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Cancer rehabilitation: Psychosocial rehabilitation needs after discharge from hospital?

A qualitative interview study

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Abstract

Objective. This study explores former cancer patients' psychosocial rehabilitation needs after hospital discharge. **Method.** Three focus-group interviews with 15 patients. **Results.** Five main areas were identified: (1) Need for continuous support and information about rehabilitation opportunities; (2) Support to the family; (3) Psychological help also addressing fear of relapse of cancer; (4) Needs for social support; (5) Needs pertaining to how friends and acquaintances relate to the patients. **Conclusion.** Each of these aspects should be carefully considered for each patient, preferably by one assigned healthcare provider. Fear of cancer relapse prevails among the patients, the family and the social network and it is important in relation to psychosocial rehabilitation.

Key Words: Cancer, family practice, continuity of patient care, family medicine, neoplasms, rehabilitation

Recent years have seen a rapid rise in the number of diagnosed and the number of cured cancer patients [1,2], and a concomitant upsurge in rehabilitation efforts [3].

The World Health Organization (WHO) defines rehabilitation as: "a process aimed at enabling persons with disabilities to reach and maintain their optimal physical, sensory, intellectual, psychiatric and/or social functional levels ..." [4].

It has been proposed that cancer rehabilitation should be an integral part of the care plan and that it should enjoy a status equal to that of surgery, radiation, and chemotherapy [5]. The patients' rehabilitation needs should already be considered at the time treatment is being planned [6]. After discharge, patients are facing a life much different from what they experienced before the disease set in, and many challenges may appear that did not exist or were not apparent during their hospital stay. In another study [7] we analysed the role of the GP in

relation to cancer rehabilitation. Whereas the hospitals were not geared to handle psychosocial issues according to the hospital physicians, the GPs were, indeed, willing to address these issues [7]. However, there is a lack of knowledge on the patients' views on

The cancer survivor's rehabilitation needs reach far beyond the physical impairments from the cancer and its treatment.

- The cancer survivor often has psychosocial rehabilitation needs which are met neither by the healthcare system nor by others.
- Fear of cancer relapse seems to be an important element in the psychosocial rehabilitation process.
- The patient needs continuing contact with relevant healthcare personnel after discharge and continuous monitoring of his/her rehabilitation needs.

Table I. Summary of participating patients.

	Male		Female	
	Urban	Rural	Urban	Rural
Young	Testicular cancer ^{1,5}	C. coli duke C. ^{2,3}	Hodgkin's lymphoma ^{2,4} T-lymphoblast. lymphoma ^{1,4} Lung cancer ^{1,5}	Cancer ventriculi ^{1,3} Lymph cancer ^{1,5}
Over 50 years	Rectal cancer ^{1,3}	Cutaneous leiomyosarcoma Right crus ^{1,4} Kidney cancer ^{1,5} Brain cancer ^{1,5}	Lung Cancer ^{1,5}	Mammary cancer ^{2,4} Mammary cancer ^{2,3} Acute myeloid leukaemia ^{1,3}

Nottes: Identified by: ¹Consultant (11 persons). ²GP (4 persons). Living and interviewed in the catchment area of hospital: ³University Hospital of Aarhus; ⁴Herning/Holstebro Hospital; ⁵Vejle Hospital.

these matters. The aim of the present study was to explore former cancer patients' psychosocial rehabilitation needs after hospital discharge.

Material and methods

Patients

In order to cover the diversity among patients treated for different types of cancer, we conducted three focus-group interviews (FGI) with 15 patients. Inclusion was based on judgement sampling and aimed at obtaining maximum variety in gender, age, type of cancer, and living in a rural vs. urban area [8].

The patients were living in the catchment area of three different types of hospitals: a local hospital (Herning, see Table I), a major local hospital (Vejle), and a university hospital (Aarhus). The interviews were conducted in undisturbed meeting facilities outside hospitals. To minimize the risk of leaving important aspects untouched, we asked hospital physicians and GPs to identify potential informants between 18 and 75 years of age, willing to participate and able to speak freely in a group [8].

Interview guide

The interview guide was semi-structured and used open-ended prompt questions [9,10] aiming to explore former cancer patients' rehabilitation needs after hospital discharge. The interview guide was based on an extensive literature review. We chose FGIs with the aim of obtaining synergetic effects, and we encouraged the informants to discuss issues in relation to their own experience [10].

