How do people with cancer wish to be cared for in primary care? Serial discussion groups of patients and carers

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Background. In most economically developed countries, patients, their informal and professional carers and policy makers are calling for more care in the community.

Objectives. To involve patients with cancer, and their carers, in designing a framework for providing effective cancer care in primary care.

Methods. Two discussion groups comprising 18 people with current cancer and carers met monthly over a year in the south of Scotland.

Results. Patients with cancer and their carers identified five key times in the cancer journey as being especially significant from their perspective: around diagnosis, during treatment, after discharge, at recurrence and the final weeks. At each key time, there were five major issues of concern: information, communication, equity, a holistic approach and patient-centred care. Using these, the group members developed a checklist of recommended interventions for each stage in the illness trajectory and suggested how they might be implemented in primary care. Proactive and ongoing contact, if wished by the patient, was considered the central plank of cancer care in the community.

Conclusions. Patients with cancer and their carers believe that there is an important and unique role for primary care in offering continuity of care and information that is patient-centred and holistic, throughout the cancer trajectory, from first presentation. This study successfully brought patient, carer and professional perspectives to the development of a care framework for primary care.

Keywords. Cancer care, cancer trajectory, palliative care, patient-centred care, primary care.

Introduction

Compared with chronic disease management, where guidelines and primary care protocols abound, cancer care across the whole illness trajectory is poorly coordinated in primary care. An impetus for change in the United Kingdom is the introduction of the new General Medical Services contract, which led to over 95% of general practices creating computerized registers of patients with cancer. Refinements to the Quality and Outcomes Framework of this contract in 2006 encourage practices to develop a separate supportive and palliative care register.

There is an increasing focus on the user across the full range of public services in the United Kingdom, with government policy repeatedly calling for services to become more responsive to the needs and wishes of their recipients. Service users are now seen as key stakeholders to be involved in partnerships with practitioners and researchers.
and their carers, can bring unique insights and knowledge to discussions about what interventions in primary care would be most helpful.\(^9\)

Palliative care provided by GPs is in general highly valued by patients, especially continuity of relationship and being listened to by someone with knowledge of the greater context of their illness.\(^9\) The Gold Standards Framework in community palliative care, which was developed with patient and carer consultation, is increasingly being used to help practices plan and deliver needs-based palliative care, and, in some areas, this is being extended to cancer care earlier in the illness.\(^10,11\) A national guide to good practice is available.\(^12\) There is, however, little research evidence regarding current patients’ and carers’ views on which interventions in primary care would be most helpful and how they would wish to see cancer registers used.

The key question concerns how primary care can best support cancer patients. Using an action research framework, we set out to formally involve patients with cancer and their carers in designing how, throughout the illness trajectory, they would like to be cared for in the current context of cancer register development in primary care.

**Methods**

*Methodological approach*

Action research describes, interprets and explains social situations while executing a change intervention through partnership between researchers and participants.\(^13\) It therefore delivers more than a traditional, descriptive qualitative study. We selected an empowering and professionalizing model of action research, as we aimed to work collaboratively with patients, carers and professionals, to develop shared understandings of key issues and to develop services with optimal utility and acceptability.\(^14\) Working with these key stakeholders as co-researchers ensured that the perspectives and expertise of patients, carers and professionals were all influential throughout the research and development process. We used qualitative methods of data generation in order to seek in-depth understanding of experiences, views and needs in an area where there is little research evidence. We sought to produce generalizable findings, both theoretically and methodologically, which would be of use instrumentally in particular practices and programmes, and also conceptually in the wider development of cancer care in primary care.

**Sampling**

Since we were using a community development approach, the main criteria for inclusion were that people had recent experience of cancer as a patient or carer and were motivated to participate.\(^15\) Using the regional cancer network database, we identified 15 people who had previously expressed an interest in taking part in research. They were purposively selected to cover a range of cancers, ages, stages and social settings. We sent them information and an invitation to join an ongoing discussion group for as long as they wished. Eleven people replied, and after arranging meetings with them to outline the project, we established two patient and carer groups, one based in the south-east of Scotland and one in the south-west. If they were too unwell to attend a meeting, participants were offered a variety of ways of continuing to contribute to the group—for example, e-mail or telephone. As some participants in the groups died, remaining group members decided whom to recruit and how, in order to best meet the developing aims of the study. This permitted discussion around all stages of the cancer trajectory. In total 18 members contributed (see Table 1).

