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Boulton, M, Adams, E, Horne, A, Durrant, L, Rose, P and Watson, E (2016) A qualitative study of cancer survivors' responses to information on the long term and late effects of pelvic radiotherapy one to eleven years post treatment. *European Journal of Cancer Care*, 24 (5). pp. 734-747.

doi: 10.1111/ecc.12356

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Available on RADAR: August 2016

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**A qualitative study of cancer survivors' responses to information on the
long term and late effects of pelvic radiotherapy one to eleven years
post treatment**

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The study was funded by a grant from Macmillan Cancer Support.

A qualitative study of cancer survivors' responses to information on the long term and late effects of pelvic radiotherapy one to eleven years post treatment

Abstract

As more patients survive cancer for longer, the long term and late effects of treatments become increasingly important issues for cancer survivors and providing information to enable survivors to recognise and manage them becomes increasingly pressing challenges for health care professionals. The aim of this study was to explore the experiences of cancer survivors regarding information given on potential long term and late effects of pelvic radiotherapy. Semi-structured interviews were conducted with 28 cancer survivors who had had radiotherapy to the pelvic area for a range of cancers 1 to 11 years previously. Participants were recruited using maximum variation sampling from a larger questionnaire survey of patients treated at one hospital. Interviews were recorded, transcribed and analysed using Framework. Participants recognised the value of information to reassure and to inform action but also its potentially undesirable effects to frighten or raise anxieties about future problems and its inherent limitations in meeting their wider needs. They identified the timing, amount of information and context in which it was given as of particular importance. Information based on personal experience was also valued. These findings highlight the importance of appropriate, individualised information during treatment, at hospital discharge and subsequently in primary care.

Key words:

Cancer survivors, long-term effects, pelvic radiotherapy, information, patient experience

Introduction

Providing information to cancer patients is now widely recognised as an important aspect of care. It has been shown to relieve anxiety and improve psychological wellbeing (Booth et al, 2005), enable patients to make informed treatment decisions (Ziegler et al, 2004), contribute to positive adjustment in the transition from active treatment (Stanton 2012; Sandsund et al, 2012) and empower patients to take an active role in their own health care (Rees et al, 2003). The provision of information has been highlighted as a key priority in major policy documents internationally, including the Cancer Reform Strategy in England (Department of Health, 2007) and the report of the President's Cancer Panel in the USA (President's Cancer Panel, 2006). In the context of an increasing emphasis on patient choice (Department of Health 2004, 2010a, 2010b, 2010c), and supported self-management (National Cancer Survivorship Initiative, 2009; BC Ministry of Health, 2011; <http://selfmanagementuk.org/>), concern with aspects of the provision of information to cancer patients is likely to continue to grow.

Of the substantial body of research that has accumulated on this topic, most has focused on the information needs and information-seeking behaviour of patients at the time of diagnosis or active treatment. Relatively little attention has been given to the information needs of cancer survivors in the years following the end of active treatment (Cappiello et al, 2007; Beckjord et al, 2008, Stanton, 2012). For example, in a systematic review of cancer patients' needs for and sources of information, Rutten et al (2005), observed that while cancer survivors in the post-treatment phase were well represented in the studies they reviewed, the majority had been asked to report on their information needs retrospectively with the result that 'this body of literature primarily addresses patients' information needs and sources during diagnosis and treatment' (page 255). Gansler et al (2010) also observed that while the information needs and priorities of people undergoing cancer treatment were extensively categorised, 'less is known about information needs and priorities after completion of treatment and at the time of recurrence' (page 310).

Research conducted in recent years has begun to address this deficit and has suggested that the information needs of patients in the post-treatment survivorship years are quite distinctive. While Rutten et al's (2005) review reported that those in the post-diagnosis and active treatment stage were primarily concerned with cancer-specific information and treatment options and side-effects, studies of cancer patients in the post-treatment survivorship stage suggest that persisting adverse effects of treatment is a major area of

concern (Rozmovits et al, 2004; Cappiello et al 2007; Gansler et al, 2010; Stanton, 2012). Few studies, however, have considered when and how to provide cancer survivors with the information they may need to address this concern. Without a better understanding of these issues, attempts to provide information may be of little value to patients.

Radiotherapy is one of the most widely used forms of treatment offered to cancer patients and one for which there is growing evidence of long term adverse effects. The aim of radiotherapy is to kill the target tumour cells whilst sparing nearby healthy tissue as far as possible but some damage to healthy tissue is inevitable. Patients with pelvic cancers are commonly offered radiotherapy, often in combination with surgery, chemotherapy and hormonal therapy regimens. Around 17,000 people are treated with pelvic radiotherapy each year in the UK alone (West and Davidson, 2009). Severe adverse effects are rare, but research suggests that up to 50% of patients are left with long term chronic gastrointestinal side effects including diarrhoea and faecal urgency or incontinence (Andreyev, 2007; Olopade et al, 2005; Putta and Andreyev, 2005; Das et al, 2010). Similarly, studies of patients treated for gynaecological cancers indicate that 20% to 50% of patients are left with symptoms associated with bladder, bowel or genitalia (Vistad et al, 2008; Maher and Denton, 2008; White, 2008; Routledge et al, 2003; Anacak et al, 2001). These side effects can have a significant detrimental impact on the person's physical and psychological wellbeing, and affect wide aspects of the person's quality of life including their personal relationships (Barker et al, 2009; Cannon et al, 2009; Hedestig et al, 2005). However, most of this research is based on patients in the early survivorship stages and much less is known about the experience of longer term survivors who are no longer being followed-up by the hospital clinic.

