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Patients' needs following colorectal cancer diagnosis:

where does primary care fit in?

Abstract

Background

Colorectal cancer is the third most common cancer in the UK. Patients with colorectal cancer spend most of their time in the community, but the role of primary care in their management and follow-up is unclear.

Aim

To explore colorectal cancer patients' experiences of psychosocial problems and their management in primary and specialist care.

Design and setting

Longitudinal qualitative study of participants recruited from three hospitals in the west of Scotland and interviewed in their own homes.

Method

In-depth interviews with 24 participants with a new diagnosis of colorectal cancer, and then follow-up interviews 12 months later.

Results

Participants' needs following a diagnosis for colorectal cancer included physical, psychological, and social issues. GPs played a key role in diagnosis, after which they were less involved. Participants valued GPs making unsolicited contact and offering support. Participants described being well supported by clinical nurse specialists who are expert in the illness, and who provide continuity of care and psychological support. A year after diagnosis, when there was less contact with GPs and clinical nurse specialists, participants still faced challenges associated with the ongoing impact of colorectal cancer.

Conclusion

While some patients enjoyed straightforward recoveries from surgery, others experienced longer-term implications from their disease and treatment, particularly bowel-function issues, fatigue, anxiety, and sexual problems. The potential for primary care to contribute more to the ongoing care of colorectal cancer patients was identified.

Keywords

colorectal neoplasms; follow-up studies; primary health care; qualitative research.

INTRODUCTION

Colorectal cancer is the third most common cancer in the UK, with 38 600 new cases diagnosed each year. Five-year survival rates have doubled over the past 40 years; around half of those diagnosed will survive for more than 5 years, and those diagnosed at the earliest stage have an over 90% chance of surviving for more than 5 years.¹

Diagnosis and treatment (usually surgery with or without adjuvant treatment²) bring a range of well-documented problems with ongoing impact on a person's physical, psychological, and social wellbeing.³⁻⁶ Some problems relate specifically to colorectal cancer and its treatment (for example, bowel dysfunction); others are problems commonly seen following a cancer diagnosis (for example, psychological distress, fatigue).^{7,8}

Patients with colorectal cancer spend little time in hospital, and in countries such as the UK, they are primarily under the care of their GP and primary care team. In recent years, specialist care has included input from clinical nurse specialists, whose role includes the coordination of care between healthcare settings, as well as the provision of advice, information, and psychosocial support for patients and their families.^{9,10} Current national guidelines related to

colorectal cancer recommend that all newly diagnosed patients should have access to a clinical nurse specialist from the point of diagnosis.^{2,11}

The role of GPs in the care of patients after a diagnosis of cancer is under scrutiny, partly as a result of the cancer care indicator within the general medical services contract Quality and Outcomes Framework,¹² and partly as a result of the survivorship agenda, which is relatively new to the UK,¹³ but established in North America in particular.¹⁴ Survivorship strategies are likely to include a shift in emphasis from specialist-based supervised follow-up to personalised care planning, self-management, and tailored support.¹⁵ Despite assertions that point to a central role, with specific expertise in facilitating access to high-quality specialist cancer care, management of comorbidities, and psychosocial care,¹⁶⁻¹⁸ the role of GPs in the care of patients after a diagnosis of cancer is not well researched.

It is timely to consider how patients perceive the role of the primary care team following a diagnosis of colorectal cancer. This paper reports the qualitative findings from a larger study that focused on quality-of-life issues for colorectal cancer patients.¹⁹ The qualitative arm reported here

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How this fits in

Colorectal cancer results in patients experiencing physical, psychological, and social challenges. Traditionally, ongoing care has been provided by specialists. This study has identified the potential for a greater role for GPs, in particular, managing digestive dysfunction, fatigue, anxiety, and sexual problems. Unsolicited contact from primary care is appreciated by patients.

sought to explore patient experience of colorectal cancer in more depth, and in particular their management by primary and specialist care.

