Implementing a service users’ framework for cancer care in primary care: an action research study

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Background. We previously facilitated the development of a service-user designed framework for providing proactive care for people with cancer in the community.

Objective. To validate this framework in clinical practice.

Methods. We used an action research approach, helping five diverse general practices in the South of Scotland to implement the care framework. The process and outcomes were evaluated using in-depth interviews (18 patients and their family carers and 49 health professionals), participant observation and an ongoing dialogue between the practices, the research team and the original user groups.

Results. Practices implemented the framework in a variety of ways. In general, they used their own customized cancer register to improve communication within the practice and began to offer proactive care from a diagnosis of cancer, not just when the disease became advanced. Local innovations included an intranet-based register, information sheets and regular multidisciplinary meetings. Patients, family carers and professionals suggested that the framework had helped achieve continuity of care, teamwork, proactive care and improved support and information for patients and carers.

Conclusions. Proactive personalized care can be improved in primary care for patients with cancer and their family carers through flexible adoption of a framework to embrace key characteristics of good care, as perceived by patients and carers, throughout the illness. Practices can achieve this by choosing approaches suited to their setting, experiences, structure and resources.

Keywords. Primary care, family practice, qualitative research, action research, cancer register, patients’ views, community.

Introduction

In 2004, there were 342 000 new diagnoses of cancer made in England, and primary care is generally involved from diagnosis to death or survivorship\textsuperscript{1}. Only 22\% of cancer deaths in the UK occur at home, and this has fallen since 1998, despite more community palliative care services\textsuperscript{2}. The low home death rate masks the fact that people with cancer generally have more frequent contact with primary than secondary care, and much palliative care is provided in the community, even if patients are eventually admitted to hospital or hospice to die. In the community, resources can be limited, care has little evidence base and communication problems within the practice, with out-of-hours providers, with secondary care and with social care are common\textsuperscript{3}.

Detailed clinical guidelines exist in primary care for most progressive chronic illnesses, and their implementation is funded to encourage adoption\textsuperscript{4}. Strategic policy and practice documents advocate community-based cancer care where practical and effective\textsuperscript{5,6}. Evidence-based frameworks for proactive cancer care in primary care are needed. The Gold Standards

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Framework (GSF) was developed to improve co-ordination of supportive and palliative care. It has now been introduced in over 40% of English and 75% of Scottish general practices, and its use is being encouraged earlier in the cancer trajectory. However, little research evidence relating to outcomes and acceptability to patients and their carers has been published.

This paper reports the findings from the second stage of a project to develop cancer care in the community. In the first stage, two groups of current cancer patients and carers met monthly for 10 months to identify the times and issues that were most problematic in the course of their illness, and propose a care framework, based in primary care, to address these. Their discussions were informed by relevant policy documents and interviews with professionals involved in cancer care. The second stage, reported here, comprised piloting and evaluation of this service-user developed framework of care in five general practices. It is a necessary preparatory work for an intervention trial and equates with stage two of the MRC framework for complex interventions. Diverse primary care settings, in a part of Scotland yet to adopt the GSF, were chosen to evaluate the effect of the framework on care from the perspectives of patients, family carers and professionals.

Methods

Methodological approach
In line with the study’s aims, we employed an action research approach as this is a group of research methods designed to promote action and change. Its key feature is a cyclical process between action and critical reflection so that data collection and interpretation are continuously refined in the light of the understandings developed in earlier cycles. It is an emergent process which takes shape as understanding increases and an iterative process which leads towards a better understanding of the area under investigation. Action research uses mainly qualitative methods because it is concerned with participants’ meanings and understanding. It is usually participative since change is more easily achieved when those affected are involved in the process.

Development of locally appropriate interventions
We sought maximum variation within the five participating practices, and so recruited practices with a range of list sizes and locations, taking one practice from each of the four local health regions and a second practice from the largest region (Table 1). The researcher, a social scientist with experience in user involvement and action research, discussed with each primary care team the key issues found to be important to patients and carers in stage one of the study, including the service-user framework the patients had constructed. See Boxes 1 and 2. We then encouraged each practice to develop interventions based on the user framework that were relevant to their local context.

We provided modest funding (£1200) so that each practice team could give one staff member dedicated time to lead on the project.