In order to investigate the long term and late effects of treatment and patients' information needs in relation to them, we conducted a mixed methods study of cancer survivors who had had radiotherapy to the pelvic area for prostate, cervix, uterine, vaginal, rectal, and bladder cancer in the previous one to eleven years. In a previous paper we reported the findings of a postal survey which described the prevalence of long term and late effects, the impact of time since treatment on the prevalence adverse effects and the relationship between adverse effects, psychological morbidity and quality of life (Adams et al, 2014). As part of this study we also conducted an embedded qualitative study which explored a sub-group of respondents' experiences of the long term and late effects of pelvic radiotherapy and their views on and responses to information provided in relation to these. In this paper we focus on the information theme and describe the nature and range of participants' responses to the information they were

given on long term and late effects of pelvic radiotherapy with a view to informing future clinical practice in this important area.

Methods

Recruitment

All patients who received radiotherapy treatment with curative intent to the cervix, uterine, vagina, rectum, bladder or prostate, between 1999 and 2009 at one hospital in Oxford were eligible for inclusion in the initial questionnaire survey. The sample was stratified by gender and by time since treatment (1-5 years; 6-11 years). A random sample of men, and all women treated in this time period were selected to include approximately equal numbers of men and women. Patients with a recurrence were excluded. Approval for the study was obtained from the Southampton & South West Hampshire Research Ethics Committee (Ref 10/H0502/60). A total of 849 participants (449 women and 400 men) were invited to participate.

On the last page of the questionnaire, respondents were asked to indicate if they would be interested in participating in an interview study to follow up issues identified in the questionnaire.

Of the 418 respondents who returned a completed questionnaire, 181 (43%) indicated that they would be interested in participating in an interview. A maximum variation sample of 30 respondents was selected on the basis of gender, cancer site, time since treatment and responses to open-ended questions asking if there were any other issues they would like to raise, with a higher proportion of those who indicated they had something they wanted to say included in the sample.

All participants who took part in the initial questionnaire survey were informed that they could order a copy of the Macmillan booklet 'Pelvic Radiotherapy in Men/Women [as appropriate]: possible late effects' and were given the free-phone number and website address. The booklet included a general introduction to pelvic radiotherapy and its possible side effects, followed by sections on specific symptoms and how to deal with them, and a final section on other sources of help. At the time of arranging the interview, participants in the interview study were asked if they had already received a copy of the booklet, and those who had not were sent a copy a few days prior to the interview. The booklet thus provided a common basis for discussion of aspects of the provision of information on long term and late effects.

Data collection

EA or MB contacted the selected respondents by telephone to provide further information on the interview study and, for those who were still interested in taking part, to arrange the time and place of the interviews. Written consent was obtained before the interviews were conducted.

Semi-structured interviews were conducted by EA or MB, both experienced qualitative interviewers, using a topic guide which had been constructed following a review of existing literature and consultation with user representatives and amended further following initial pilot interviews.

The broad areas covered in the interview were:

1. Treatment received
2. Symptoms (adverse effects) experienced following treatment (immediate, on-going and late), their impact on everyday life, and how they managed them
3. What they were told about long term and late effects, by whom and when, and how they felt about this
4. What they had learned from other sources and how they felt about this
5. Views on the best time to provide information about long term and late effects and how it should be provided

Interviews were conducted in the participants' own home and lasted between 30 and 90 minutes. With participants' consent, they were digitally audio-recorded and fully transcribed.

Analysis of interviews

Interviews were coded and analysed by MB (senior qualitative researcher in sociology of health and illness) using the Framework approach (Ritchie and Spencer, 1994; Lewis and Ritchie, 2003). Framework was developed specifically for applied and policy-relevant qualitative research where the objectives of the study are typically set in advance, often in relation to the needs of the funding body. The analytical process involves five stages: familiarisation; identifying a thematic framework to index (code) the data; indexing; charting (summarising information under themes and sub-themes); and mapping and interpretation.

The first four interviews were also coded by EW (senior health service researcher) and discussed to agree and refine the thematic framework. Throughout the analysis period MB and EW discussed how the thematic framework was applied to the data to ensure the credibility and trustworthiness of the analysis. EA (health psychologist) reviewed the final analysis and report to the funder.

In presenting the findings, quotes from the interviews are identified by the interview ID code (eg F56.022), followed by the age and gender of the participant, the cancer site and the number of years since treatment grouped into 1-5 years or 6-11 years. An ellipsis (. . .) is used to indicate the omission of words or sentences, and names of individuals or hospitals have been replaced with XXX. Square brackets [] are used to indicate any additional information or précis of omitted words or sentences.

Results

Sample Characteristics

Twenty eight interviews were completed (12 men and 16 women). Interviews with the other two patients could not be arranged in the time available. The characteristics of study participants are given in Table 1.