METHOD

Participants for the larger study were recruited from hospitals across Scotland. Participants were eligible for inclusion if they had had a definitive diagnosis of colorectal cancer, and had commenced their initial treatment (normally surgery or, in non-resectable cases, palliative radiotherapy or chemotherapy). Participants were excluded if they were unable to give informed consent or, in the opinion of their clinical team, had a life expectancy of less than 1 month. A full description of the recruitment method and sampling strategy used has been given elsewhere.¹⁹ Participants for the qualitative arm were recruited by one researcher via three hospitals in central Scotland. Potential participants had indicated their willingness to take part in the qualitative phase as part of a questionnaire completed in the larger study. They were then approached by telephone, when the aim of the interview study was explained, and a suitable time for interview was arranged if they were still willing to take part. Written consent for this was obtained when they met with the researcher. The study sought to capture a wide range of experiences and, as such, a maximum variation sample was sought.²⁰ The sampling frame was informed by sociodemographic and clinical characteristics (for example, age, sex, socioeconomic status, level of coexisting morbidity), and participants were selected purposively to ensure adequate representation of patients across these attributes. Typically, qualitative studies do not include large numbers of participants,²¹ and the sample size was based on achieving a sufficient number to capture differences in patient experience. Interviews were completed when interviews revealed no new

ideas, experiences, or insights.

First-wave interviews were conducted by one researcher during 2006/2007 and follow-up interviews 12 months later by the same researcher. Initial interviews lasted about an hour, while follow-up interviews were generally shorter. Interviews were carried out in the participants' homes. All interviews were audiotaped and transcribed verbatim.

Twenty-four colorectal cancer patients undertook an in-depth interview within 3 months of diagnosis with colorectal cancer; 19 of these patients were reinterviewed 12 months later. Interview guides were developed prior to interview and included questions on the role of GPs, other primary care professionals, hospital specialists, and clinical nurse specialists; self-care; social networks; and input from families.

Two researchers independently read and re-read the transcripts, after which a coding frame was jointly developed. The raw data were coded thematically, following discussion on emerging themes between the two researchers and with the wider study team. Some key themes like 'patient experience of care' and 'patient need' were identified prior to analysis, based on the aims of the study.²² Additional themes, such as 'the role of the clinical nurse specialist', were identified from the data, following systematic and interpretative analysis. Transcripts were further read and coded to identify patterns, similarities, and differences in the data. Deviant (or contradictory) cases were actively sought in order to refine the analysis and ensure validity. QSR NVivo 2.0 was used to facilitate data retrieval and coding, analysis of themes, and systematic comparison (<http://www.qsrinternational.com>).

RESULTS

The sample comprised nine males and 15 females aged from 34 to 84 years, and included a range of Dukes stages (Table 1). Twenty-two participants had had surgery, one was receiving palliative treatment, and one was receiving chemoradiation while they attempted to lose weight to become fit for surgery.

It was not possible to re-interview five participants, as two had died, one felt too unwell to be interviewed, and two were no longer contactable.

Patient-identified problems

The problems discussed by the responders included physical, psychological, and social issues.

Table 1. Participant characteristics

Characteristics	Patients (n = 24)
Number of interviews	
1	5
2	19
Age at first interview, years	
≤50	5
50–70	12
≥70	7
Employment status	
Employed/self-employed	7
Retired	14
Unemployed	2
Looks after home	1
Dukes stage	
A	4
B	9
C	7
D	2
Missing	2
Sex	
Female	15
Male	9
Education level	
No formal qualifications	10
O levels/A levels	5
University/college degree	2
Other qualifications	7
Deprivation quintile	
1 (most affluent)	7
2	4
3	1
4	3
5 (most deprived)	9
Stoma	
None	19
Temporary	2
Permanent	3

Physical issues. Participants who had undergone surgery said they experienced ongoing digestive dysfunction problems, including reduced bowel control, faecal urgency, increased frequency of bowel movements, diarrhoea, constipation, and increased flatulence:

'I got it [surgery] done in June or something and it took right up tae December, January the start of January and up tae then I had more or less constant diarrhoea.' (male, age 81 years, interview 2 of 2)

Sexual issues were a problem for some, for example, the participant below, had been unable to achieve an erection since surgery:

'Also trying tae resume a sexual relation with my wife again which I found great

difficulty [with] ... I think we were getting to the age where, you know, it starts tae tail off a bit anyway your sex life eh it would be nice tae have it noo and again right enough tae have the option ... But definitely the operation has done something.' (male, age 55 years, interview 1 of 2)

Additional physical problems following surgery included physical fatigue, weakness, sleep difficulties, pain associated with adhesions, infected wounds, and wounds that were not healing.