Evaluation
We generated data at each of the practices in turn using the same cyclical approach:

(i) Semi-structured interviews with key members of the primary health care team at the beginning of the project, concerning their current care for patients with cancer, and any barriers and aids to introducing more and better-managed care. These also served to highlight areas of the user framework that were already being addressed by the practice.

(ii) In-depth interviews with three to four patients with advanced cancer and their family carers at home, around 6 months after the local interventions were in place to explore their perceptions of care and the extent to which key aspects of the framework were being delivered. We sought to interview a diverse sample of patients whose care might have been affected directly by use of the framework in their practices and asked them about both the organization and quality of their care.

(iii) Interviews with a range of primary health care team members at the end of the project to discuss the process and outcomes of implementing the framework.

Data were also available from researcher field notes and a progress diary kept by the lead member of each primary care team.

Analysis and ethics
The interviews were recorded, fully transcribed and entered into the software package Nvivo by MK, along with her field notes and the local research diaries. We conducted the data analysis in a variety of ways by practice, all patient and carer data and illness stage. The thematic analysis sought to understand if and how the framework might have impacted on patients and carers, in addition to changing organization of care. Interim findings were shared and developed in discussion with the user advisory group that had developed the framework originally, the staff at each practice and the project steering group. As all these groups continued to meet, this iterative and dialogic process continued and expanded. Thus, all participants enriched the analysis and tested its claims. Ethics and
management approval was gained from the relevant organizations. No data attributable to individuals were shared among participants to maintain confidentiality.

Results

Five practices were recruited sequentially during a 12-month period from July 2004, with interventions taking around 6 months to implement and evaluation continuing for around a year. We conducted 18 patient and carer interviews and 49 interviews with staff at the five pilot practices. Table 1 summarizes the practice characteristics, the three main issues identified by each practice, and their main interventions. The need for proactive, anticipatory care, as opposed to reactive care, was a common theme. Staff at all the different practices thought the fact that patient and carer groups had developed the framework was important in giving a wider view of patient perspectives on which to base developments in their own practice.

Having that studied before-hand to base your thoughts on is very very important for us. Practice 3 GP2

Having access to the opinions of the ongoing patient and carer groups led to a number of patient-centred changes and refinements in the specific interventions, e.g. in the wording of the information sheets and in the timing of the phone contacts.
Implementing a service users' framework for cancer care

**Box 2  Recommendations for patient-centred care by stage of illness**

**Around diagnosis and staging**
- Establish good relationships and identify ongoing arrangements
- Help prepare for hospital appointments and tests
- Offer personalized information and support
- Offer to discuss treatment plans after hospital consultation
- Understand the family situation

**During treatment**
- Maintain contact through the named doctor or nurse
- Listen, talk through treatment options and side effects
- Consider the psychosocial impact of the treatment
- Consider and support carers
- Send information to out-of-hours services

**After discharge from initial treatment**
- Routine follow-up call from primary care soon after discharge
- Information on symptoms to look out for, and what to do, side effects
- Discuss adjusting to life after treatment—relationships, employment, loss of confidence, body image and support groups
- Offer directions to local and national information and support groups
- Encourage contact with the practice if further queries arise

**At recurrence**
- Let the patient express their main concerns, whether physical, social psychological or existential
- Help to prepare for appointments; advise on what will happen, what to ask, tests
- Help with social and practical issues: look at the whole picture
- Respect patients' personal values and choices
- Consider offering appointment to support carers

**Last weeks**
- Keep in regular contact
- Be flexible and responsive to different patient and family ways of coping
- Frequently review and co-ordinate care at home as appropriate
- Help patient and carer raise difficult end-of-life issues
- Remember to update out-of-hours services frequently
- Provide bereavement contact to debrief on issues and for carer support

**Practice 1**

This small rural practice decided to concentrate on the issues of communication, information and equity highlighted by the framework and its emphasis on providing proactive care from diagnosis to bereavement. It addressed equity by establishing regular team meetings to discuss the care of all patients on the cancer register. This also improved communication and a sense of team working within the practice and highlighted the practice’s key role in caring for any patient with active cancer. External professional expertise was brought in to some of the team meetings and new knowledge developed. Professionals felt the meetings were effective in providing continuity and enhancing proactive care.