In terms of their experience of long term and late effects, interview participants described a similar range of bowel, urinary and sexual problems as those in the initial questionnaire sample. For many these effects were significant and distressing but all had developed self-management strategies which enabled them to carry on their daily lives. For some, however, this involved limiting their activities in ways which they regretted and which set them apart from their peers.

Contrasting perceptions of information provided on immediate and long term or late effects of radiotherapy

Most of those interviewed said that they had received excellent information and support from their clinical team regarding the immediate adverse effects of pelvic radiotherapy.

F01.024 – 65, female, rectal, 6-11

I definitely got information about the immediate side effects that I could have and felt pleased with myself that I wasn't having them. I didn't have any problems with

my skins and . . . everybody gets tired when they're having radiotherapy. So I felt the information was [good], I found it quite good really. (333-342)

M49.065 – 65, male, rectal, 1-5

Yeah, they told me about both, the heating up thing is a radiotherapy thing. You can feel tired, drowsy, that sort of thing, and they talked about the chemotherapy. There's all sorts of different side effects, sickness, blisters in the mouth, general tiredness again and a nasty taste in your mouth all the time, a sort of metally taste. (151-165)

However, few participants appeared to be aware that these adverse effects could persist for a lengthy period or develop some time after the end of treatment.

F56.020 – 67, female, uterine, 1-5

All they told me was that you could have sickness and diarrhoea actually while you were having radiotherapy. Nobody told me a thing about after. . . . I just thought, that was it, but it wasn't, there was still a lot to come but of course I had no idea of that. . (555-592)

F89.063 – 67, female, rectal, 1-5

As for late side effects of radiotherapy, I didn't even know there was any. . . . Until I'd got that questionnaire I didn't know that there was a possibility that I might get other things crop up and it be put down to that (441-508)

M93.010 – 76, male, rectal, 6-11

I wasn't really given much information at all about what possible reactions one would get. I certainly didn't think I'd get this shocking pain but I possibly might not have done. (854-861)

Responses to information provided on long term and late effects

In the course of the interviews, participants elaborated further on their assessments of the information they had received (from a variety of sources) on the long term and late effects of pelvic radiotherapy. It is this aspect of the interviews that is the focus of this paper.

Two main themes, each with three sub-themes, were identified in the interviews. Figure 1 shows the development of the final set of themes and sub-themes in the analysis

process. The first column shows the initial Thematic Framework developed and used in Indexing the transcripts. The second column shows the revised thematic framework used in Charting the indexed transcripts. The third column shows the final set of two broad themes – their response to what information they were given and to how it was given – with three sub-themes within each, which was developed by reviewing, comparing and contrasting the Charts in the final Mapping and Interpretation stage of Framework (Ritchie and Spencer, 1994; Lewis and Ritchie, 2003).

1. Responses to 'what' information was given

In talking about *what* information they were given on the long term and late effects of pelvic radiotherapy, study participants described the complex and potentially contradictory ways in which they responded to it. While the *value* of information was recognised, participants also expressed an awareness of its potentially *undesirable effects* and of its *limitations* in helping them deal with the consequences of cancer and its treatment.

(i) Valued information for reassurance and to inform action

The most common reason for valuing information was for the *reassurance* it provided. As the following examples suggest, by reducing uncertainty and relieving anxiety, information can lead to a marked improvement in patients' quality of life.

M49.135 – 80, male, prostate, 1-5

I was so happy reading it [Macmillan booklet, first seen as a study participant]. We came across, on every page we turned over it was relating something that was happening to me. It was diarrhoea, it was wind, it was bleeding, it was tiredness – and you know it can happen immediately after or it can not be apparent until two or three months after or you could be stuck with it for life. I thought 'Well, I'm one of the unfortunate ones that's stuck with it for life then, because it's gone on and on. But I felt relieved because I did think there was something the matter to be honest and every time I went to see the consultant I was expecting him to say something and he didn't. (1181-1190)

F34.001 – 47, female, cervical, 6-11

The thing I was concerned about was that I would have to stop taking Imodium or Loperamide. That was the one thing. . . . So I would have liked the information [in the Macmillan booklet, that I could continue to take Imodium indefinitely]

earlier because I was concerned and I was struggling because I felt I shouldn't be taking it all the time [but it was the only thing that helped]. (1346 – 1359)

Other participants valued information to *inform action*, enabling them, for example, to ask questions of their health care professionals, to make informed decisions and to take a more active role in their own health care. Perhaps not surprisingly, this was particularly evident to those who felt that, at the time they had needed it, they had *lacked* information to take appropriate action, as the following examples illustrate:

M93.059 – 67, male, bladder, 6-11

If that [Macmillan booklet] had been around, that would have been helpful because from that you can then ask your own questions to your doctor. (643-44)

F45.006 – 55, female, cervical, 6-11

I [would have liked] a much more detailed account of what happens when you are radiated. If I'd known that it was going to deteriorate the bone, I would have known that I was looking at having a hip replacement several years sooner than I was planning to have one [and could have prepared for it]. (1028-1031)

However, acknowledging the value of information did not necessarily mean that they wanted all the information that was available:

F45.006 – 55, female, cervical, 6-11

It is quite hard to know how to give that information without giving packs of leaflets and stuff that people don't read, *don't want to read*, because you don't actually really want to know.