The interviews

We initially encouraged the informants to tell the group about what they had experienced in relation to the rehabilitation theme. In practice, they often

started describing their treatment, situation, and needs. The interview guide worked as a checklist of topics that should be brought up for discussion. During the interviews, which lasted approximately 2½ hours, the informants were encouraged to speak freely and were allowed to introduce new aspects. The moderator (THM) kept the discussion on track in relation to the patients' perceived rehabilitation needs and summed up the discussion. THM also ensured that all informants had the opportunity to speak out. The atmosphere was good and empathic, and most of the informants were eager to contribute with their experiences. Interviewing stopped when no new themes were brought up.

Analysis

The FGIs were transcribed in full and analysed in NVivo 2.0 individually by THM, JS, and FO. The FGIs were subsequently discussed. Our prejudices were based on a literature study and, as far as JS and FO were concerned, also on many years of clinical practice experience.

We primarily used an inductive approach focusing on the informants' experiences, perceptions, understandings, and ideas. We also applied a deductive analytic strategy based on the themes of the interview guide and a pre-established list of former cancer patients' rehabilitation needs elicited from a literature search. [10].

Results

Needs identified through the FGIs fell into five categories: (1) Need for continuous support and information about rehabilitation opportunities; (2) Support to the family; (3) Psychological help also addressing fear of relapse of cancer; (4) Needs for social support; (5) Needs pertaining to how friends and acquaintances relate to the patients.

Need for continuous support and information about rehabilitation possibilities

After discharge from hospital, the patients often felt “abandoned” by the healthcare sector; they felt distressed and missed someone to whom they could turn to discuss both physical and psychosocial problems.

When the treatment ends, you are left all alone It's like you have been abandoned by everybody. (Female patient, 69 years)

The discharge procedure apparently did not take the patients' situation in life into account, e.g. their domestic situation. The majority of the patients proposed that a person should follow them both during treatment and afterwards, and that this person should take care of their psychosocial situation. This person should have insight into the treatment, its side effects, possible rehabilitation needs, and available rehabilitation offers.

I feel that there should be someone who knew something about all those things. Someone who came and told you about the opportunities . . . and who maybe also called you later, after the treatment, and asked how you were doing. Are you back at work, are you seeing your friends, and how is work going and so on. (Female patient, 32 years)

Hospitals often do not inform the patients that the GP can assist with these problems. Furthermore, the patients often do not visit the GP to get this type of support.

Support to the family

The family often needs information about how the cancer could affect the patient's and the peers' psychosocial situation and information about support during and after treatment. Many patients said that their relatives' psychosocial situation was not properly addressed either during treatment or afterwards. The patients specifically requested that their peers' well-being be addressed.

Sometimes it is harder on the family than it is on us, I think I am thinking about the kids. They have just as many needs as our partners have. (Male, 52 years)

In particular, children below 18 years of age and the patient's close family were often mentioned as having a particular need for support:

I needed help with my son. This was the hardest part of getting cancer, that he had psychological problems. Afterwards, I needed someone to turn to Then the fear of death comes. When you reach the bottom, the family tilts. (Female, 38 years)

Psychological help also addressing fear of relapse of cancer

Anxiety and low spirits were frequent problems. Patients found it hard to believe that they had actually been cured of cancer.

Do you also feel like . . . well you have been told that you are cured, but do you believe 100% that you have been cured? (Female, 56 years, 7 years after diagnosis) No. (Male, 60 years, 2 years after diagnosis) I have a hard time believing it . . . In the beginning, I thought that I was coping very well. But after the treatment I think about it every day. It preoccupies me a lot and that surprises me. (Female, 32 years, 18 months after diagnosis)

The patients' fear of relapse could last for several years and was distressing.

Mood disorder was also often mentioned in the FGIs. Not all of the informants were informed that depression could be a side effect of cancer.

Needs for social support

A need for support groups was often voiced, in particular among young female patients. It appeared from the discussions that these groups should preferably be targeted at specific age groups.

I really needed someone of my own age to talk to and she [a psychologist at the Danish Cancer Society] has not been able to find anyone At the hospital, I have not met anyone my age. (Female, 32 years)

After discharge from hospital and after having been declared free of cancer, the patients sometimes experienced isolation from their friends. The patients requested that their peers be informed about the disease and how to deal with the patient during and after treatment.

Well, OK, now you have been cured. And then I think that during treatment they [family and friends] called and were quite good at calling, but afterwards they seem to think now she is cured and back on track. And now they have stopped calling, but I need them to call, just once in a while, asking me how I am doing. (Female, 32 years)

Needs pertaining to how friends and acquaintances relate to the patients

Some patients felt ill-treated or stigmatized by those who were not members of their close social environment, which became more distant both during and after treatment.