I think, for me, the thing is that you probably get a sense of reassurance that people aren’t falling through the gap. And the other thing is that you’ve got to be ruthless about time keeping, we take an hour, and we try to make the last 5 or 10 minutes on a new topic, or a bit of information such as change in syringe drug policy. GP 1

A handover form for the out-of-hours service was developed and used for an increasing number of cancer patients. However, the third intervention, a printed information sheet developed by the practice to be offered to the patient and/or family carer around diagnosis, was rarely used, nor did the idea of offering separate consultations for carers prove popular with professionals. This highlighted differences in patient and professional expectations, with some clinicians expressing concern about the appropriateness of these interventions, and apprehension about issues of confidentiality, although acknowledging the importance of supporting both patient and carer. In general terms the practice team felt:

A successful outcome would be for patients and carers to feel less fearful, alone and vulnerable. Practice Nurse.

Patients in this practice felt well supported from diagnosis and that communication was sensitive and helpful.

Then I came home and on the Monday morning following my GP came in here and he came in to see that I was alright and chased me up and see if there was anything I needed, he says I’ll keep in contact, I’ll come in and see how you’re doing and he was in two or three times and the local practice nurse came down as well. Patient 1

The GP had to tell us the news [that is was cancer] She was very good to us and has been ever since. Patient 3

**Practice 2**

The main intervention developed in this larger practice in response to their main issues (as listed in table 1) was an intranet register, based around the five key challenging times identified in the service-user framework, and including a proactive contact from the practice at each time point (Box 2). The register was updated weekly by all primary care team members, and follow-up was monitored (Box 3). This system also improved team working and communication, since it required input from all the team, and was part of the routine weekly work, with regular electronic reminders and updates. In addition, it standardized and ensured regular and equitable contact with all patients on the register. The practice felt that there were too many professionals and patients involved to make regular face to face meetings a practical option for their practice.
Certainly in a big practice it (the Intranet register) helps with communication between district nursing staff and the GPs ... and it’s a prompt as to whether we’ve notified the out-of-hours service about palliative people etc so, it has its uses. GP 1

I think that it certainly has stopped patients slipping through the net. I think it has sharpened our act as regards to framing questions and it’s picked up those that have been missed. GP 2

By using the register the way we’re doing, you can see if things change, if people suddenly go from being treatable to being palliative – what paper work has been done, what interventions we need to do, so it’s much clearer. District Nurse

Now we’re making contact even if we don’t hear from people so I am sure they appreciate that. GP 3

Patients and carers particularly valued being kept well informed about their care and appreciated feeling that there was an active plan in place for them, which the intranet register facilitated.

I’ve had good care with them, you know they’ve kept me sort of informed about everything that was going on. “So really, you are worried yeah, but you know exactly what was going to happen to you. Patient 3

**Practice 3**

This urban practice thought the framework highlighted the need in their situation to provide ongoing support from the diagnosis of cancer and especially after initial treatment. The main intervention was the development of a cancer care protocol and a practice information sheet to be given out at diagnosis.

I think the key thing that we’ve uncovered and we’ve recognised is to provide patients with a focus on one or two people in the practice who they feel comfortable to come to to co-ordinate their care. GP 2

This practice had a similar system for supporting patients with asthma and diabetes, and so this was a familiar way of working for the team. The cancer care protocol was developed and approved by all the team, posted on the practice intranet, and set to be reviewed annually. It covered the times and issues identified in the service-user developed framework.

It seemed fairly common-sensical. It was easily approved because we recognised that we were either doing it already or we have the expectation that of course that was sensible and appropriate care. I mean, we are going paper-lite soon so the more PC-based reminders and protocols that can actually be utilised from the screen the better. That’s what we are trying in different areas. GP 2

Professionals reported that patients benefited from the proactive approach and knowledge of resources that the protocol engendered.

I think there may be ways in which we can help people that they have maybe not known about or not really felt it was important enough, that’s where I think really the benefit of the pro-active care comes in. …because in the surgery, especially just in ten minutes will be very symptom focussed and it might be that the social side hasn’t been addressed as well as it could be, we’ve now got a resource pack that’s got all the different contacts. Practice Nurse

However, there was also evidence that the protocol was not being used by all the team, perhaps because there was not a frequent enough audit or a requirement for this, and professionals sometimes forgot to hand out the information sheet.

Patients at this practice noted supportive personalized care instigated from diagnosis of cancer, by both community nurse and GP:

The nurse I got first time back before I started the chemo, lacked that manner—she definitely dealt with me just as another blood sample for whatever. Patient 1

The doctor’s behaviour was also noted to change at diagnosis of cancer.