(499-502)

(ii) Concerns about potentially undesired effects

Participants recognised that information could also bring undesired consequences, observing that information could *frighten* people as well as reassure them, and in some cases potentially *deter* them from having treatment:

M93.157 – 70, male, prostate, 6-11

[The booklet] can give too much information at times of what could happen, as though they were trying to put you off from having the treatment. . . . I think it's

too much, I don't know if it will scare people off from having the treatment in the first place. (493-524)

M49.121 – 51, male, bladder, 1-5

I'm being honest, I don't think I would have had the radiotherapy if I'd have read that [Macmillan] book five years ago. I don't think I'd have had the radiotherapy because the pros and cons is too much against having it. (527-538).

Participants also pointed out that providing information on potential long term or late effects could create *anxieties* or *negative expectations* that they would experience those effects in the future and some expressed concern about the potential consequences of this:

M49.094 – 80, male, bladder, 1-5

I think it can be helpful but at the same time imagination can be a terrible thing. I think if you suggest something, there's every chance you're sure you've got it, in your own mind. (498-500)

F56.022 – 63, female, uterine, 1-5

. . . like all information you can almost build up an expectation about how people are going to feel and it isn't necessarily so. (1615-1616)

Others described the distressing impact that reading the Macmillan booklet had had on themselves:

M49.121 – 51, male, bladder, 1-5

It [Macmillan booklet] is quite shocking. . . . I thought 'Am I experiencing just the start of it?' That's one of the things I asked myself when I had finished reading that book. I thought, 'Oh god, this might just be the start of a lot more problems to come on.' (1305-1312)

A further but less common concern was that, by identifying certain symptoms as long term or late effects of pelvic radiotherapy, cancer survivors might be misled as to their meaning and *miss the early signs of cancer recurrence*:

F56.022 – 63, female, uterine, 1-5

It says the long term side effects, and then it puts *tiredness*, and I'm thinking 'Well surely that – what do you mean by *long-term* and *tiredness*? How long should

you expect to feel tired?' . . . What I mean is that you might not report that you're still very tired when in fact it's a symptom that you are not at all well. . . . That might be the immediate effect after radiotherapy but [3 years on] there's something very wrong, you shouldn't expect to feel tired. (1576-1611)

(iii) *Encountered its limitations in meeting their support needs*

Finally, some participants had encountered the limits of information in meeting their wider support needs. Some described this in relation to the limitations of information alone in preparing them for the reality of the experience and in addressing its emotional impact:

F45.006 – 55, female, cervical, 6-11

. . . I did read up on these things and I had an idea of what it was going to be like. But until you're actually in that situation, *you've no idea*. (199-201)

F78.053 – 39, female, rectal, 1-5

So yeah, there was information given but I just, I just felt it was very *cold*. I don't expect anybody to go 'oh there, there love, it's all going to be better' but it was just . . . you're totally on your own all the time. (489-494)

Others described it in terms of the inability of factual information or practical advice to answer more *existential concerns* or *change the reality* of a cancer diagnosis.

F78.053 – 39, female, rectal, 1-5

You do think to yourself, 'why me'? I was 35 years old with a young family. OK, I'm still here, I should be grateful, there are people out there that've got terminal cancer, and da de da, but yeah, I do think to myself 'why', yeah I do. (398-402)

M49:135 – 81, male, prostate, 1-5

I I don't want to know. I know what is wrong, I know the treatment I'm having. I don't want to know the ins and outs and all that. I suppose it's like putting your head in the sand, but I think you can discuss it and go over it, over and over again, and *it doesn't make it any better, does it*. (1357-1361)

2. Response to 'how' information was given

Participants' accounts also highlighted the importance of *how* information was provided, including the *timing*, *amount* and *context* in which it was given. Information based on

personal experience was valued in meeting a range of needs not addressed by medical science.

(iv) *Timing*

A common theme in the interviews was the importance of *timing*. Most participants had a view on what times were better or worse for receiving information on long term and late effects though not all agreed as to what they were. Some participants wanted information on *both* immediate *and* long term and late effects as soon as the decision to give radiotherapy had been made and before treatment started:

M49.121 – 51, male, bladder, 1-5

Right at the beginning before you actually have it. Definitely. I think you should be made more aware of what could possibly happen. (493-507)

M93.173 – 80, male, prostate, 6-11

I think they should tell them all of this [early on], so that they can make their own mind up. I think probably they should. I mean, if they'd have told me all this, I would still have gone ahead with it because I wanted to live, you see.

(615-621)

As these quotes suggest, the rationale for giving information before the start of treatment was to give patients the opportunity *to make an informed decision* about whether to have radiotherapy or not. However, participants also described being pre-occupied in the early post-diagnosis stage with more immediate and profound concerns regarding their own survival which meant they were *not receptive to information* on potential adverse effects of radiotherapy which might (or might not) occur in the distant and uncertain future:

M49.073 – 56, male, rectal, 1-5

When you've been told you've got cancer and you're going to have radiotherapy, and even if they said these are the possible side effects, I don't think we even took it on board. Because there isn't a choice, is there, really. If somebody said, 'If you do survive you're going to have waterwork problems, sexual problems, etc, etc' you wouldn't go, 'Oh well, I think I'll die then,' would you? You have to put it in perspective. (829 - 835)

M93.134 – 76, male, rectal, 6-11

It doesn't take many minutes to go through a few side effects that might occur. . . [But] then people don't listen, really. When they're told they've got cancer, they don't listen anymore. It shuts their mind off. (750-753)

This may help explain why participants were not generally aware of potential long term or late effects of pelvic radiotherapy prior to the study. Health care professionals may routinely raise the implications of treatment, including long term and late effects, as part of the process of informed consent but because they are so remote from their current concerns, patients may not be able to take it in. It may also help explain the view that information on long term and late effects was best provided *after* radiotherapy had been completed, when they had had time to recover, or at the point of discharge from hospital follow-up, when they had begun to think about the future.

