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Review

Patients' expectations and preferences regarding cancer follow-up care

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ABSTRACT

Introduction: Most survivors of cancer enter a follow-up routine after their treatment, the aim of which is to detect recurrence, provide psychological support, monitor treatment-related side-effects, and to evaluate care. Due to rising numbers of people with cancer and better survival of these patients, current follow-up routines are under pressure. We reviewed the literature on patients' expectations and preferences regarding this care.

Methods: We systematically searched the databases of Pubmed, CINAHL, and PsychInfo. Studies were screened and data extraction was double performed by three authors. Data were collected from quantitative and qualitative studies and described thematically.

Results: After screening, 12 full-text articles were included, comprising 849 patients aged from 28 to 90 years. Patients expect follow-up visits to detect recurrence of cancer. They want to undergo extensive testing to get reassurance. Furthermore, patients expect relevant information to be provided and to get advice about different aspects of their illness. Psychosocial support is also expected. Patients express a desire for consistency of care as well as continuity of care, and prefer long and intensive follow-up.

Discussion and conclusion: After cancer, patients appear to lose confidence in their bodies and fear cancer recurrence after the end of treatment, which may lead to intensive screening wishes. This is not desirable, since care for cancer is already under pressure due to rising numbers of survivors. We have to ensure that follow-up routines are sustainable and effective. Patients should receive good information about the need for follow-up tests. Doctors should be trained to give this information.

Illustrative case

Martha is 39 years old. A year ago, she was diagnosed with breast cancer. She had one positive lymph node. After breast conserving surgery she received radio- and chemotherapy. This was a hard time which she endured well. She was a role model for the current slogan of the Dutch Cancer Society 'let's fight against cancer'. She was supported very well by her husband, who also helped with the care for their young child. She still uses anti-hormonal therapy and trastuzumab and started working half-time two months ago. While picking up a box at her work she suddenly felt severe back pain. For the first time she completely panicked. She ran from her workplace and sought the support of her parents. The thought of an early death came to her for the first time.

Introduction

Due to an ageing population the number of people with cancer is expected to rise in the foreseeable future [1]. Luckily, most common cancers have been detected at a more favorable stage over the past

decade, staging and treatments have been improved, leading to more curatively treated patients [2]. A cancer diagnosis and the subsequent treatment is frequently perceived as a life-altering experience, having a substantial physical, psychological, social, and emotional impact on the patient, their family and friends [3–6].

After treatment patients make the transition to being a survivor of cancer. This phase brings new challenges for survivors, and the transition is not always easy [4]. Survivors of cancer return to their daily routines while they are at risk of new cancers [7–9]. They also face a variety of possible long term effects, physically, psychologically and emotionally [10,11]. Therefore, most survivors of cancer enter a follow-up regime after completion of treatment. These follow-up regimes have multiple goals. The most important goals are: early detection of recurrences, provision of psychological support, monitoring treatment-related side effects, and the evaluation of care [12].

Debate about the optimal organization of this follow-up care is ongoing. To provide a patient perspective to inform this debate, we reviewed the literature on expectations and preferences of survivors of adult cancer about their follow-up care. We will discuss the

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implications for current follow-up routines.

Methods

Definition of follow-up care

For the purpose of the current study, we defined follow-up care as follows: “Planned care after the end of initial cancer treatment. This care involves regular medical check-ups in an organized way and is not patient-initiated.”

Eligibility criteria

Studies were included if they met the following criteria: description of expectations or preferences of survivors of cancer about follow-up cancer care; adult survivors of cancer (≥ 18 years); curatively treated or at least some life expectancy; data gathering after the end of treatment; and reported original data about survivors. Studies about adult survivors of juvenile cancer, patients in the terminal phase of care and patients during initial treatment were excluded. If studies reported data on a wider scope, we presented data from the questionnaires or interviews only.

Information sources and search strategy

The databases of Pubmed, CINAHL, and PsychInfo were systematically searched using a combination of MeSH and free-text words for cancer, survivors, preferences, beliefs, expectations, and follow-up care. Supplementary Table S1 shows the full search details. The search criteria were combined with the AND statement. No date or language restrictions were applied.