We also conducted interviews with 16 professionals involved in cancer care, again seeking a broad range of experience and views from different perspectives. We included ‘grassroots’ and strategic perspectives; GPs, community nurses, senior nurses in palliative care, primary care managers and Macmillan General Practice facilitators.

**Data generation**

The two discussion groups each met monthly over 10 months. MK, a social scientist with experience of working with voluntary groups, and SH, a patient-involvement worker, facilitated the groups. Initially the members discussed their own experiences of cancer care. Feedback notes from each group were circulated to both groups, and to the project steering group, to build up a dialogue between them. As relevant issues began to emerge, the groups also considered the findings from the interviews with the professionals and suggested new questions for subsequent interviews, such as the acceptability and feasibility of contacting patients around diagnosis. Concurrently, the groups examined a number of strategic documents such as The National Cancer Alliance’s Teamwork File, The Macmillan Cancer Relief Principles of People-centred Care\(^16\) and the Gold Standards Framework documentation\(^17\) that served to contextualise the issues they, and the professionals, were raising. As a care framework of key times and issues began to develop, later meetings discussed how the main issues could best be addressed, by whom, and what the main aims and outcomes of care might be.

**Analysis and ethics**

The discussion groups, interviews and field notes were fully transcribed and entered into the software package Nvivo. They were analysed as the groups continued, according to the research questions and for important themes that were emerging, and for how these might best be addressed. Interim findings were discussed with all groups, lay and professional, including the project
steering group. As the groups continued to meet, this iterative and dialogic process continued and expanded. Thus, all participants enriched the analysis and tested its claims.18,19 We paid much attention to ensuring that all participants renewed their consent on every occasion.

Results

The members of the patient and carer discussion groups designed a comprehensive framework detailing their views and preferences about cancer care in primary care throughout the illness trajectory. They were empowered by the action research process, and several have gone on to contribute to other service users’ initiatives. The key issues that professionals identified are summarized in Box 1. These focused on communication between primary and secondary care, out-of-hours problems, carer support and access to specialist advice. These were debated within the discussion groups and the steering group, in order to decide if and how they could be incorporated into the care framework. The group members gradually identified five key times in the cancer trajectory, and five major issues of concern, and affirmed a pivotal role for members of the primary care team in supporting patients with cancer and their carers. The groups developed a cohesive framework for cancer care in primary care, which took the form of a grid covering these key times and concerns. At each key time in the cancer trajectory, it was suggested that these major areas of concern should be explored by clinicians for typical issues that may be present as the illness trajectory develops (Box 2). By working through each grid in the matrix, discussing what the main problems were and how they might be addressed, the groups gradually developed a checklist of suggested interventions across each key time and for each care issue; for example, the provision of information about clinics and tests at diagnosis, proactive contact with primary care staff when treatment finishes and the offer of appointments for carers at any stage. Detailed checklists were drawn up for each time according to the matrix. We now summarize these issues according to the illness stage, and show their most important recommendations for primary care management at each stage (Box 3).

**Time 1: Issues around diagnosis—‘You feel so alone’**

Those patients who had received information and support from the first suspicion of a cancer diagnosis affirmed its value. Gaining a diagnosis and deciding...
on treatment was an often lengthy journey. They described problems such as how hard it is to take in what one is told, how alone one feels, how difficult it is to know how to tell other people and being in shock.

Researcher: Is there a particular time when people need support?
Mr H: The minute they’re told!
Researcher: Right! So, start at the beginning. What do people need then?
Mr G: Information.
Mr H: Information.
Ms F: There’s no doubt about it. Information. Given in the right way. Given in a way a patient can understand.

East Discussion Group: Session 1

Members spoke of the perils of easy access to information on the Internet without expert guidance or quality control, feeling that they needed personal contact, and information tailored to their particular situation. In addition, people welcomed help in preparing for key consultations.

Ms. F: Yes, really you need someone to help you prepare for all these meetings, so that you know what to ask and what to say, to get the most from them. You need someone to sit with you, face to face, especially at first.

East Discussion Group: Session 2

Time 2: Issues during treatment—‘There’s so much to do and think about’

This was another difficult time, when support from familiar members of the primary care team would be particularly valuable.

