the medicalisation of death taken away skills and power from families and communities so that they are no longer able to accommodate the distress of dying?

Many of Smith’s principals of a “good death,” such as relief from pain, dignity, and privacy, were absent in our Kenyan group.¹⁶ But also absent were fear of dying, anger, and a retreat into isolation, common in the West. Despite physical suffering and sometimes lack of basic food, care, and equipment in Kenya, many patients received hope and comfort from their religious beliefs and church friends and were able to make sense of their lives in spiritual terms and hence cope with death. The Meru study, like others,^{17–19} suggests that in Kenya

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

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 belief in itself, to care for dying people and to cope with death.

Health professionals should be concerned about growing inequalities in health and wealth.²⁰ Care at the end of life is a major problem for global public health. Singer and Bowman have outlined a vision for strengthening capacity in global health ethics, which they insist must include consideration of end of life care.¹ A key recommendation from *Macroeconomics and Health* is for the world’s high income countries to work in partnership with poor countries to scale up their health systems to provide access for all to a limited number of essential health interventions.²¹ Surely pain relief for the dying is such an intervention.

Conclusions

Though living in a resource rich country with cancer a national priority, Scottish patients described unmet psychosocial needs. Meeting physical needs did not alone ensure a good death. In developing countries, while physical needs often go unmet, the family and the local and religious community can and do meet many of the psychological, social, and spiritual end of life needs: “higher order” needs can be met amid physical distress, evicting Maslow’s typology of need.²²

In the West, the palliative care movement has succeeded in improving pain control. For humane end of life care in Africa, an analgesic “ladder” must be available and affordable. 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. A way must be found to improve the physical care of dying people in Africa without destroying the capacity of the patient, the family, the community, and religious organisations to meet other needs. Western medicine can learn from developing countries to empower patients, families, and communities to accommodate the distress of the dying.

We thank all patients and their informal carers for giving their time and energy to this study. We are grateful to K Swarski at Edinburgh Royal Infirmary, R Fergusson, and D Borthwick at the Western General Hospital, Edinburgh, and doctors at Chogoria Hospital for identifying patients. We thank Eunice Muthoni for conducting the interviews in Kenya and Allison Worth and Judith Brown for reviewing data analysis in Scotland and Kenya, respectively. We thank Kirsty Boyd and Derek Doyle for commenting on drafts of this paper and Arthur Andere, James Mwenda, and Jane Njeru, members of the advisory group which provided support in Kenya.

Contributors: SAM designed the Lothian study, was responsible for the recruitment, contributed to the interpretation of the data, and is guarantor for the paper. EG designed the Meru study, was responsible for the recruitment and interviewing of participants in Kenya, and analysed the Kenyan data. AG designed the Meru study and helped with recruitment and analysis in Kenya. MK undertook the interviewing and analysis in Scotland. All authors wrote the paper.

Funding: These studies were funded in Scotland by a grant from the Chief Scientist Office of the Scottish Executive, and in Kenya by a donation from an Edinburgh patient to Edinburgh University. The guarantor accepts full responsibility for the conduct of the study, had access to the data, and controlled the decision to publish.

Competing interests: None declared.

Ethical approval: The Scottish study was approved by the local research ethics committee and trusts. The Kenyan study was approved by the local ethics committee and hospital board of management.

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(Accepted 23 December 2002)