M93.034 – 76, male, rectal, 6-11

I would say, let people get over it because it's quite a traumatic thing all the way through, it really is. I would say three months, because they check you as regular as anything there. I would have thought then. (616-629);

F12.012 – 75, female, uterine, 6-11

I would say to give it to people when they're better, when they're in remission or whatever and surgery has been successful. I don't know, I suppose a year, about a year. (453 – 457)

F34.001 – 47, female, cervical, 6-11

I think probably a year after my treatment I would have loved that [Macmillan] booklet. I think anything before then would have been too soon. . . . It's only after the event, you know [that you are ready to hear more]. I've been five years clear, or seven years clear, [and] its only after the event that you actually stop thinking about the cancer and start thinking about *you*. (1316-39)

Others suggested that no single time was best for providing information on long term and late effects but that information needed to be provided at 'appropriate' times throughout their lives as cancer survivors:

M93:010 – 76, male, rectal, 6-11

I think once the trouble has happened, it's too late. On the other hand, you don't want to scare them. I think the easiest thing would be to say that you will find differences in your lifestyle, physically. Don't hang about, go to your GP or stoma

nurse or whatever, straight away and then they could take you up the ladder. . . . So a certain amount wants to be before, but maybe not the whole bucketful. But certainly a lot more than I had. (870 - 880)

M49.065 - 65, male, rectal, 1-5

[I think give information] afterwards, because you're going to get all these symptoms after, not before, so you can read all that and say, 'Crumbs, I'm going to have all these symptoms' and no, because you won't have all them symptoms. I think afterwards but if people want to have it before, let them have it before, if it reassures them in some way or they want to know what they're going to experience. (852-857)

It is also interesting to note that those given the Macmillan booklet as part of this study up to 11 years after treatment nonetheless reported benefits from reading it in terms of reassurance and the practical management of long term effects.

(v) amount and context of written information

Also important to patients was the way information was given, which could make it more or less accessible and acceptable. For written information in particular, *too much information* or too much detail was seen as counter-productive: large quantities of information were regarded as too indigestible for patients to finish reading or too intimidating for them even to start:

M93.134 -79, male, prostate, 6-11

You don't want too much information. It's like the Maggie's Centre produce a booklet but I would say that probably 50% of people do not read all of it. . . . We all sat around the table and decided that an A4 size is the best thing, because it's less reading. It gives you the information on an A4 sheet which is folded into a booklet. . . . We found that people like that, because they can read all of it and not sort of say 'Oh, I can't read any more of that.' (426-437)

Some participants added that extensive information was likely to be more worrying:

M49.094 - 80, male, bladder, 1-5

I mean the more they tell you the more you've got to worry about. I suppose it depends how onerous the things they haven't told you could have been. (461-463)

M93.157 – 71, male, prostate, 6-11

Going through [Macmillan booklet], I think [it gives] too much information at times of what could happen, as though they were trying to put you off from having the treatment. . . . [It's] too much, too much information. (493-525)

Amongst women in particular, the *context* in which written information was given was also important: information was valued most when it was given in the context of an established, supportive *personal relationship*, for example with their specialist cancer nurse. Several participants made the point that this personal relationship changed the nature of the exchange so that they took notice of information sheets or booklets they would otherwise have ignored, and felt supported and reassured by this exchange with their cancer nurse itself.

F56.022 – 63, female, uterine, 1-5

The fact that she *gave* me the book made a difference. She didn't say, 'Phone up and you can get one.' . . . It was the fact that she gave it to me and said 'if you need any more information, come back to me . . . I think the best way is person-to-person. (740-787)

F34.001 – 47, female, cervical, 6-11

I think if [just any] nurse had given me that booklet I would have treated it exactly the same as the letters coming through the post – you read it, you scan through it and you put it away. But having that relationship with [the Clinical Nurse Specialist], . . . if she said 'This is going to help', I trusted her. We already had that relationship, so it wasn't a stranger giving it to me. . . . Knowing that you've got information and a safety net is the key. (1475 – 15280)

(vi) *The unique value of experience-based information*

While participants valued the information given by clinical staff and other 'medical' sources, they also valued the information provided by other patients who brought a different kind of expertise based on personal experience. Clinic staff encouraged this, recognising that patients were better placed to provide both *hope and reassurance* about the future and the kind of *practical information and advice* that they would find helpful in managing everyday life. Participants themselves described how they had taken strength from the experience of other patients:

M93.157 – 70, male, prostate, 6-11

A colleague, her cousin had the same as what I eventually had and she told me how well it had gone and he'd completed cleared now and everything, which helped no end. (606 - 612)

F01.024 – 65, female, rectal, 6-11

I can remember being in some support groups and things where I had a chat with the odd person, which really helped me in my decision about having a swap from an ileostomy to a colostomy. I got a lot of useful information in making that decision, so I think access to that sort of [. . . thing] is very good. (801-810)

They also described how they looked to more experienced patients for practical advice in managing the long term treatment effects, and found it particularly helpful.

