Title:

‘They’re survivors physically but we want them to survive mentally as well’:

Health care professionals’ views on providing potential late effect information.

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Abstract

Purpose: The concept of providing personalised care plans for cancer survivors is receiving increasing attention; a recognised element of a care plan is to provide an indication of the risks and consequences of treatment. This paper reports health care professional (HCP) response to providing cancer survivors with information on potential late effects of their cancer treatment.

Methods: Eighteen HCPs from five cancer centres and three general practices in the UK completed semi-structured interviews which were digitally recorded, transcribed and qualitatively analysed using framework analysis.

Results: HCPs' view of health care was that it is currently focused on acute care and needs are responded to as they may arise, including those which are late effects of cancer treatments. The concept of pre-empting a discussion of potential late effects during the survivorship phase was felt to be discordant with this approach and could impact on adjustment to life after cancer treatment.

Conclusion: Providing cancer survivors with information on potential late effects requires further consideration. Evidence for survivor preference for late effect information and the benefit afforded to survivors who receive it could inform the practice of HCPs. If a culture of proactivity is to be encouraged regarding discussions of future potential risk, HCPs may need support in considering ways of presenting survivors with reality whilst being mindful of their need to retain hope during the survivorship phase.

Background

Advances in medical oncology mean increasing numbers of patients will live with and beyond a cancer diagnosis and enter a phase now termed *survivorship*; the question of how best to offer support to cancer survivors is paramount. The 2005 Institute of Medicine (IOM) report '*From Cancer Patient to Cancer Survivor: Lost in Transition*' [1] raised the concept of a survivorship care plan (SCP) as a tool to provide comprehensive and co-ordinated care to cancer survivors. In 2010, the National Cancer Survivorship Initiative (NCSI) in the UK published the *Vision* document [2] and joined the USA in their support for 'a shift from a one-size fits all approach to follow up to personalised care planning based on assessment of individual risks, needs and preferences'. The *Vision* document provided an outline of information and advice to be included in SCPs, indicating, where appropriate, they should address the following needs: the management of current physical, psychological, social and spiritual problems and concerns, financial benefits, return to work, lifestyle, access to support groups and self-management training programmes, risks and signs of recurrence and planned surveillance tests, risks of future psychological problems, including fear of recurrence and risks and signs of consequences of treatment.

Published literature indicates a growth in the development and implementation of SCPs internationally [3-7] but assessment of their impact on patient experience is rare. Van de Poll-Franse and colleagues have published their protocol of a randomized controlled trial (RCT) evaluating the impact of an SCP on gynaecological cancer survivors' satisfaction with information disclosure and care, quality of life, illness perception, and health care use [8] but there are no results to date. Grunfeld et al. [9] conducted an RCT examining whether providing breast cancer survivors with an SCP improved patient-reported outcomes, but found that SCPs provided no further benefit than a standard discharge visit, however it has been suggested that this negative result could be an artefact of the

outcome measures employed, the level of comorbid care survivors of breast cancer already receive and the quality of the Canadian health care system [10].

Creating a SCP is a potentially resource consuming task. Partially driven by an attempt to offer an economically viable solution to the creation of care plans, the US has led the way in creating free of charge web-based SCP tools for use by cancer survivors, their clinicians and family/friends. A survey of HCPs in the USA reported high levels of satisfaction with web-based SCP tools [11], and it has been suggested that they could 'provide essential information to all cancer survivors worldwide' [12] (p.12). However, cultural differences may impact on the acceptability of these tools for use in other countries. As part of the National Cancer Survivorship Initiative (NCSI), Macmillan Cancer Support and NHS Improvement were tasked with exploring new models of support for cancer survivors in the UK. The aim of the service evaluation was to explore HCP perceptions of the acceptability of a US-created web-based SCP tool for use with cancer survivors in the UK (to be reported in a separate paper). The focus of this paper is on HCP response to the concept of providing information on potential late effects to cancer survivors in the UK during the survivorship phase.