Data collection

Studies were screened for eligibility based on titles and abstracts by three authors: one screened all titles and abstracts (DB), two other researchers (AJB and GHB) both screened half of the titles/abstracts. Disagreement was discussed until consensus was reached. The same procedure was applied to the screening of full-texts for eligibility for inclusion and to the data collection of the included studies. From the included full-texts data were collected about the authors, country, study type, study aim, patient’s in- and exclusion criteria, the percentage of patients that were willing to participate (response rate), patient characteristics (age and gender), and tumour characteristics and treatment (localization, staging, type of treatment, and time since treatment). Data on patient’s expectations and preferences about cancer follow-up content, duration and frequency of follow-up care were extracted.

Results

Selection of articles

Fig. 1 summarizes the search and selection process. We found 847 articles and after removal of duplicates we screened of 812 titles and abstracts. We excluded 772 articles and screened 40 full text articles, leading to the exclusion of another 29 articles. Finally, 12 articles were included for data extraction: 5 used quantitative research methods, and 7 used qualitative research methods.

Patients

The studies comprised 849 patients in total, with ages ranging from 28 to 90 years. The majority of these patients were breast cancer survivors, followed by soft tissue sarcoma, haematological cancer including lymphoma, ovarian cancer, germ cell cancer, and lung cancer survivors, as well as some prostate, colon, liver, thyroid, and skin

cancer survivors. More information on study aims, applied in- and exclusion criteria, and patient characteristics is displayed in supplementary Table S2.

Results from articles

The expectations and preferences of patients regarding the content, frequency and duration of follow-up care are displayed in Tables 1 and 2. Below we will provide a thematic overview of the main findings.

Detection of recurrences

Patients reported that the main reason to attend follow-up services was to check for cancer recurrences [13]. Detection of recurrences was also frequently reported as something patients expect their follow-up to provide [14–16].

Providing reassurance

Patients also mentioned to expect their follow-up care to provide them with reassurance about their health. This was mentioned by three-quarter of the younger adult survivors [13] and half of the lung cancer survivors [17]. Follow-up visits were viewed as reassuring and functioned as a safety net for patients [18].

As was hypothesized by one of the studies, there appeared to be an almost unanimous belief that surveillance, manifested by testing, provided reassurance that cancer was in complete remission [14]. It appeared that patients received reassurance from tests and examinations and wanted more tests, such as blood tests, bone scans, X-ray, mammography in the case of breast cancer or even total body scans to be a part of their follow-up [14,16,17,19,20]. Women in one study stated that they were not reassured by mammography alone [16]. Clinical investigations were perceived as the most important reason for attending follow-up services [20].

Breast cancer survivors in one of the qualitative studies mentioned they wanted their doctor to speak about “cure” for cancer instead of cancer being “in remission”, exemplifying the need for reassurance [19]. Paradoxically, apart from providing reassurance follow-up visits also evoked feelings of fear and anxiety [14,19].

Information and advice

Patients expected follow-up visits to address information and give advice about different aspects of their illness. Information about late effects was important for about 40% of the younger adult survivors [13]. Breast cancer survivors deemed information on long-term effects and side-effects very important, as well as information on prognosis, prevention and lifestyle [20,21]. Lifestyle advices were also mentioned as important by younger adult survivors [13]. Almost 10% of lung cancer survivors reported advice and information to be useful in their follow-up routines [17]. Breast cancer survivors reported fatigue, pain, genetic factors and prevention of breast cancer to be important discussion topics during follow-up visits [21].

Psychological/emotional support

A fair proportion (17%) of younger adult survivors of different cancer types also reported psychological support to be of importance in follow-up routines [13]. This was also expressed by breast cancer survivors who felt that psychological wellbeing could be discussed more during follow-up visits, as were late symptoms of depression and fear for recurrence [15]. Survivors of cancer appeared to have high expectations of their doctors in terms of the provision of emotional support [14].