F56.051 – 84, female, uterine, 1-5

I go to meetings [of a stoma group] four times a year in [town], you know. I go to see if I can find out anything. You always wonder, you like to talk to somebody who's got one [ileostomy] the same so you can compare notes. (420-422)

F34.001 – 47, female, cervical, 6-11

I think it would be really good if there was a body of people that were on a phone list, of varying ages, that had experienced it, that people could ring and say 'Can I just ask you something?'. . . . Because there have been occasions I wish I could just ask someone who isn't a professional. (1907-1916)

Finally, participants described how the exchange of views and experience with other cancer survivors helped them meet the emotional and existential needs that 'medical' information alone could not meet. Support groups for cancer patients and survivors provided a supportive community and a reference group through which they could make sense of what was happening to them and make the *psycho-social adjustments* needed as a cancer survivor.

M93.134 – 78, male, prostate, 6-11`

I went to [a group for prostate cancer at the XXX hospital] and I spoke to various people about different things and I think that is the way you can get over a lot of these problems, by people talking together about their problems. (214-217)

F12:038 – 83, female, rectal, 6-11

Once I knew I had cancer I wanted to meet somebody else that had cancer and the same cancer that I had. . . . It's one of the few cancers that people are a bit shy about and really when you go into hospital and you find everybody in the beds opposite, by the side, has the same thing, you don't feel you're on your own any more. (446-545)

As they suggest, other patients with whom they could share their experiences and concerns, speak about taboo subjects and feel 'normal' provided the support they needed to learn how to manage their condition and the effects of treatment and to construct a new identity as a cancer survivor.

Discussion

Summary of findings

As more patients survive cancer for longer, the long term and late effects of treatments are becoming an increasingly important issue for cancer survivors and providing information to enable cancer survivors (and their partners) to recognise and manage them is becoming an increasingly pressing challenge for health care services (Hedestig et al, 2005; Andreyev, 2007; Maher and Denton, 2008; White 2008; Hazewinkel et al, 2009). While previous studies have begun to document cancer survivors' *desire for* information on long term effects of treatment (Gray et al, 1998; Thewes et al, 2004; Gansler et al, 2010), this study is amongst the first to explore in detail survivors' *responses to* information on this topic and their views on how it might be best provided. In common with other studies (Jenkins et al, 2001; Cox et al, 2006), we found that survivors valued information on long term and late effects of treatment. However, we also found that they appraised information, and how it was provided, in more critical terms than might have been expected. While there were positive comments on information provided on immediate adverse effects of radiotherapy, many participants were not aware that adverse effects could continue or emerge after the end of treatment. Their views on and responses to the provision of information underline the complexities and challenges faced by health care professionals in helping patient and carers prepare for potential adverse effects of radiotherapy to the pelvic area. Participants observed that information was not always welcome, describing a range of potentially undesirable effects and the limitations of information alone in meeting their needs. They also identified a number of considerations associated with the timing of information and the way and context it was given as well as the unique value of other patients' experience.

Overall, what participants wanted was 'just enough' information, delivered in a personal context, at the times it was relevant to them.

The range and variety of responses to what and how information was provided raise many challenges for those who wish to support cancer patients and their carers. These are compounded by the limitations of medical knowledge itself: there is currently no reliable model to predict who will go on to develop long term treatment effects nor any predictive marker to inform what information should be given to patients. While printed booklets and up-to-date websites may be of great value in providing information on long term and late effects of pelvic radiotherapy, our findings suggest that health care professionals need to discuss with patients themselves what information they want and how they want to receive it and to do so iteratively over the course of the treatment, follow-up and survivorship stages (Russell and Ward, 2011; Zeugler et al. 2012).

Relationship to previous literature

While a number of surveys have reported that most cancer patients want as much information as possible on their condition and its treatment (eg Jenkins et al 2001, Wittmann et al, 2011) and that a significant minority are dissatisfied with the amount they receive (eg Jones et al, 1999), qualitative studies have begun to challenge the simplistic nature of these findings. Our finding that cancer survivors did not always welcome information is consistent with previous studies conducted at earlier stages in the cancer journey (Czaja et al, 2003; Friis, 2003). Leydon et al (2000), for example, in a study of patients with a variety of cancer types, reported that their participants found even basic information frightening and argued that this was one of the main reasons for patients not seeking, or actively resisting, information. Our study suggests that this may remain the case at much later stages in the cancer journey and that in addition to frightening cancer survivors, information is seen as potentially leading to other undesirable effects, such as anxieties or negative expectations about future adverse treatment effects and obscuring the symptoms of a possible recurrence of cancer.