A year later, most participants said their physical health had improved but physical issues persisted. Tiredness was the main ongoing issue, even into the second year after diagnosis:

'I just never been right since I had the operation. I havenae got any energy at all.' (female, age 64, interview 2 of 2)

'I was still tired and to tell you the truth I'm still tired, sometimes I'm very tired, I don't know what that's to do with but at the weekend there I just felt absolutely exhausted really. So I don't know whether that's normal or not, normal or what, I don't know. I'm abnormally, well at the weekend I felt I was abnormally tired, you know, I could hardly bring myself to do anything and it just sort of reminded me of the way I was when I came home from hospital, you know.' (female, age 67 years, interview 2 of 2)

Digestive dysfunction issues also persisted and there was discussion around diets, which had been altered to avoid constipation, diarrhoea, wind, and abdominal pain. Sexual issues still posed problems. One woman said intercourse had become painful, something she had not discussed with any health professional.

Psychological issues. Uncertainty emerged as a key theme: uncertainty about what lay ahead, often in terms of the effect and effectiveness of treatment. Uncertainty was described about surgery, (surviving surgery, the effectiveness of surgery, complications with surgery, whether a stoma would be required), whether the cancer might have spread, the cancer being treatable, death, and the impact of their illness on their families. Additional psychological challenges included participants' struggle to understand what had caused their cancer, problems with self-image associated with scars, weight loss, or stomas, and coping with chemotherapy, especially the dread of feeling unwell. These issues were

understood to have led to feelings of anxiety.

One year later, the focus of participants' anxieties had shifted to the possibility of cancer returning:

'Every so often obviously it comes into your head and you do scenarios and panic.' (male, age 59 years, interview 2 of 2)

These fears could be triggered by pain and the worry that it might be associated with a recurrence. Fears were heightened whenever participants attended investigations at follow-up appointments:

'If you've got a pain or something like that you think "oh what's that?" and then you think "oh I hope it's not anything to do with what I've had".' (female, age 34 years, interview 2 of 2)

'When I was there getting that scan I was still scared. You heard some stories [in hospital] and you think you're alright but they would say "Oh I had that" and the next time they've went back and they've thought they were all clear and it's not been all clear.' (female, age 65 years, interview 2 of 2)

Social issues. The physical and psychological effects of colorectal cancer impacted the social dimensions of participants' lives, particularly work and relationships. Returning to work posed problems as participants endeavoured to deal with physical issues such as digestive dysfunction and fatigue away from home:

'I went back to work 4 weeks after my chemo finished ... But I only went back like for two mornings I only did about 9 till 12 it was just in the office really it was just sitting doing paperwork and then the Christmas holidays. Then after the Christmas holidays ... I did like one full day one week and then the next week I did two full days, the next week three full days ... I've been back full time since then.' (female, age 37 years, interview 2 of 2)

Travel and holidays featured in the second interviews, with discussion of managing digestive dysfunction issues while travelling, and managing diet away from home.

Support from spouses, both practical and emotional, was cited as the key source of support for the majority of participants soon after diagnosis, and again a year later. Participants' partners provided practical support with domestic chores, cooking, and driving, but providing this support could prove difficult, particularly where partners

were older or not physically fit themselves.

Professional input accessed by participants to address needs

Support from clinical nurse specialists. Support from clinical nurse specialists was highly valued because they had expert knowledge of colorectal cancer, they provided continuity of care, they were accessible, and their expertise extended from the illness itself to treatment, treatment effects, and side effects, and to the wider psychological and social implications of the disease:

'I was concerned going to the toilet many times, many times, you know and she said that she was not surprised because usually because they cut near the rectum that's why she said she was not surprised I was going to the toilet many times.' (female, age 50 years, interview 1 of 2)

The continued presence of clinical nurse specialists from diagnosis through to subsequent consultations, follow-up clinics, and telephone contact ensured continuity of care. In addition, the nurses provided access to the surgeon's knowledge — taking queries to the surgeon and informing participants of the surgeon's advice. Some of the uncertainty participants felt was addressed with explanations of treatment plans and what they might expect to happen:

'Oh yeah, uh huh, because what she did was ... she put it into sequence of events and when things would happen and I took a note there and then and that was a big help.' (female, age 68 years, interview 1 of 2)

Sometimes clinical nurse specialists showed people the high-dependency unit and introduced them to other health professionals who would be involved in their care. One man said the one person he felt able to talk about his illness with was the clinical nurse specialist. Another woman discussed fears about death with the clinical nurse specialist. Participants said clinical nurse specialists had urged them to get in touch if they had problems coping:

'Well certainly X [the nurse] has just been a great help about discussing em the current situation and also how things may develop and just really, you know, you need to, because you're not sure, you haven't been through this before you're not sure what may happen next. And just, you know, putting me at ease.' (male, age 51 years, interview 1 of 1)