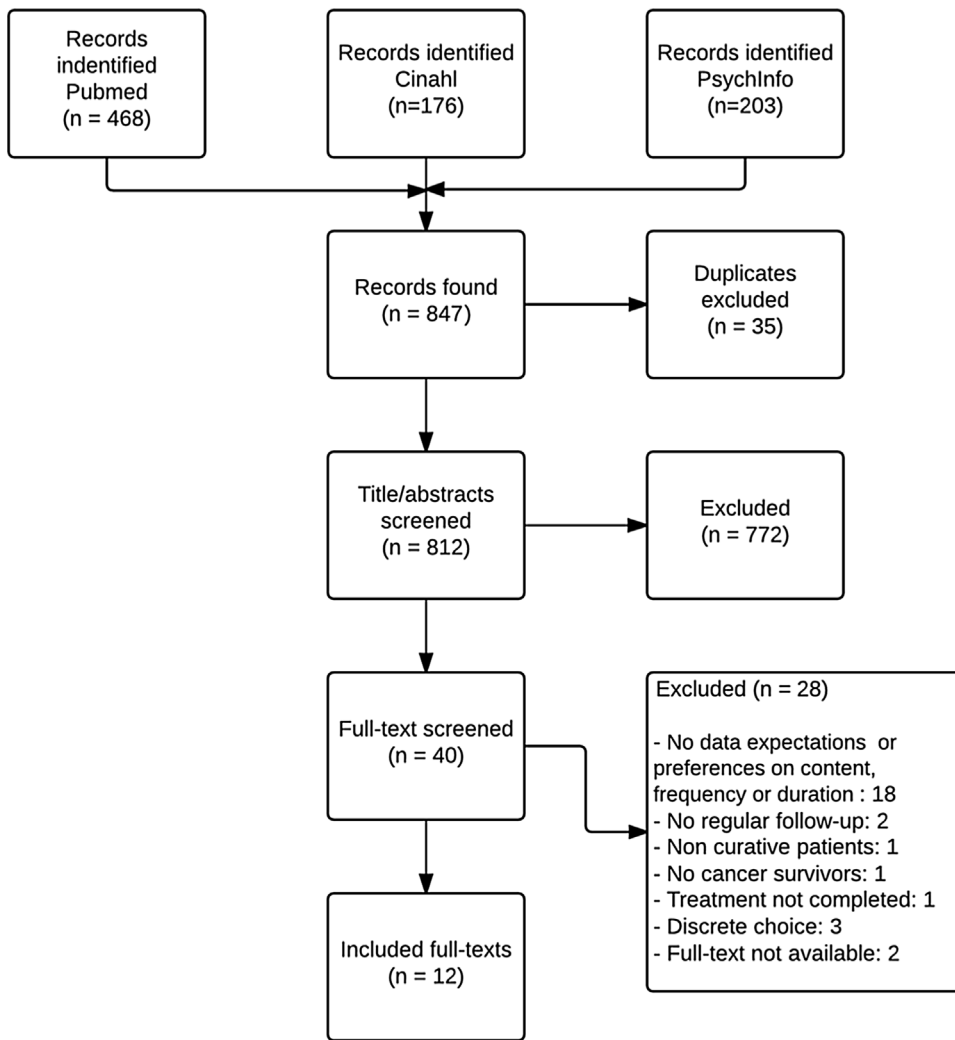


Fig. 1. Flow diagram displaying article selection.

Continuity of care/doctor

Breast cancer patients expressed a preference for continuity regarding the follow-up care provider, which made it possible to develop a relationship with this follow-up care provider [22]. When this relationship has been established, follow-up visits were more appreciated by patients [18]. Another study also showed the importance of continuity of care, especially regarding the need for consistent advice [15]. Patients in that study expressed that communication between different team members being involved in follow-up care is therefore crucial.

Lifetime follow-up

Many survivors in the included studies appeared to prefer lifetime follow-up for cancer. Two Dutch studies among breast cancer survivors showed that more than half [20] and almost two thirds [21] of surveyed survivors preferred lifelong follow-up. Interviewed survivors of breast cancer also expressed a wish for a longer follow-up period, until lifelong [16,23]. Reasons for this were anxiety for recurrent distant metastasis and the need for guidance and reassurance.

Frequent follow-up

From the few studies that examined preferences about frequency of follow-up visits it appeared that most survivors of cancer would like to continue the frequency as it is [16]. Survivors expressed in another qualitative study that they felt vulnerable during the period after the

end of treatment and before their first follow-up visit and that they would like contact with the hospital during this period [18].