Method

Sample

The intention was to interview one nurse and two oncologists from each identified speciality: ovarian cancer, prostate cancer, breast cancer, haematological cancer, colorectal cancer, plus three general practitioners (GPs). A snowball sampling technique was employed, starting with a known sample of HCPs working in these specialities; each interviewed HCP recommended subsequent HCPs within their speciality. Invitations to participate in the evaluation were emailed to 30 HCPs working in secondary care and five

primary care practices (plus two additional GPs) and information on the evaluation was delivered at a meeting of Macmillan GPs. The resulting sample, whilst not intended to be representative of all HCP working with cancer survivors, nevertheless included representatives from the selected occupational groups within each identified speciality. Eighteen HCPs from five cancer centres and three general practices in the UK took part in the evaluation; eight oncologists, five clinical nurse specialists, one physiotherapist, one nurse counsellor and three general practitioners (GPs). Seventeen semi-structured interviews were conducted in the relevant cancer/medical centres and one interview was conducted over the telephone. Table 1 indicates the number of HCPs interviewed from each speciality. Interviews ranged from 32 minutes to 1 hour and 50 minutes, with a mean length of 51 minutes.

Procedure

An exploratory qualitative approach was employed for this evaluation. To introduce and explore the concept of SCPs five simulated patient case studies were developed through consultation and collaboration with two oncology clinicians (who were not part of the interview process). These case studies reflected five cancer patient groups (breast cancer, ovarian cancer, prostate cancer, rectal cancer, Hodgkin disease) with diversity in age, gender and experience, each case study included at least one type of long-term or late effect as a result of cancer therapy.

During the interviews, each HCP was asked to enter one of the simulated patient case studies (relevant to their specialism) in to the SCP tool. Semi-structured interviews were conducted with the use of a schedule which included questions on experience of using SCPs, attitude to e-technology solutions to the production of SCPs, and clinical view of information and advice provided by the SCP produced during the interview. The interviews

were all audio-recorded with the participants' written consent. With permission, a copy of the SCP and a stamped addressed envelope was left with the participant to enable further consideration and comment on the tool following the interview.

Analysis

The interviews were digitally recorded, transcribed and qualitatively analysed using framework analysis [13]. Transcripts were coded with the use of Nvivo software. A health psychologist (AC) analysed the interviews, rigour was enhanced via the on-going input of the principal investigator (SF) who independently verified the thematic coding framework. The emergent themes were consistent across groups, hence results are not broken down by speciality or occupation.

Results

HCPs felt that providing cancer survivors with information on the potential late effects of their treatment was discordant with the culture of a health care system which responds to need as it arises. It was felt that providing information on late effects could have a negative impact on psychological adjustment to life as a cancer survivor and may actually increase the experience of late effects through autosuggestion. HCPs report needing more evidence for the benefit of providing cancer survivors with late effect information and for advice on *which* late effects should be discussed and *how* the risks should be communicated. These results will be presented below under the following sections: *'Patients bring us a problem and we deal with it'*, *'To come out the back of cancer and then live through life in this permanent shadow'*, *'Some people, not just patients are very susceptible to autosuggestion'*, *'We need to assess whether it's actually going to benefit the patient'* and *'What are the likelihoods of these things happening?'*.

‘Patients bring us a problem and we deal with it’

The respondents felt that the current approach of HCPs in the UK is to inform the patient of any potential late effects prior to treatment, i.e. during the consent procedure, and subsequently to monitor for any consequences of treatment and address issues as they occur. The concept of initiating a discussion of potential late effects during the survivorship phase was felt to be discordant with a culture of acute healthcare management. There was a sense that cancer care is currently more focused on responding to needs as they may arise, including those which are late effects of cancer treatments:

‘I think we discuss them before they have their treatment, they have to know, you know all the possible complications of their treatment before they sign up to it, so I’d say it’s pretty well discussed at the beginning and then at any time afterwards should a late effect arise’ (HCP07);

‘I think you have to start talking about late effects from the start, from when you initiate treatment and then monitor for them on an ongoing basis’ (HCP11);

‘Our health care service is quite reactive and we tend to....patients bring us a problem and we deal with it’ (HCP03);

‘we would address when they came but there’s no telling which patients would get those problems, so if the problem comes up then we would be addressing them’ (HCP01).