One of my good friends told me that when I am working in the garden, people find it strange that I can do the gardening when I am on a pension ... so I am not supposed to do the gardening, because I should stay in bed, you know. (Female, 56 years)

Meeting people was not always a pleasant experience for the patients. Another informant said:

I have met silence where I did not expect it. But I think cancer is a difficult disease, because everyone has an opinion about it ... It is a topic where all myths, prejudices and attitudes thrive ... at the same time we challenge people's fear of death when they meet us. (Male, 52 years)

Cancer patients seemed to be facing declining social support from friends, who seemed to fail to realize that they had a continuing need for support after treatment.

Discussion

The present paper identifies former cancer patients' psychological and social rehabilitation needs on the basis of FGIs with patients displaying a substantial variety in terms of sex, age, and place of living (urban/rural).

After discharge from hospital, the patients often felt alone and missed someone to whom they could turn and who could follow and assist them during their rehabilitation. The patients' relatives also needed help. The patients and their relatives harboured a fear of relapse and death and sometimes felt stigmatized.

The patients had a variety of diagnoses and had been undergoing different treatments. Moreover, the number of patients was small, they were relatively young and all were residing and treated in the western part of the country (Denmark). The hypotheses guiding the present study were based on a literature study and, as far as JS and FO were concerned, also on their clinical practice. The results of the present study should therefore be interpreted with caution. We were, of course, aware of these matters during the interviews, and the analysis is therefore not biased by unconscious prejudices.

Another potential bias lies in the patients' perceived freedom to raise issues during the FGIs. It was our impression that there were no major barriers, but, indeed, social constraints will usually always hinder some themes from surfacing, e.g. issues relating to sexual function. Moreover, we cannot exclude the possibility that representation of other types of cancer and more severe deficits due to the cancer and its treatment might have enriched the analysis.

The fear of death from the cancer, including the fear of relapse, seems to mark the patients and their family and social life long after the end of treatment. Even so, the patients are expected to be back on their feet after the end of treatment.

Some of the patients requested information about mood disorders. Depression, which is known to be a possible side effect of cancer [11,12], came as an unpleasant surprise to some of the patients after the end of treatment.

For many of the patients, the fear of relapse persisted and it did so for many years. Therefore, cancer patients request good, continuous contact with healthcare professionals and much information on and help with the possible side effects of the cancer and cancer therapy [13–15]. GPs see patients on a regular basis for other reasons after their treatment has ended and these needs could therefore probably be catered for in general practice.

Previous studies from other countries with other healthcare systems have shown that patients often feel that they lack information and professional assessment of their concerns during treatment [16–18]. Our study supports these findings and shows that this problem continues after treatment. However, research into patients' need for information after treatment cessation remains scarce [19]. The information given to the patients in our study was not consistent and seemed to vary from patient to patient. Whether this difference was related to differences among departments, healthcare personnel, or patients could not be ascertained in our material. The patients requested personalized information on possible side effects from cancer and treatment by a single healthcare provider. This is in concordance with Miedema [20], who says that the patients ought to be clearly informed about who is responsible for their ongoing care after the acute treatment [20].

Socially, the patients experienced various problems ranging from lack of energy to contact friends to the social stigmatization that springs from challenging people's death fears at gatherings. These aspects may partly be met by information to the patient and his/her family and friends, but it may

also be encountered through support groups for former cancer patients. Such groups could give them an opportunity to share their experience and perhaps find solutions. These groups should be targeted at the users and preferably be established locally to enhance user accessibility. Cancer support groups are known to have positive effects on mood disorders such as anxiety and depression as well as on the patient's quality of life, marital status, and illness adaptation but further research is needed on this topic [21].

The family's need for help during treatment is well known [22,23]. However, our study shows that the need persisted also after the end of treatment and the patient found this important. The patients found themselves first struggling for life, then struggling to resume life, often feeling alone as they realized that their peers, and often also their children, needed help to get on with their lives. This aspect has only scarcely been described [16]; however, it should be addressed like any other psychosocial aspects of cancer, and it could be an integrated part of cancer rehabilitation. In a Danish context, the whole family is often listed with the same general practice [24]. This task could therefore probably be managed by the general practice. In addition, many of the problems experienced by cancer survivors diminish as time since cancer treatment increases [25].

In conclusion, the cancer patients' experienced rehabilitation needs regarding psychological and social aspects are often met neither by the healthcare system nor by others. The cancer survivors need continuous contact with relevant healthcare personnel after discharge from hospital, and most would probably benefit from an assessment of the relevance of these aspects and from information on possible rehabilitation offers. From a psychosocial rehabilitation point of view, the family's and the social networks' fear of relapse is important. All these aspects need to be assessed in each case and the patients should know who to contact in the healthcare system after hospital discharge.

Ethical approval

This project was approved by the Danish Data Protection Agency and the Danish Multipractice Study Committee.

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