Mr. K: I mean did no one phone you at all? I was appalled that you were on your own, and no one was helping you, and you were in a very bad way.
Mrs. J: I could hardly get up for a drink of water, you know. Towards the end of the chemotherapy I just felt worse and worse and was being sick all the time, but nobody seemed to bother.

East Discussion Group: Session 2

At this stage the main needs were help with deciding which treatment to have (if any), how to deal with the side effects of treatment, support and advice on transport difficulties, childcare arrangements and employment issues. Problems caused by poor information
flow between the various services and sectors involved, such as lost notes, missed appointments and mixed messages from different professionals all added to people’s distress.

Ms B: Cos that’s what you worry about the most—is really leaving everything, and if you know it’s being sorted out, you can get on with getting your treatment.

Ms D: I think it’s not just a question of going somewhere new, for your treatment it’ll be leaving the children and things.

West Discussion Group: Session 8

In particular the groups felt that primary care staff might have both a better knowledge of the patient/carer and their wider social and illness situation, and more time to listen and talk through issues, than hospital staff.

Time 3: Issues after discharge—‘A black hole’

Feeling abandoned after a time of regular contact with specialist staff, yet in great need of psychosocial support, made this a very vulnerable time. This is a time when, “it all catches up with you” (Ms C). Group members described worries about facing the future as a person who had been treated for cancer, fearing its recurrence, and losing confidence in their body image and self-identity.

Ms F: It was like a black hole! I remember being discharged from hospital, and for the first few months it did feel like a black hole.

Mr H: This is where your GP practice should kick in.

Mr G: Yes, when your treatment is finished, the specialist should tell them you’re home and suggest they check up on you.

Ms F: That’s such a vulnerable time. I think that was when I felt unable to contact anyone myself. But I would have really wanted someone to contact me.

East Discussion Group: Session 3

People felt that patients should be encouraged to contact the practice with any further queries.

Mr N: At the time that you part company, so to speak, that’s when you (professionals) need to make sure they (patients) know where to come back if they are experiencing difficulties.

Ms F: That’s right.

Mr N: Have a contact person number or whatever, so that they’re not left in limbo.

East Discussion Group: Session 7

Time 4: Issues at recurrence—‘The second time is worse’

Recurrence was worse than the initial diagnosis, yet often the erroneous assumption was made that the patient would know what to do and would cope well because they had been through the experience before. In fact, the group members felt this time was worse because of knowing what the treatment would be like, and described a struggle each time to return to the cancer world—even for check-ups.

Ms V: I would think that’s probably one of the most frightening situations when you’ve thought you’ve beaten it, and you suddenly realise you’re going to have to go through that all over again and maybe not make it next time around.

East Discussion Group: Session 4

Another major issue was deciding when to stop treatment, how to balance hope with realism and longer life with quality of life. There was sometimes a perceived conflict between what the patient wanted to do and thought they should do, with the advice and expectations of family and professionals. How to discuss treatment decisions with family and friends was a major challenge. Support for carers was also important at this stage.

Time 5: Issues in the final weeks and bereavement—‘It needs to be flexible and personal’

Flexibility and an ability on the part of professionals and services to respond quickly to rapid changes were required, and the capacity to fit in with family and different personal ways of coping. Being able to provide good care at home was appreciated by many.

Mr A: When they’re getting near the end of their life, sometimes you’ll have family that’ll come—they’ll come for so long, and then they have to go back to their children or their work or whatever, so you need the support to be flexible to fit with that.

West Discussion Group: Session 6

At all stages in the illness, realizing that their individual experiences of care and support were hugely variable, the group members affirmed that care and support should be offered equitably to all, not just to those with a certain GP or nurse.
Should the frameworks start from diagnosis?

Group members learnt from the interviews with professionals that some professionals were concerned that starting proactive care from diagnosis would both distract attention from those who are actually dying, a special group with special needs, and also unnecessarily make people into active patients. The group disagreed with these concerns. Rather, they felt that starting from diagnosis would improve care at the later stages, because early contact would save much anxiety throughout the journey, through the knowledge gained and relationships established, and that a diagnosis of cancer automatically makes you into a patient: life is never the same again. The group felt that such professional concerns were not patient-centred. Some people felt it perhaps reflected professionals’ concerns about phoning people at home, and a fear of embarrassment on both sides. In their opinion, the best approach was for the GP or community nurse to make contact and ask the individual how much contact and follow-up they wanted. This would make it clear that a partnership approach to care was welcomed and would encourage people to ask questions, rather than worrying at home or fearing they would be seen as malingerers. That kind of anxiety would disappear if staff were proactive in making contact. Concerning who should contact the patient, skills and attitude were considered more important than role. It needed a friendly, caring tone, positively inviting one-to-one contact. The cancer register can offer practices a useful tool for managing these patient contacts.