'To come out the back of cancer and then live through life in this permanent shadow'

Dual justifications were given for a reactive approach to late effects management; the HCP referred to the potential impact on NHS resources but the main emphasis of their concern was regarding the possible impact on the psychological adjustment of the cancer survivor. The HCPs who were interviewed placed an importance on allowing the patient to retain hope for their future. There was a suggestion of wanting to protect the patient from *needless* anxiety regarding effects they may never experience at the point where they had already undergone their treatment and there was seen to be little that could be done to alleviate future risk.

'If they are over the moon and going on their long earned holiday because they finally finished 6 months of treatment would they want to look at the nasty side effects they may be looking forward to 6 months down the line?' (HCP06);

'If I was 88 and I'd just been through lots of cancer treatment and I just want to get on and enjoy my life and having somebody telling me that I think I'd be...well I'd either ignore it, but what you wouldn't want is people going away really worrying about all of this' (HCP07);

'They've just got over this huge hurdle and then you present them with that and think well I thought it was going to be a lot different, there was a future, but to me that doesn't offer a future' (HCP12);

'I think to come out the back of cancer and then live through life in this permanent shadow that you have to take all of these extra precautions, and some of them are marginally increased risks in your life time, it can be quite daunting' (HCP13);

'You can never be absolutely certain you haven't got cancer somewhere can you so how can you not tap into peoples existential anxiety, and give them the confidence with the information that they need without frightening them.....they're survivors physically but we want them to survive mentally as well' (HCP08).

Some people, not just patients are very susceptible to autosuggestion'

Concerns were expressed regarding autosuggestion; HCPs felt that by raising the potential of a future consequence of treatment they may induce change in the mental and/or physical state of the cancer survivor. This refers to a method developed by Coué [14] which relied on the belief that 'any idea exclusively occupying the mind turns into reality' (p22), although only to the extent that the idea is within the realm of possibility. The HCPs interviewed expressed concern that causing survivors to think negatively about the consequence of their treatment and their future health status may be detrimental to their current physical and mental health.

'I think it is bringing up potential things that they may never get and I think if they do get it and you're having a proper dialogue with them you'll tell them but some patients are...some people, not just patients are very susceptible to autosuggestion, you know they'll go home and there'll be a whole new set of things to worry about' (HCP09);

'..and in some situations I know it could possibly cause people to focus on it a little bit, label it as a post chemotherapy fatigue and therefore not allow them to move on with their lives' (HCP13).

'We need to assess whether it's actually going to benefit the patient'

It was evident that the HCPs taking part in this evaluation were not prepared to accept an assumption that providing cancer survivors with information regarding late effects would necessarily benefit them:

'They get information about the side effects of the treatment, the chemotherapy, radiotherapy anyway, so is it going to benefit them...to get those again after they've completed their treatment' (HCP01);

'I don't think we should assume that every patient is going to benefit from having this kind of detailed list of all the possible things that could occur after their treatment. I think there'll be some people actually made worse by it' (HCP04).

The variety of individual preference was recognised, it was felt that not all cancer survivors can be assumed to want the same level of information; the emphasis should be on providing each individual with access to the level of information which they feel is most beneficial to them:

'I think the essential elements are that patient has access to information about all the aspects of their life that their diagnosis or its' treatment may affect which is very far ranging, now how much any individual patient wants to know about each of those things is of course very variable' (HCP11);

'Everybody copes in a different way and if their coping strategy is head in the sand, it is their choice I think, as long as they know where they can get the information from and they can go home and think about it, I think the most important thing is that emphasis of here we are, you want to talk to us, we're available to you' (HCP09).

‘What are the likelihoods of these things happening?’

When considering the communication of potential future effects, HCPs voiced confusion regarding the actual risk of each late effect occurring and the level of risk required to warrant discussion of an effect:

‘Well I mean I suppose it would be nice to think that we could reassure people to a certain extent but I’m not quite sure, you know, I mean once again it comes down to ‘what are the likelihoods of these things happening?’ and I don’t think that we necessarily have that information so we can’t falsely reassure patients’ (HCP05);

‘The way my understanding is at the moment, medico-legally is that we are supposed to mention all serious side effects and all frequent side effects but you don’t mention all uncommon side effects or you’d be there all day with every drug you know, but then you’ve got the question of how you define serious’ (HCP04);

‘It [the care plan] should address anything that is likely to happen, which by implication implies it shouldn’t include things which aren’t likely to happen but how do you define that?’ (HCP06).