'Also just checking anything to do with like the, you know, the wigs or anything or feeling emotionally upset or if there's any other problems, family problems anything like that she's just there.' (female, age 55 years, interview 1 of 1)

Primary care support. For the majority of participants, GPs played a key role in the diagnostic process, typically referring to secondary care. GPs featured much less in participants' accounts of care accessed after diagnosis:

'The last time I saw my doctor was when he got me my appointment for X [the hospital] and that was months before I had my operation.' (male, age 75 years, interview 1 of 1)

Some participants were contacted by their GPs on their return home from hospital after surgery. GPs either telephoned or called in person, and offered their support and enquired about participants' recovery:

'She just wanted to know how things were, she phoned and said "Make an appointment". Just to see how I was and how I was coping and then once the chemo started I got in touch with her again 'cause she wants to know how I'm coping with the treatment. And if I had any queries at all I could phone her 'cause she's easy to talk to.' (female, age 72 years, interview 1 of 1)

This contact was unsolicited and was appreciated by participants, who were comforted by the knowledge that help was available (and occasionally the lack of an unsolicited contact was a source of dissatisfaction):

'I was a bit disappointed in her after my operation because eh so many folk said "Your doctor will make a courtesy call" and she didn't bother.' (female, age 70 years, interview 2 of 2)

GPs flagged up the possibility of psychological issues arising with a cancer diagnosis, and offered to help should the need arise. However, accounts of consulting GPs on the psychological impact of colorectal cancer were rare: very few participants mentioned, or planned to mention to their GPs the anxiety they felt.

Where participants contacted their GPs, consultations were primarily regarding physical matters including digestive dysfunction problems, problems with

wounds, and side effects from chemotherapy. In a few instances, GPs assisted participants with social challenges associated with colorectal cancer, for example, helping with a cancer charity grant application. Contact with district nurses tended to be for short-term wound management, and 1 year later no one was still seeing a district nurse.

One year later, contact with GPs was seldom with regard to issues associated with colorectal cancer. Those who were seeing their GP regarding other issues occasionally mentioned issues related to colorectal cancer as an aside. A minority did consult their GP on the ongoing impact of their colorectal cancer, particularly the physical aspects such as fatigue and diarrhoea.

Health professionals were not consulted by all the participants who experienced problems associated with their colorectal cancer, but those who did seek advice regarding issues related to colorectal cancer often chose to consult secondary care, most usually their clinical nurse specialist.

Barriers to accessing primary care. When asked why they had not contacted primary care about ongoing issues associated with colorectal cancer, responders typically replied that they 'didn't like bothering people':

'I haven't asked for any help. I'm a bit like that mind you. I wouldn't ask unless I, I don't like bothering people, em, so I would have to be sure I should ask really, really, really sure. Why did I originally go? Why I do not, I don't know. I was so lucky. I was so sensible why it's just not like me I tell you.' (female, age 64 years, interview 2 of 2)

Some said that if they were going to seek help they would first consult a clinical nurse specialist, suggesting that there may have been greater perceived barriers to accessing care from primary care than from a clinical nurse specialist. Disincentives to contacting primary care cited by participants were the perceived lack of expertise related to colorectal cancer, and the lack of ongoing contact throughout the illness. They also spoke of issues around accessibility compared to phoning a clinical nurse specialist directly, as well as the GP's inability to provide emotional support directly, in comparison to conversations with clinical nurse specialists, where they had previously sought advice and reassurance, and had voiced their fears.

However, it may also be the case that consulting a clinical nurse specialist in the first instance is simply a reflection of the perceived expert role of the nurse, combined with the continuity that nurse specialists offer as a direct point of contact.

Elsewhere, participants chose not to consult their GP on issues associated with their colorectal cancer because their faith in their GP had been eroded during a problematic diagnostic process. Although GPs often pursued other avenues of investigation before referring to secondary care, there were instances where participants felt the time between their initial presentation with symptoms and their referral to secondary care was unnecessarily long, and constituted poor care:

'I wouldn't phone them [the GP], I've no confidence in them at all even when I was poorly after I came home after 7 days and I wasn't well, I really wasn't well. I thought I'll have to get a doctor out or something, I can't cope with this, I phoned the hospital and they said "Just bring her in". So I did that rather than phone my GP because they're more supportive.' (female, age 53 years, interview 1 of 2)

DISCUSSION

Summary

In the months following diagnosis, participants faced physical issues, particularly digestive dysfunction and sexual problems. Later, fatigue emerged as the most prominent physical challenge, with some digestive dysfunction and sexual problems persisting. Uncertainties and anxieties about the future were the greatest psychological challenges described in the first interviews. Later anxieties were focused on the fear of recurrence. Colorectal cancer impacted the social dimensions of participants' lives, resulting in protracted absences from work and difficulties travelling.