In addition, our study has reported novel findings on survivors' perceptions of the limitations of information in meeting their supportive care needs. Study participants described the ways in which they felt 'let down' or 'disappointed' by information on its own. While information may have enabled them to *know about* long term treatment effects, it could not adequately prepare them for the *experience* of those effects or their impact on their life. Similarly, information could inform them of *what* was likely to happen but it could not answer the more spiritual or existential questions of *why* it had happened to them and while it could *inform action*, it could not *change* the basic facts of their

situation. Information was important but they conveyed their shock and frustration when they encountered its limitations in meeting their needs.

Our findings have also pointed to the importance of timing in providing information, particularly in relation to the emotional readiness of cancer survivors and the relevance of the information to daily life. While there were advocates for giving information at a variety of points, many participants expressed the view that the post-treatment stage was a particularly good time. This is consistent with the findings of other studies (Sandsund et al, 2012). Friis et al (2003), for example, reported that patients did not recall detailed information given in the post-diagnosis stage which they explained in terms of a 'shock reaction' to the diagnosis, while Gansler et al (2010) found patients were little interested in long term side effects until after treatment was completed, when the effects were expected to occur. This evidence suggests that, while the diagnosis and active treatment stage may provide a 'teachable moment' for motivating individuals to adapt risk-reducing behaviours (McBride et al, 2003; Rabin, 2009), this is unlikely to be the case in relation to managing late and long term effects of treatment.

An interesting finding of our study was that for several female participants it was particularly important that information booklets were given to them by a health care professional with whom they had an established a personal relationship. This may reflect a shift in the nature of trust, characteristic of late modern society (Giddens 1990), which has been observed in other health care contexts (Alasewski & Horlkick-Jones, 2003; Brown 2009). While trust in the source of information is fundamental to its effectiveness, it can no longer be assumed that patients have trust in health care professionals and the publications they produce simply on the basis of their professional status or institutional accreditation. Trust must now be earned through the quality of the relationship a professional establishes with an individual patient and the competence, care and empathy that she or he displays (Taylor Gooby and Zinn 2006; Calnan and Rowe 2008). Information provided in the context of such a relationship may also carry a weight of meaning and significance beyond that of the substance of the information itself, and may go some way to meeting the emotional support needs not met by information on its own. Our finding that participants also looked to other patients for information of a different kind is also consistent with a growing challenge to professional authority and a widening of the basis for claims to expertise in late modernity and is also supported by the findings of other studies.

Implications for clinical practice

While previous studies have documented that information needs change over time (eg Matsuyama et al, 2013) and may decrease post-treatment (eg Guleser et al 2001; van Weert et a, 2013), we are not aware of any other study that has examined patients' information needs and preferences up to 11 years period post-treatment. The findings of this and other studies (Gamble, 1998; Guleser et al, 2001; Zeugers et al, 2012) suggest that patients want information on the side effects of radiotherapy but may not see information on long term and late effects as relevant, nor be able to take it in, during the active treatment stage. Providing information on the adverse effects of radiotherapy *throughout* active treatment, follow-up and survivorship, and addressing questions that patients themselves define as relevant at the time they arise, may prove more effective. Patients may find particular benefit when such information is provided in the first outpatient appointment following the end of treatment. An information booklet such as the one used in this study (Macmillan Cancer Support, 2009), for example, can be valuable at this stage in helping patients manage long term effects (Andreyev et al, 2013). Any continuing concerns or questions could be elicited and addressed in subsequent appointments and reviewed at the final appointment before discharge from hospital follow up.

As written information on long-term and late effects may cause anxiety or distress or the need for further clarification, it may be best provided by a health care professional with whom the patient has an established relationship. In the early years following treatment this is likely to be a member of the hospital team such as a clinical nurse specialist or radiographer. However, with the likely increase in supported early discharge of cancer patients from hospital care in the England (National Cancer Survivorship Initiative, 2009) GPs may be required to play a greater role in the future. This might involve, for example, a treatment summary provided to both GP and patient at discharge from hospital care. Such a document could help empower patients to request further review of possible long term effects and also act as a reminder to the GP to ask routinely if the patient has any questions or concerns. GPs themselves are likely to need some preparation to deal with this and more work is needed to establish what this is likely to entail and how it could be provided (Watson et al, 2010).

Health professionals are also in a good position to support patients in meeting other patients with similar conditions and should be encouraged to do so through individual patient contacts, local support groups such as a Maggie's Centre or more formal services such as the expert patient programme (Wilson, 2008).

Strengths, limitations and reflections on the study

Strengths of this study are the inclusion of both men and women, the variety of pelvic cancer types and the range in time since treatment, up to 11 years. Limitations include the restriction of recruitment to one centre and the low number of participants from ethnic minority backgrounds. As patients who had experienced a recurrence of cancer were excluded, the sample may have been healthier than the population from which it was drawn and less likely to experience, or more able to deal with, long term effects. In addition, while the response rate to the main survey was relatively good (56%), it is possible that those who completed the questionnaire were not representative of the sample as a whole. This may have been compounded by the sampling procedure for the interview study which selected more of those who indicated they had something they wanted to talk about.

As with all qualitative research, this study was shaped by the context in which the interviews were carried out. We used an information booklet produced by Macmillan Cancer Support, a well known and respected charity which also funded the study, as an example of information that could be provided to individuals who had had radiotherapy to the pelvic area. Had we used a different booklet or not used one at all, we might have elicited a different set of comments. However, using an existing booklet helped participants to focus attention on specific aspects of information provision and provided common ground for comments across the interviews. While most participants made positive comments about the booklet, many also made critical comments. More importantly, they did not restrict their comments to the Macmillan booklet but ranged widely in discussing information they had obtained from other sources, including health care professionals and other patients.