If potential consequences of treatment are considered necessary for discussion, HCPs stressed the importance of quantifying the individual’s risk in a meaningful way; it was felt that some presentations of risk information regarding potential effects can cause survivors’ to elevate the likelihood of their occurrence thus causing needless anxiety and confusion:

‘When we present risks to patients, we try to give them an idea of how common it is and we often break it down into groups of risks that are less than one in a 100 people

will get, between 1 and 10 in a hundred people will get, or many patients will get and I think that's quite helpful' (HCP03);

'I really stress the need to quantify it in terms that are understandable to individuals with varying degrees of education, that's very important.' (HCP16)

'I do think it has to be a balance between reassuring that this is expected and don't worry about it but not overloading with this is going to be so awful, how am I going to cope with that. I don't know. I think drug inserts/datasheets get it wrong. I know they do that for protection, legal ease and everything but I think they get it wrong. Most patients when they read their standard anti- hypertensive medication drug sheet think why on earth am taking this. So it has to...you have to inform but I think at the same time you shouldn't scare' (HCP06).

Discussion

The clinicians taking part in this evaluation demonstrated a reluctance to communicate the potential future consequences of treatment during the survivorship phase. HCPs appear to be sceptical regarding the benefit of providing cancer survivors with details of possible late effects following their treatment when these were felt to have been sufficiently discussed during pre-treatment consent. Preference for a more reactive approach to information provision regarding late effects received threefold justification; there was considered to be insufficient evidence of physical or psychological benefit to cancer survivors and in fact a suggestion of potential detrimental effect of providing information on potential late effects; a perceived lack of clarity on which risks required discussion and how these risks were to be presented; and it was not felt to be in keeping with the current

culture of cancer care to provide information on risk prior to reported symptoms. These justifications will be discussed in turn.

The provision of information regarding late effects was perceived by HCPs to inhibit a survivor's ability to retain hope for their future. HCPs felt that following the challenging experience of a cancer diagnosis and subsequent treatment, survivors should be encouraged to enjoy life and not be denied hope for their future. However, withholding information is not necessarily a hope instilling approach. A survey investigating preferences for prognostic information in patients with incurable cancer reported that an individualised and realistic prognosis from a confident, collaborative and supportive HCP is experienced as more hopeful than an avoidant approach [15]. However a review of preferences for prognostic information [16] found that for some patients hope and realism were irreconcilable and concluded that 'professionals have a responsibility to provide information to patients, but also to respect the need to maintain some ambiguity about the future' (p29). In a study of childhood cancer survivors, a lack of positive future expectations was identified as one of the most important determinants of psychological distress [17]; could providing information on the potential late effects of treatment suppress an individual's optimism? This poses a difficult dilemma for HCPs when determining the level of information to disclose to their patients. Prospective research evaluating the impact of providing survivors with information on late effects could offer HCPs with clarity regarding the benefits or consequences of this practice.

The complexity of identifying and communicating risk should not be underestimated. Questions regarding *which* risks warrant discussion in terms of their severity or likelihood and subsequently *when* and *how* these risks should be conveyed are valid and require consideration. Ever developing treatment protocols could complicate the certainty with

which HCPs can quantify the future potential risks of cancer survivors. Web-based SCP tools are able to identify potential future risks using what we assume to be accurate algorithms but awareness of and referral to web-based cancer information resources is low among clinicians [18]. Evidence suggests that even if web-based information is independently sought and accessed by patients they subsequently seek an interpretation of the information from their clinician [19] therefore it is imperative that HCPs are skilled in appropriately communicating these risks.