Some participants had discussed physical problems with their GPs but few had visited their GPs with regard to psychosocial problems. This was particularly the case 1 year after diagnosis, in spite of the enduring nature of many issues.

Clinical nurse specialists were preferred to primary care for support, for both their accessibility and expertise. Barriers to primary care involvement in care emerged as reluctance to bother their GP and instances in which diagnosis was felt by participants to have taken longer than necessary.

Strengths and limitations

The main strength of this study is that it reports in-depth interviews with newly diagnosed cancer patients and again 12 months later, exploring their needs at both times and how they were being met. Participants were not chosen on grounds of delay in diagnosis, yet this emerged as an issue.

Specialist nurses recruited patients to the larger study that incorporated this qualitative arm, and it is possible that there was selection bias towards those that they were more involved with, perhaps explaining the patients' lack of contact with primary care. In addition, patients perceived by nurses to be too ill to be included may not have been approached, and it is possible that this group may have had more contact with primary care following discharge from hospital. However, the participants in this qualitative study were recruited directly by the researcher, and were purposively selected to ensure maximum variation in responder characteristics. Sampling was informed by both patient and clinical factors, including stage of cancer, and coexisting chronic illness, and it is likely that recruiting patients to represent the spectrum of these characteristics (early and late-stage cancers, comorbidity and no comorbidity, affluent and deprived) will have mitigated any potential bias. In addition, lack of primary care contact persisted into the second interview a year later, at a time when the specialist nurses had far less involvement with patients, suggesting that this is a real observation that is unrelated to clinical nurse specialist input.

Comparison with existing literature

Previous work has identified similar needs following a diagnosis of colorectal cancer.^{3,23,24} Although others have identified the potential importance of the role of primary care in addressing physical, psychological, and social issues following a cancer diagnosis,^{16,17} this study showed these needs to be unmet, and that patients often did not identify their GP as the main source of potential help in meeting such needs. Patients identified with their nurse specialist, with whom they had built a relationship. However, they did place importance on contact from their GP, initiated by the GP soon after diagnosis.

Implications for practice

This study provides a basis for considering the appropriate role for primary care with respect to the survivorship agenda. It is increasingly likely that patients will have

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Ethical approval

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Provenance

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Competing interests

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limited contact with specialists, and that this will be dependent on their treatments; so, for example, patients receiving adjuvant or palliative chemotherapy will have more prolonged contact. Those who do not require such treatments will be discharged from specialist care earlier. It is therefore important that patients have information, not just about their cancer and its treatments, but also about likely symptoms (both cancer-specific and general) and know where to seek help for these. Many of these symptoms are ones that primary care has great experience in dealing with, but according to the results of this study, GPs are not necessarily being contacted by patients. For colorectal cancer patients, these include symptoms such as diarrhoea and constipation, and sexual problems, and for cancer patients more generally, symptoms such as fatigue, anxiety, low mood, and other psychosocial problems.

Other specific issues for clinical practice arose from this study. First, where

participants feel their diagnosis has taken longer than ideal, this should be directly addressed. There were other participants who had delayed diagnosis yet continued to have faith in their GPs as they understood why alternative explanations for symptoms had been investigated first. Secondly, GPs should contact patients after a cancer diagnosis and offer practice and personal input. This would provide an opportunity for discussing and addressing patients' needs and providing information about ongoing needs and support. Contact of this kind would include the opportunity to engage with patients about the uncertainties of their diagnosis and treatment options, seeking to allay uncertainty where appropriate. If this happened as a matter of routine, it can be postulated that primary care would be seen as a core part of the ongoing care of patients with cancer, not just by those with a specific interest in the topic,¹⁶ but by patients themselves, who at present too often view the role of primary care as peripheral.