He never visited me or phoned me or anything like that at that point it was just if there was like

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**Box 3** *Database fields in intranet register*

<table>
<thead>
<tr>
<th>Name</th>
<th>Date of birth</th>
<th>Usual GP</th>
<th>Diagnosis</th>
<th>Date of diagnosis</th>
<th>6-Month review</th>
<th>Therapy started</th>
<th>Midway contact</th>
<th>Therapy complete</th>
<th>Completion contact</th>
<th>Palliative register</th>
<th>DS 1500</th>
<th>Analgesia</th>
<th>Pain audit</th>
<th>Out-of-hours note</th>
<th>Date of death</th>
<th>Place of death</th>
<th>Date of debrief meeting</th>
</tr>
</thead>
</table>

...
infection or something. Then (later) doctor was very thorough and he did that nearly every month I got a call from him and it got to the point “oh yes routine” sort of style ... He said “it doesn’t matter how small, tell me”... and he marked it all down and asked me the next time—you know if I was still bothered with that or—nothing was trivial and I thought that was brilliant. Patient 4

When asked what they found most helpful or useful in a person or a service, one patient highlighted how effective the team was in providing information, a key objective adopted in this practice:

I just thought the actual doctors and nurses here at the practice, as I say they explained everything to you, step by step, and they make sure that you know what’s going to happen to you and prepare you. They are really friendly and supportive and explained everything to you which I think’s really good because it’s what you don’t know that frightens you. Patient 3

**Practice 4**

This practice realized they should be more aware of the needs of cancer patients and their carers generally. So discussion about the care of cancer patients was added to the regular multidisciplinary clinical meetings. Handover forms for out-of-hours care were developed and utilized. The practice appointed one of its community nurses as a ‘cancer care co-ordinator’ to establish and run a practice-based support group and oversee co-ordination of the care of patients on the cancer register. This post lapsed, however, due to staff changes, so the practice-based support group never started. Lack of enthusiasm and commitment from the general practitioners to this nurse-led intervention, and financially driven competing priorities in other clinical areas, meant it failed when the key advocate left the practice. No patient interviews were undertaken at practice 4 as the key initiative was not sustained.

**Practice 5**

The main interventions here were the development of a computerized cancer register and a structured grid to co-ordinate patient follow-up, based on the service-user framework, along with an expanded out-of-hours handover form, and a system for its regular review, facilitated by the practice manager checking dates and sending out reminders. For a single-handed practice with several part-time staff and locum GPs, they felt this system provided a more effective way for information to be shared among the team than their previous informal structure. Some aspects of this care model informed non-cancer chronic disease management.

I think small city-centre practices are much different. I think that is where I maybe struggled with the Gold Standard Framework ... with such small numbers of cancer patients, it just felt “Oh Gosh, is this of value?” We have so much more chronic disease management so looking at them as another group with a chronic disease that you monitor in a certain way is fine because that is what we can do. GP 1

The practice manager thought the framework improved patient care:

The QOF was more a data recording exercise. It wasn’t about patient care as such... it didn’t have anything about carers or preferred nurses. One of the things we have been very aware of is to always know who the next of kin and carers are so that we have those emergency contacts especially for when people get frailer. The spin-off is to other groups of us having this information; we use it for other people as well because we are aware of it and its importance. When people are really ill, you know, we need to know who their carer is. We need to know what support they are already getting from social services, district nurses, whatever. Practice manager

Patients interviewed felt well supported by their practice team and confident that all members of the team communicated with each other and were aware of them and their condition. They saw the GP or community nurse as their key supporter throughout their illness.

I got a lot of back up from them you know I knew they were at the end of the phone I mean the nurse said to me you know if I had any worries just to give them a phone and there would always be somebody there for me to talk to. Patient 2

One patient interviewed valued an invitation to consult at any time:

Yes I have got an open sort of thing like that open surgery thing that I could go down anytime you know that helped a lot. Patient 1

**Discussion**

The framework was found to be valid and useful when implemented in clinical practice to develop locally relevant care. Most practices identified internal communication issues as main priorities, especially in ensuring that no patients ‘fell through the net’. All practices also improved communication with out-of-hours services
and started to offer proactive care from a diagnosis of cancer. All the professionals interviewed affirmed the validity of the five key stages and the five key issues in the framework in their own practices and considered a flexible approach to identifying specific interventions realistic and beneficial. There was resistance to any centrally imposed, ‘one size fits all’ model of care. Patients knew less about the practice initiatives, but interview data from patients and carers revealed positive outcomes in keeping with the initiatives.