Discussion

Patients and carers believe there is an important, and unique, role for primary care staff throughout the cancer trajectory, starting from diagnosis, in offering information and patient-centred, holistic care to everyone on their practice list. Some professionals, however, fear that early proactive contact might be unwanted and tended to consider such an approach only when death was more imminent. The patients and carers did not expect primary care staff to be experts in cancer, but valued their ongoing support. They focused on issues of process and relationships, while professionals focused on symptom control and specific outcomes.

The study has several limitations. The number of participants was small and all based in southern Scotland, although they were registered in different general practices. Ethnic minority groups were not represented. Participants were partly self-selected, relatively young and largely in remission, although some had active disease, with five dying during the project. Their expectations and experiences of care in Scotland may be different to other countries, especially with dissimilar primary care systems. We shared and explained specific documents with the patient groups, to inform them of current developments. This might have affected their thinking, although some issues such as pain control that were central in such professionally led materials were not embraced.

The strength of the study was its longitudinal qualitative approach that allowed relationships to form among all the group members, and opportunities to return to discuss a subject in depth, and to refine and reflect on suggestions. Participants were co-researchers and co-analysts, and the problems identified and solutions proposed were as much their work as the researchers’. They presented findings at various meetings and helped with publications for a variety of audiences. Areas of concern that might have been missed in less patient-centred methods were explored, and proposals were made for integrating them into the framework in ways acceptable to patients, carers and professionals. The longitudinal nature of the discussion groups allowed new members to be recruited as some died, which enabled them to consider all stages of the cancer trajectory, including terminal care, and the work of the group to continue. Our method allowed generalizable findings, both theoretically and methodologically, to evolve that are currently being implemented in selected practices across Scotland. The method also permitted conceptual development of cancer care in primary care while working in partnership with patients and carers, and is potentially transferable to patients with other progressive and chronic illnesses.

These five times and similar themes have been described before from the professional perspective, and in a patient consultation exercise. Patients and carers believe there is an important, and unique, role for primary care staff throughout the cancer trajectory, starting from diagnosis, in offering information and patient-centred, holistic care to everyone on their practice list. Some professionals, however, fear that early proactive contact might be unwanted and tended to consider such an approach only when death was more imminent. The patients and carers did not expect primary care staff to be experts in cancer, but valued their ongoing support. They focused on issues of process and relationships, while professionals focused on symptom control and specific outcomes.

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These five times and similar themes have been described before from the professional perspective, and in a patient consultation exercise. This research study supports these times and issues as being vital to patients, but additionally reveals their particular relevance to primary care. Most patients would like proactive contact across these stages, and see primary care as ideally placed to provide this. The focus on maintaining relationships and the importance of how the care is provided differs from most professionally developed frameworks, which tend to focus on specific outcomes such as symptom relief and ‘quality of life’. Contacting patients signals a willingness to offer support, a valuing of the person, which will help patients retain a sense of autonomy and worth.

Implications for clinicians and policy makers

Cancer patients consider that continuity of care and an individualized approach are important. This matrix (Box 2) could be used for care planning at different stages in the illness and might ensure that cancer registers are used to drive patient-centred care forward, and not merely to audit patient numbers and contacts. Box 3 summarizes key recommendations for
professionals to consider according to the illness stage, integrating the five themes. Patients may hesitate to call for help. Patients with cancer like a guide to the unknown, a guide who will listen and explain about the course of the illness and treatments, respond quickly to whatever urgent need is felt, support them and possibly prepare them for death.

Ms F: Just as when you are pregnant you need a midwife, so you need a midwife later when you are facing death.

Conclusions

Patients with cancer may see many different staff and services. What is lacking is a constant, known clinician with a holistic approach. Patients and carers agree that proactive and ongoing personal contact should be the central plank of cancer care in the community. They are able to develop frameworks of care that integrate their own views with policy documents and professional perspectives. We have identified an effective method of patient and carer involvement in the development of care planning in the community.

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