REFERENCES

1. Cancer Research UK. *Bowel cancer statistics — UK*. <http://info.cancerresearchuk.org/cancerstats/types/bowel/> [accessed 11 Jul 2011].
2. Scottish Intercollegiate Guideline Network. *Management of colorectal cancer: guidelines (SIGN 67)*. Edinburgh: SIGN, 2003. <http://www.sign.ac.uk/guidelines/fulltext/67/index.html> [accessed 11 Jul 2011].
3. Sahay TB, Gray RE, Fitch M. A qualitative study of patient perspectives on colorectal cancer. *Cancer Pract* 2000; **8(1)**: 38–44.
4. Denlinger CS, Barsevick AM. The challenges of colorectal cancer survivorship. *J Natl Compr Canc Netw* 2009; **7(8)**: 883–893.
5. Phipps E, Braitman LE, Stites S, et al. Quality of life and symptom attribution in long-term colon cancer survivors. *J Eval Clin Pract* 2008; **14(2)**: 254–252.
6. Rozmovits L, Ziebland S. Expressions of loss of adulthood in the narratives of people with colorectal cancer. *Qual Health Res* 2004; **14(2)**: 187–203.
7. Carlson LE, Angen M, Cullum J, et al. High levels of untreated distress and fatigue in cancer patients. *Br J Cancer* 2004; **90(12)**: 2297–2304.
8. Sharpe M, Strong V, Allen K, et al. Major depression in outpatients attending a regional cancer centre: screening and unmet treatment needs. *Br J Cancer* 2004; **90(2)**: 314–320.
9. National Cancer Action Team. Macmillan Cancer Support. *Quality in nursing. Excellence in cancer care: the contribution of the clinical nurse specialist*. London: Department of Health, 2010. <http://www.macmillan.org.uk/Documents/AboutUs/Commissioners/ExcellenceinCancerCaretheContributionoftheClinicalNurseSpecialist.pdf> [accessed 11 Jul 2011].
10. Daly WM, Carnwell R. Nursing roles and levels of practice: a framework for differentiating between elementary, specialist and advancing nursing practice. *J Clin Nursing* 2003; **12(2)**: 158–167.
11. National Institute for Health and Clinical Excellence (NICE). *Improving outcomes in colorectal cancers: manual update*. London: NICE, 2004. <http://www.nice.org.uk/nicemedia/live/10895/28832/28832.pdf> [accessed 11 Jul 2011].
12. British Medical Association. *Investing in general practice: the new general medical services contract*. London: BMA, 2004.
13. Department of Health. *The National Cancer Survivorship Initiative Vision*. London: Department of Health, 2010.
14. Jacobs LA, Palmer SC, Schwartz LA, et al. Adult cancer survivorship: evolution, research, and planning care. *CA Cancer J Clin* 2009; **59(6)**: 391–410.
15. Nekhlyudov L. 'Doc, should I see you or my oncologist?': a primary care perspective on opportunities and challenges in providing comprehensive care for cancer survivors. *J Clinical Oncol* 2009; **27(15)**: 2424–2426.
16. Campbell NC, Macleod U, Weller D. Primary care oncology: essential if high quality cancer care is to be achieved for all. *Fam Pract* 2002; **19(6)**: 577–578.
17. Pascoe SW, Neal RD, Allgar VL, et al. Psychosocial care for cancer patients in primary care? Recognition of opportunities for cancer care. *Fam Pract* 2004; **21(4)**: 437–442.
18. Earle CC, Neville BA. Under use of necessary care among cancer survivors. *Cancer* 2004; **101(8)**: 1712–1719.
19. Gray NM, Hall SJ, Browne S, et al. Modifiable and fixed factors predicting quality of life in people with colorectal cancer. *Br J Cancer* 2011; **104(11)**: 1697–1703.
20. Sandelowski M. Sample size in qualitative research. *Res Nurs Health* 1995; **18(2)**: 179–183.
21. Marshall MN. Sampling for qualitative research. *Fam Pract* 1996; **13(6)**: 522–525.
22. Kelle U. Theory building in qualitative research and computer programs for the management of textual data. *Sociological Res Online* 1997; **2(2)** <http://www.socresonline.org.uk/2/2/1.html> [accessed 11 Jul 2011].
23. Rozmovits L, Rose P, Ziebland S. In the absence of evidence, who chooses? A qualitative study of patients' needs after treatment for colorectal cancer. *J Health Serv Res Policy* 2004; **9(3)**: 159–164.
24. Simpson MF, Whyte F. Patients' experiences of completing treatment for colorectal cancer in a Scottish District General Hospital. *Eur J Cancer Care* 2006; **15(2)**: 172–182.