Discussion

Main findings

From a cancer survivor perspective on follow-up care, the following themes are considered as important. At follow-up visits recurrences are expected to be detected. But maybe more important, patients would like to get the reassurance that they have no recurrences. Patients would like to undergo extensive testing to get as much reassurance as possible. They expect that during follow-up visits, relevant information will be addressed and they expect to get advice about different aspects of their illness. Psychosocial support is one of the aspects that should be addressed. Consistency of care as well as continuity of care is very important for patients. The lifetime increased risk for cancer recurrences makes patients vulnerable, leading to a wish for long and intensive follow-up periods.

Implications

According to patients, the ideal follow-up care provider is continuously available, has strong psychosocial competencies, has extensive knowledge on cancer diseases as well as its treatments, and has access to extensive facilities to exclude the presence of cancer recurrences. In general, follow-up can be provided by the hospital doctor

Table 1
Expectations and preferences of survivors of cancer about the content follow-up care.

Absolom et al 2009	<p>Reasons for attending follow-up care</p> <ul style="list-style-type: none"> • Check for cancer recurrence: 90.3% • Get reassurance about health: 74.1% • Get the best medical care: 68.3% • Help staff learn more about late effects of cancer: 50.2% • Get information about late effects: 42.1% • Talk to staff who understand what I have been through: 23.6% • Get advice about how to keep healthy: 23.0% • Receive psychological support: 16.8% • Get advice about everyday things, such as insurance: 10.7%
Adewuyi-Dalton et al	<ul style="list-style-type: none"> • Breast cancer patients expressed a preference for continuity (same doctor): inability to build a relationship, uncertainty about the inability to build a relationship with the doctor; uncertainty about the expertise of different staff; the apparent lack of knowledge of the individual case history or comorbidity; the difficulty of asking questions; and, concern at the prospect of being told bad news by a stranger. not all women were worried about discontinuity, they advantage in second opinions. • The availability of specialist expertise in follow-up care, especially in first years was valued • Lack of time during consultations led to dissatisfaction
Brennan et al	<ul style="list-style-type: none"> • High level of satisfaction with current follow-up care. Women felt that the most important reason for follow-up care was to address the issues of ongoing treatment and detection of cancer recurrence. • Psychological well-being and menopausal symptoms were mentioned as the areas that should be discussed more often during consultations. Late symptoms of depression and fear for recurrence were mentioned. • Continuity of care was deemed very important and communication between team members was seen as crucial. The need for consistent advice was raised.
Cox et al 2006	<ul style="list-style-type: none"> • 48.3% of lung cancer survivors wanted a general check-up and reassurance from follow-up care. • 19.4% wanted to ask questions and help with specific problems. • Survivors expressed what they thought usefulness about follow-up care • Reassurance: 38.7% • Given some form of treatment: 16.1% • Updated on their condition: 16.1% • Advice/information: 9.7% • Not stated: 9.7% • Nothing: 6.5% • Everything: 3.2% • Of the patients interviewed, few were able to articulate exactly what they would want from follow-up as they described the fact it was all “unknown” with regard to what would happen to them and that they only found things out as they went along, there was little forecasting and predicting of potential care pathways. • Patients valued the hospital follow-up visits, which were seen as “check-up appointments”, because it gave them access to tests that they would not otherwise have, for example, X-ray. They did not necessarily want to visit the clinics but were looking for reassurance when they did attend and the X-ray was seen as one way of achieving that.
Damery et al 2014	<ul style="list-style-type: none"> • All participants felt attending follow-up visits was important. • 86% of patients felt it important to be included in decisions about follow-up regime • 73% of patients stated that the most important broad aspect of follow-up care was the nature of clinical investigations undertaken
De Bock et al	<ul style="list-style-type: none"> • Patients had high-expected benefits from follow-up, especially from mammography and early detection of a breast cancer recurrence. • 88% of patients believed that early detection of distant metastases would contribute to cure. • Breast self-examination as an instrument of early detection of breast cancer was not highly valued • Patients preferred additional investigations (like X-ray and blood tests) to be part of routine follow-up visits. • Being able to discuss prevention of breast cancer, hereditary factors, and changes in the untreated breast were considered as very important by most patients. • Women with a higher fear of recurrence preferred a more intensive routine follow-up schedule. • Information on long-term effects and side effects of treatment and prognosis was considered very important, as well as discussing prevention of breast cancer, hereditary factors, and changes in the untreated breast. • More than half of the patients preferred lifetime follow-up, twice a year and performed by a hospital doctor.
Van Hezewijk et al	<ul style="list-style-type: none"> • Aspects highly appreciated to be part of the follow-up program were information about prognosis, side effects, life style habits and additional investigations • Important discussion topics were: fatigue, pain, genetic factors, prevention of breast cancer and arm function/lymph edema • Less valued aspects were information about peers, conversations with psychologists or social workers, breast reconstruction, and acceptance by family/friends
Kwast et al	<ul style="list-style-type: none"> • For patients the main purposes of follow-up were: examination of the breast, followed by reassurance, guidance of patients and answering questions. • Mammography was considered as the most important control. • Some women were not reassured by a mammogram only. Especially if nothing had been seen at the mammogram at the time of their initial diagnosis. • About a third of the patients were disappointed that additional tests, such as blood tests or a total body scan, were not performed. They felt that you could never be sure that something is wrong elsewhere, without a total body scan
Laporte et al	<ul style="list-style-type: none"> • All of the women said that they lived with a feeling of uncertainty caused by the fear of relapse. This feeling was exacerbated by rounds of examinations and follow-up visits. • Paradoxically, most patients were in favour of complementary examinations, because they provided reassurance • They would have liked to hear the word “cure,” but their doctors spoke only of “remission.” The cancer expert seemed to them to be the person best able to give them reassurance. • At the end of their institutional treatment, many women felt abandoned, as if in a vacuum. Consultations at the cancer centre stopped without an official handover to the GP or another outside doctor.
Lydon et al	<ul style="list-style-type: none"> • Unpleasant clinical examinations in follow-up are necessary and important for indicating signs of disease recurrence and progression • Follow-up visits were viewed as ‘reassuring’ and ‘a safety net’. • All participants perceived that the purpose of their visits to the outpatient follow-up clinic was for medical staff to monitor their disease status and check