The analysis of qualitative data is also shaped by the views, assumptions and interests of the research team as well as the circumstances and characteristics of the participants. The research team was guided by a strong sense of advocacy and a desire to improve supportive care and information for cancer survivors, a stance which appeared to be shared by the participants who largely wanted to contribute their views and experience for the benefit of others. This common desire to 'improve' provision of information may have encouraged a particularly critical approach in the interviews and a focus on the problems of information provision in the analysis of the interviews. However, the range of views expressed suggests a degree of balance was achieved overall.

Acknowledgements

We would like to thank the patients who gave up their time to take part in this study. We would also like to acknowledge Macmillan Cancer Support for funding this study. The funding body had no input into the design, data collection, analysis or manuscript preparation.

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Table 1: Characteristics of sample

	Females (n = 16)		Males (n = 12)		Total (n = 28)	
	n	(%)	N	(%)	N	(%)
Age:						
< 40	1	(6)	0		1	(4)
40 – 49	4	(25)	0		4	(14)
50 – 59	1	(6)	2	(17)	3	(11)
60 – 69	6	(38)	2	(17)	8	(29)
70 – 79	1	(6)	5	(42)	6	(21)
80 +	3	(19)	3	(25)	6	(21)
Mean age:	61.5 years		72.6 years			
Diagnosis:						
Bladder	1	(7)	3	(27)	4	(14)
Rectal	6	(38)	4	(36)	10	(36)
Cervical	4	(25)			4	(14)
Endometrium/ uterus	5	(31)			5	(18)
Prostate			5	(36)	5	(18)
Treatment (in addition to radiotherapy)						
Surgery	6	(38)	2	(17)	8	(29)
Chemotherapy	4	(25)	1	(8)	5	(18)
Hormones	0		1	(8)	1	(4)
Surgery & Chemotherapy	4	(25)	4	(33)	8	(29)
Surgery, Chemotherapy & Hormones	2	(13)			2	(7)
Other, none			4	(33)	4	(14)
Time since Treatment:						
1 to 5 years	8	(50)	6	(50)	14	(50)
6 to 11 years	8	(50)	6	(50)	14	(50)

Figure 1: Development of themes over the course of analysis

Initial framework based on a priori issues	Revised Framework used in indexing	Themes used to map range of views & experiences, grouped under two broad headings
	Impact of information itself	1. Response to <i>what</i> information was given
What information provided (topics raised): <ul style="list-style-type: none"> • Bladder • Bowel • Fatigue • Sexual function • Other male • Other female 	Benefits of information <ul style="list-style-type: none"> • Reassurance (reduce uncertainty) • Act more effectively <ul style="list-style-type: none"> • Informed decisions • Ask questions • Explain to others • Plan for future 	Valued information: <ul style="list-style-type: none"> • For reassurance (reducing uncertainty relieves anxiety) • To inform action: <ul style="list-style-type: none"> • Ask questions and explain to others • Make informed decisions • Take active role in managing treatment effects
	Costs of information <ul style="list-style-type: none"> • Frighten (create anxiety) • Create expectations of future effects • Obscure early signs of recurrence 	Concerned about potential undesired consequences <ul style="list-style-type: none"> • Frighten • Create anxieties or negative expectations for future • Obscure/miss early signs of recurrence
	Limitations of 'factual' information alone <ul style="list-style-type: none"> • Does not prepare for the experience • How it is provided also important • Too general, not specific to individual • Does not change things 	Encountered its limitations in meeting their support needs. <ul style="list-style-type: none"> • Cannot prepare them for 'reality' of experience or its emotional impact • Cannot answer existential questions • Cannot change the basic facts
	Aspects of providing information	2. Response to <i>how</i> information was given
When was information provided: <ul style="list-style-type: none"> • When provided • Best time to provide 	Preferred timing of information <ul style="list-style-type: none"> • Before radiotherapy • At end of radiotherapy • After discharge from follow-up 	Timing of information <ul style="list-style-type: none"> • Early in order to make informed choice • Not early on while preoccupied with diagnosis and treatment and so unreceptive • After end of treatment when ready to think of future • Whenever information is relevant to current concerns
Sources of information: <ul style="list-style-type: none"> • Clinic staff (doctors, nurses) • Printed information • Internet • Other patients • Support groups 	Sources of information: <ul style="list-style-type: none"> • Clinic staff (doctors, nurses) • Printed information • Internet • Other patients • Support groups 	The amount and context of written information <ul style="list-style-type: none"> • too much information is counter-productive • best provided in context of personal relationship
Satisfaction with information <ul style="list-style-type: none"> • Satisfied (met needs) • Would like more (not met needs) • Suggestions for improving 	Amount & level of detail of information <ul style="list-style-type: none"> • About right • Would like more • Too much • Not relevant 	Unique value of experience-based information from other patients <ul style="list-style-type: none"> • Inspires hope and reassurance • Provides practical advice • Facilitates psycho-social adjustments