Information on future potential risks must be presented to cancer survivors in a clear and meaningful way in order to raise awareness without inducing disproportionate fear. A recent review of risk communication advises that natural frequencies are easier to understand and interpret than percentages or probabilities [20]. A study of adolescent cancer survivors [21] demonstrated that interpretation of risk is affected by past experience. Survivors have by definition already experienced the impact of a cancer diagnosis and this may affect the way they interpret information on late effects. Information on the potential risks of cancer are distressing to any individual but survivors are likely to feel particularly vulnerable due to their earlier experiences and can be launched into an immediate state of heightened anxiety. It is also important to be mindful that not all patients find statistics useful, the CancerHelp UK website [22] gives the reader a forewarning that potentially distressing information is about to be presented and offers the reader the chance to 'skip this page', this may be a useful consideration if presenting cancer survivors with potential future consequences of treatment.

Evidence from childhood/adolescent research supports the view of the participating HCPs that the current culture of cancer care is not to proactively raise survivor awareness of their future potential risks. Hess *et al.* [23] reported that 66% of survivors of malignant

lymphoma (85/128) were not aware of any potential late effects. In contrast to paediatric oncology, there are few guidelines for the identification and management of late effects in the adult cancer setting. Late effects expertise was identified by a sample of UK health care professionals as one of the most important factors in delivering a quality follow up service; 'learning more about late effects' was selected as the top priority of follow-up appointments [24]. However, the data from our evaluation suggests that the current culture of cancer care is for the HCP to retain this expertise to enable effective monitoring for late effects rather than imparting their knowledge to individual cancer survivors again post treatment until symptoms are reported and the information is felt to be potentially relevant and beneficial.

The Survivorship Sub-group of the National Cancer Research Institute Primary Care Clinical Studies Group recently proposed a framework for risk stratification [25]. They offer a definition of risk stratification as 'the process of quantifying the probability of a harmful effect to individuals resulting from a range of internal and external factors (e.g., demographic characteristics, genetic make-up, medical treatments) and propose that only those long-term and late effects which meet a pre-determined criteria qualify for risk stratification. This criteria is a modification of the Wilson - Junger [26] criteria for an effective screening test. This criteria stipulates, in part, that in order for a late effect to warrant risk stratification it would need to be considered an important health problem for which there is an effective intervention available to the survivor. Watson and co-authors identify that there are currently very few late effects which qualify for risk stratification using this full criteria and recommend that health care practice should continue to manage late effects as they arise. These recommendations are in line with the preference and practice of health care professionals who took part in our evaluation.

Limitations

This evaluation used a purposive sample of health care professionals known to have an interest in cancer survivorship; whilst this may limit the representativeness of the sample it was felt to offer more insightful responses to the concept of providing survivorship information. The health care professionals who took part in this evaluation were asked to create a care plan for hypothetical patients using a web-based care plan tool, whilst it is not the aim of this paper to evaluate the tool itself, it is necessary to acknowledge that the responses of the health care professionals to the concept of providing cancer survivors with information on potential late effects may have been influenced by the representation of late effect information in the care plan created. It is the opinion of the authors that the web-based care plan tool utilised by this evaluation is not dissimilar to other available care plan tools; future research should consider other care plan tools when asking health care professionals to consider the appropriateness of providing survivorship information. This evaluation only considered the views of health care professionals and is not able to present the perspective of cancer survivors themselves. Consideration of survivor preference for information on potential late effects of cancer is required in addition to research evaluating the actual benefit to survivors who are afforded this information.

Conclusion

Consideration of the benefit of providing cancer survivors with information on the potential late effects of their cancer and its treatment is in its relative infancy as a research area. Future research is required prior to encouraging a culture of proactivity regarding discussions of future potential risk. More research studies are needed to accurately quantify and predict the late effects survivors may experience; determine the preference of survivors regarding provision of this information; establish the availability of effective interventions to address these identified risks; and ascertain the most effective approach

to communicate potential risks to cancer survivors. In light of our evaluation, if clinicians are encouraged to present survivors with information on potential late effects of cancer and its' treatment they may need support in considering ways of presenting survivors with reality whilst being mindful of their need to retain hope during the survivorship phase.

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Conflict of interest

The authors do not have any conflicts of interest to disclose. The authors have full control of all primary data and agree to allow the journal to review this data if requested.

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