(continued on next page)

Table 1 (continued)

	<ul style="list-style-type: none"> for signs of further problems. The relationship that is established between patients and specialist oncology nurses, makes a follow-up appointment appreciated, even if they had no need for information at that particular time.
Miedema et al	<ul style="list-style-type: none"> The majority reported a positive experience with follow-up care. Most dominant theme was the fear of recurrence Many wanted invasive exams such as “blood tests” and “bone scans” on a regular basis. There was almost unanimous belief that surveillance, manifested by testing, was important because it provided assurance that the cancer was in complete remission. Paradoxically, cancer testing brought with it a lot of anxiety Emotional support provided by physicians was considered important. In fact, participants had very high expectations of their FPs’ and specialists’ support.
Sandeman et al	<ul style="list-style-type: none"> A good communication with the consultant and good experiences with other staff within the oncology department are critical, as this relationship provides stability, continuity, and safety. This good relation serves to balance the issues that patients bring to clinic (anxiety, vulnerability, uncertainty, and symptoms) and the issues (reassurance, relief, encouragement) that patients take from clinic

Table 2

Expectation and preferences of survivors of cancer about the frequency and/or the duration of follow-up care.

De Bock et al	<ul style="list-style-type: none"> More than half of the patients preferred lifetime follow-up, twice a year, performed by a hospital doctor
Van Hezewijk et al	<ul style="list-style-type: none"> Almost two thirds of patients preferred lifelong follow-up visits
Kwast et al	<ul style="list-style-type: none"> Most patients were uncomfortable with the idea that follow-up could become shorter than 5 years. Many patients preferred an even longer follow-up period (until lifelong) than currently offered. Reasons for this were: anxiety for recurrent distant metastases, the need for guidance and reassurance, or the fact that the national screening program me only starts at age 50. Only a few patients indicated that the duration of follow-up could be shortened. Regarding the preferred frequency of visits, almost all patients agreed with the recommended frequency according the guidelines
Lydon et al	<ul style="list-style-type: none"> The time between the end of treatment and the first follow-up visit (usually three months) was when participants reported feeling most ‘vulnerable’. They would have liked more contact with the hospital at this time but considered it inappropriate to contact the hospital with their concerns. The structure of appointments could inhibit patients from reporting any concerns or seeking information, as they did not want to bother busy doctors and nurses when they knew that a hospital appointment was forthcoming
Sandeman et al.	<ul style="list-style-type: none"> Although some participants were anxious about attending, all expressed the desire to continue follow-up.