The interventions that worked best were those that fitted well with a practice’s usual working pattern, that had commitment and encouragement from the GPs, were undertaken as a whole team effort and were monitored and followed-up. This is in keeping with innovation theory where innovations that work are ones monitored and followed-up. This is in keeping with innovation theory where innovations that work are ones that fit well in the situation, are seen to be of benefit and have buy-in from key players. No one model seemed best. Rather it was a case of taking the general times and principles highlighted by the patient-derived framework and turning them into a context-specific model. Although smaller practices may be able to hold regular meetings, larger ones with more staff and larger numbers of cancer patients to consider may function better via electronic communication. Most practices felt that it was important to start with the overall framework and then to develop specific interventions from it over time and build incrementally on each success, rather than tackling the whole framework at once, and this process continues. Financially driven competing priorities may hinder development of cancer care in primary care as seen in one practice.

**Strengths and weaknesses**
A strength of the action research design was that the research team worked with key participants to identify problem areas, propose solutions and test and evaluate these. The study has several limitations. Only five practices were involved, they were enthusiastic about improving their care for cancer patients and were willing to commit time and a lead staff member for this service initiative. No minority ethnic groups were represented. Only a few patients were interviewed in each practice, and they appeared to receive proactive care, but it was hard to assess if their positive experiences of good communication related specifically to the recent interventions. As this was a formative study, not a randomized trial, we have no direct comparisons, and our intervention was in the context of other initiatives in primary care to improve cancer patient care. We did not measure specific outcomes such as better symptom control or emergency admissions. The study intervention was of limited duration—and longer term data are needed to indicate whether the interventions are sustainable. Nevertheless, we consider that the finding that practices can develop locally appropriate patient-centred care if motivated and supported with modest resources is generalizable.

**Comparisons with previous studies**
The study confirms, through patients experiencing a patient-developed framework, that most patients appreciate anticipatory care from diagnosis by a known individual, rather than reactive crisis care by whoever is available. The focus on good communications within the practice and with out-of-hours providers and the process of care is similar to previous patient-interview studies. It differs, however, from most professionally developed frameworks, which tend to focus on disease management and on specific health outcomes such as symptom relief and ‘quality of life’.

**Implications for clinicians and policymakers**
Practices can use this framework to review and implement what they think is locally appropriate anticipatory cancer care from diagnosis through to bereavement. Practices currently using the GSF for palliative care can use this new framework to help them use the GSF approach from earlier in the illness trajectory. The $5 \times 5$ matrix (Box 1) can be used as an overview for clinical care planning at different stages of the illness. Box 2 summarizes key areas for professionals to consider with patients as the illness progresses, and this guidance is now incorporated in the GSF guidance in Scotland (http://www.gsfscot.nhs.uk/). The areas we suggest be raised around the time of ‘cancer recurrence’, for example, are suitable for patients on practice Supportive and Palliative Care Registers. Advance care planning could be triggered by using the key times. Barriers to wider dissemination of structured cancer care in primary care include lack of resources in this clinical area compared to chronic disease management generally. Modest backfill funding as provided in this project may be sufficient if the development is considered relevant and practical by the staff, and an external facilitator would not be necessary.

**Implications for research**
Larger intervention studies are indicated to assess the effectiveness of providing locally designed anticipatory care for all cancer patients. Studies from diagnosis in some practices and from advanced illness/metastatic disease in others may be appropriate. Key outcomes for patients, carers and professionals must be chosen and assessed, necessitating mixed method evaluation of these complex interventions. Such studies must acknowledge and build on current developments such as the GSF. The practice registers of patients with cancer, and also registers of patients in need of palliative/supportive care, can facilitate this and help with implementation.
Conclusions

No one model was developed across the practices. Practices were reflective and thoughtful as they grappled with constraints in their own local situations, were innovative in adopting new approaches and showed flexibility and a willingness to provide the care patients and carers wanted from them. Primary care can play an increasingly important role throughout the cancer journey in offering continuity of care and information that is patient centred and holistic. Following this feasibility study, and building on lessons from the GSF initiative, definitive intervention studies are needed in primary care to test when and how it is most appropriate to identify patients and then how best to deliver practice-based proactive care.

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Declaration

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