



Editorial

Comfort Blanket or Clinical Need? The Role of Follow-up for Cancer Survivors



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Follow-up after treatment for cancer currently varies widely depending on the hospital, surgeon, oncologist, cancer diagnosis and sometimes the wishes of the patient. There seems to be no gold standard. Some are followed up frequently with scans, blood tests and physical examinations for anything up to and beyond 10 years. Others are offered 'open access' or 'patient-led' follow-up and some are referred back to their general practitioner with a guarantee of rapid access back to hospital appointments in the event of signs of recurrence.

This editorial addresses follow-up and related survivorship issues from the patient's view point.

Method

Members of the Independent Cancer Patients' Voice (ICPV)* and some National Cancer Research Institute Consumer Liaison Group (NCRI CLG) members* designed a questionnaire, which was distributed via several patient groups. The questionnaire explored patients' feelings about their own experiences of follow-up and also other models of follow-up, e.g. referral back to primary care.

Findings

In total, 109 people responded to the questionnaire. Most (68%) were female; 39% were breast cancer patients, whereas the remainder had been diagnosed with prostate,

lung, pancreas, head and neck, rectal, renal, testicular and endometrial cancer, myeloma or mesothelioma. The date of diagnosis spanned 27 years, from 1986 to 2013. Treatments experienced included surgery, chemotherapy, radiotherapy, hormone therapy and bone strengthening treatments.

Were Patients Happy with Their Follow-up?

We tried to determine whether patients were happy with their follow-up, whether it met their needs or if there were concerns that were not met. Responses showed that follow-up to cancer treatment has some way to go in order to successfully address all patients' needs and concerns.

Just over half the responses were positive:

Follow-up was excellent and I have been always been able to have an additional appointment at any time if I have any concerns.

Absolutely – nurses are at the end of a telephone in the clinic.

However, many of the rest cited problems and concerns that were not met:

Follow-ups did not meet needs, many concerns not met. Refusal to discuss new treatments or treatments that were available in England but not in Wales.

Issues with hot flushes – not taken seriously by my surgeon.

Patients' Confidence

A concern raised by an ICPV member was that patients may have a problem with deciding when and if they need to see health professionals in their follow-up period. However, most of the responses to this question were positive, with

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* For more information about the Independent Cancer Patients' Voice: www.independentcancerpatientsvoice.org.uk and the Consumer Liaison Group: www.crn.nihr.ac.uk/cancer.

around 72% of respondents indicating that they felt confident to make this decision. Many of these qualified their confidence by explaining that they had either researched the subject carefully themselves or had a relevant background, e.g. nursing. Some expressed concern about others who may not have this knowledge or background to give them confidence:

I do feel confident to ask and make an appointment as I feel I have negotiated some of my treatment options with a lot of independent research and asking questions.

Yes, but only because I knew a great deal about ovarian cancer.

I would ask if I was uncertain about anything – but I feel this disadvantages patients who are not as confident or perhaps elderly or just not well educated about their disease and what to look for.

There was an underlying unease among some respondents about taking up valuable National Health Service (NHS) time that could be needed by other people:

The main concern I have is taking up valuable NHS resources and funding that may be of greater need to other patients.

Not at all confident as do not want to be a nuisance!

Some seemed to be so worried about making an unnecessary fuss that they unknowingly compromised their own health:

I didn't like to bother them in case it was nothing... I had a few lumps and bumps investigated in 2011, all benign and when I noticed one area getting bigger I just waited as I knew my MRI scan was due soon... but the area of concern was a recurrence.

I just felt that if nothing felt too bad I would leave it until the healthcare appointment.

The responses of some who said they did not feel confident in making this decision indicated that education was the key. In these cases the patients needed clearer instructions on what to look out for and when to be worried:

I would have liked to be given more information of what to look for and the possible chances of a recurrence. This was never discussed and therefore I was in the dark when it came to recognising symptoms of recurrence and secondaries.

There was a feeling among some that the cancer should not take over their life once the treatment had finished, but concern that they should be made more aware of when to be concerned:

I think up to a point follow-up should continue, but life needs to continue and become 'the new norm' once again, so that cancer doesn't become the mainstay of your life.

General Practitioner Follow-up

We wanted to determine how people felt about follow-up being carried out in the primary care setting. Less than

5% of respondents reported personal experience of this model of follow-up. All of these had been happy with it, but most suggested that this may not be the case for everyone.

Almost 50% of respondents felt certain that this was not a good model for follow-up. The most common reason for opposing this model was that the general practitioner is not a specialist and may not be confident in recognising signs of potential cancer recurrence. Clearly this subject evokes some passionate and heartfelt reactions:

I can't state strongly enough that I think this is not a good direction. General practitioners have little knowledge about cancer except the basics in my experience and it is frightening to think that this might be the way things go.

I think this is a backward, dangerous move. General practitioners are generalists and we can't expect them to know everything about cancer. If specialists sometimes get it wrong how can we expect people in primary care to get it right?

Others felt that the model could work, but only where appropriate training had been given and where a patient had a good relationship with their general practitioner:

This has been my experience. This is so dependent on the general practitioner and practice team. My general practitioner was quite clear that I was probably the expert, and when he couldn't see a sensible solution we could agree on, we would have to contact Leeds for specialist help.

Some suggested it might be a good model for later follow-up:

I am just experiencing this 5 years after recurrence and my initial reaction is quite apprehensive, although I appreciate it is a good thing as I have reached a milestone 5 year mark. I would not be comfortable with this any less than 5 years.

Collecting Long-term Follow-up Data

We also wanted to find out about patients' views on collecting long-term follow-up data, even in cases where long-term follow-up itself may not be necessary. Most responses were positive and supportive, with almost all respondents confirming they'd be very happy to contribute data. Many felt that collecting such long-term data was essential to cancer research and advancing treatment. There was real concern among some that the treatment given for the cancer may itself cause later problems:

It is very important to collect data on long-term effects of cancer and its treatment. I am 9 years since diagnosis and I have had very significant long-term side-effects of treatment that have left me with disabilities.

Suggested methods of collecting these data were e-mail, telephone and post, with consent and data protection in place.

Conclusions

A recurring theme in the responses to this survey was that follow-up to cancer treatment should be patient based and individualised. No two patients will need or want exactly the same follow-up. As one respondent sums up:

I feel strongly this should be patient based, because each person has different needs and different levels of anxiety about this. While a good idea for some, this may be worse for others. With this follow-up, as with any other illness needing regular follow-up or monitoring in some form, I feel it is important to allow for individual choices.

Sensitivity will be needed to ensure that the effect of a cancer diagnosis is not underestimated when arranging more minimal follow-up. Good communication between

the patient and the oncologist will be key to providing follow-up to suit each individual. Adequate time with the clinical nurse specialist or another member of the multi-disciplinary team before discharge will help to ensure that the patient understands *how* their follow-up will proceed and crucially, *how* to recognise signs of recurrence themselves and then *how* to act on any findings.

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