that was responsible for the cancer treatment. Historically, this was the preferred strategy, but due to increasing numbers of survivors and newly diagnosed patients with cancer, this is considered not to be feasible anymore [24–26]. Given the relevance of continuity of care and doctor, alternative strategies have been proposed, for example the provision of follow-up care by hospital nurses or in primary care [27,28].

The nurse as provider of follow-up cancer care

Hospital nurse led follow-up care has been studied as an alternative model of follow-up care provision. For breast cancer, prostate cancer and lung cancer survivors the results of a systematic review suggest no statistically significant differences between nurse led or hospital follow-up for survival, recurrence rates and psychological morbidity [29]. It appears that health related quality of life for cancer survivors receiving nurse led follow-up settings is either equivalent or slightly better [28,29]. Nurse-led follow-up care appears to be accepted by patients [30].

Follow-up cancer care provided in primary care

Substitution of routine follow-up care to general practitioners (GPs) also has been suggested as an alternative for hospital based follow-up care for cancer in many countries [26]. GPs provide holistic care and are continuously involved in care for patients. Evidence from randomized controlled trials suggests GP-led follow-up is safe in terms of detection of recurrences, without effects on health related quality of life, anxiety, depression or patient satisfaction [31–33]. Whereas qualitative studies suggest that patients of breast or colorectal cancer consult their GP for informational purposes regarding cancer, lifestyle advice, and psychosocial support [34,35], patients do not favour the GP

as follow-up care provider [18,21,36]. However, other studies suggest that provided there is good communication between GP and specialist, and the GP has knowledge, skills, and time available, a fair proportion of patients appears to be willing to consider GP-led follow-up care [19,34]. Moreover, patients who received primary care based follow-up show greater satisfaction with care compared to patients who received hospital care [31].

Are these models compatible with patient expectation and preferences?

It appears that both hospital nurse-led and GP-led cancer follow-up care provide similar outcomes in terms of detection of recurrences and survival as compared to current hospital doctor follow-up. Since both nurses and GPs tend to have more time available for a patient compared to hospital doctors, and possibly have more psychosocial competencies due to the nature of their care, these models align at least partly with patient expectations and preferences. However, patients often feel that the GP is not knowledgeable enough about cancer [15,35], which is something patients expect from their follow-up care provider. Also, given the preference of patients to be extensively tested the GP option does not seem to correspond with their wishes. The nurse-led option, which often is situated in a cancer clinic or hospital might prove to be more in line with patients preferences.

Implications for practice

It appears from this review that patients want intensive follow-up which consists out of a lot of testing. Earlier research also showed patients’ beliefs about the aims of follow-up care do not correspond with the aims mentioned by the guidelines [12]. This is probably due to loss of confidence in their bodies and fear for cancer recurrence, which might lead to a desire for intensive screening on recurrences. This is

understandable but not desirable since care for cancer is already under pressure due to rising numbers of survivors. We have to ensure that follow-up routines are sustainable and effective. It might also be possible that patients get worried when they assume that doctors find testing necessary. Therefore, patients should receive good information about the usefulness of follow-up tests. Doctors should be trained to give this information.

Martha

The loss of confidence in her body in Martha's case is frequently experienced by survivors of cancer. Her care provider should recognize that and explain to Martha that this is normal and that this usually improves over time. Her follow-up provider should be aware of this and explain to her that more diagnostic testing for recurrence is not the solution to deal with this uncertainty. This might be difficult for a doctor when she is uncertain herself.

Contributors

All three authors contributed equally to the preparation of this review.

Conflict of interest

The authors declare that they have no conflict of interest.

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Provenance and peer review

This article has undergone peer review.

Appendix A. Supplementary data

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