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Perceptions of Dutch health care professionals on weight gain during chemotherapy in women with breast cancer

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Abstract

Purpose Dutch Health care professionals (HCPs) provide little information concerning health risks associated with weight gain during chemotherapy for breast cancer. Women with breast cancer have specified the need for more information on nutrition and physical activity to deal with weight gain. The aims of this study were to assess the perceptions of Dutch HCPs on weight gain during chemotherapy and in addition evaluate whether and what kind of information on dietary intake and physical activity HCPs provide to prevent/treat weight gain during (neo)adjuvant chemotherapy.

Methods A qualitative study was conducted using semi-structured interviews with 34 HCPs involved in breast cancer care: general practitioners, oncologists, specialized nurses, and dietitians.

Results To date, little information about nutrition, physical activity, and weight gain is given during chemotherapy because it is not part of most HCPs' training, it is not included in the guidelines and it is not the best time to bring up information in the opinion of HCPs. Weight gain was perceived as just a matter of a few kilos and not an important health issue during treatment. All HCPs felt it is better that women themselves addressed their weight gain after chemotherapy.

Conclusion More knowledge about health risks associated with chemotherapy-induced weight gain and how to combat these issues needs to be made readily available to the HCPs and should become part of their training. Existing patient guidelines should include information on how to prevent and/or reduce weight gain through self-management of nutrition intake and physical activity during and post chemotherapy.

Keywords Health care professionals · Health risks · Weight gain · Breast cancer · Dietary intake · Physical activity

Introduction

As a result of the increasing survival rates, and the growing population of breast cancer survivors, the repercussions of the side-effects of chemotherapy are becoming more important [1–6]. Over 60% of women with breast cancer receive (neo)

adjuvant chemotherapy [2]. Several studies reported that chemotherapy is associated with weight gain [7–11]. Weight gain may have long-term consequences because it can lead to a higher risk of developing cardiovascular disease, diabetes and disease recurrence in survivors of breast cancer [12–15], and at least half of the patients experience unhappiness concerning their body changes and altered physical appearance, which negatively affected their quality of life [16–19].

Several studies on weight gain in breast cancer patients during the past decade show that the majority of women with early breast cancer were concerned about their weight gain and interested in actively trying to minimize weight gain through diet and physical activity [17–22]. Patients with weight gain stated, during interviews, that they would have liked more information from their health care professionals (HCP) on how to prevent or minimize weight gain during chemotherapy [21]. Gandhi et al. [17] reported that women were not prepared for weight gain as a side effect: only 27% of

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332 breast cancer survivors were aware of the possibility of treatment related weight gain prior to chemotherapy. Other authors have suggested that HCPs can support the needs of women who gain weight during chemotherapy [23] and prepare them for the possible short- and long-term side effects of the treatment [24].

Although the literature shows evidence that exercise and dietary interventions can counter the adverse effects of chemotherapy on weight gain [8, 25–31], according to Demark et al. [23] only 33% of breast cancer patients reported that their physicians recommended exercise, or gave advice about dietary intake such as increasing fruit and vegetables and reducing fat intake to improve lifestyle. To date, it is unknown which HCPs provide what information concerning dietary intake and physical activity to prevent/treat weight gain in women with breast cancer.

The aims of this study were to assess the perceptions of HCPs on weight gain during chemotherapy and to evaluate whether HCPs provided information and if so, what kind of information on dietary intake and physical activity HCPs provide to prevent/treat weight gain during (neo)adjuvant chemotherapy.

Methods

Design

A qualitative, explorative study using semi-structured interviews with HCPs (oncologists, (specialized) nurses, dieticians, and GPs) involved in breast cancer care in the Netherlands was applied. This study is a part of the COBRA study (Change Of Body composition in BReast cancer: All-in assessment) [32]. The Medical Ethics Committee of the Wageningen University approved the entire COBRA study (ABR NL40666.081.12).

Procedure and population

Practice and organization of breast cancer care in the Netherlands

In the Netherlands, different professionals are involved in standard breast cancer care:

GPs are mostly involved in prevention and early detection of breast cancer based on the national breast cancer screening program in the Netherlands [33].

In the hospitals, surgeons provide initial breast cancer care, before adjuvant or after (neo)adjuvant chemotherapy. Information, mainly concerning side effects, is provided by a mamma care nurse of the surgical department. In the oncology department, oncologists and nurse practitioners oncology support women before and mainly during chemotherapy.

Dieticians are only involved in the treatment of breast cancer patients after referral by other health care professionals or if women themselves want to consult a dietician.

In order to ensure diversity in the sampling of HCPs, we recruited oncologists, nurse practitioner oncology, mamma care nurses and dieticians involved in breast cancer care, working in 5 hospitals across the Netherlands. Most of the GPs were recruited from group practices with varying years of experience (from 1 to more than 10 years). In total, 43 HCPs were contacted by telephone or email. Nine HCPs did not participate because they did not respond to the email sent ($n = 5$) or refused because of their busy schedule ($n = 4$). The final study sample consisted of 34 HCPs (response 79%): 18 hospital-HCPs and 16 GPs.

Interview preparation

Semi-structured interviews were developed based on an interview guide that included questions about: information provision about weight gain, nutrition, and physical activity; which information was provided by HCPs; and perspectives on their possibilities to optimize care about weight gain.

The results of the first three interviews were discussed with the research team (AK, MW, JR, MS) and as a result two additional topics were added on the interview guide: “the exchange of information on weight gain, nutrition and physical activity between health care professionals” and “responsibility of executing care about weight gain.”

Data collection

Interviews were conducted at the home of the HCPs ($n = 15$), at GPs practices, or in hospitals ($n = 19$) by two interviewers (JR, MS). Three interviews were interrupted by telephone calls and two HCPs were called away for a short period during the interview. Before starting the interview, all 34 HCPs were asked permission for audiotaping and informed consent was obtained. The average duration of the interviews was 37 mins (range 15–60 min). For data preparation, all interviews were transcribed verbatim. Transcripts were anonymized and checked for accuracy and quality by listening and rereading the transcript at the same time (AK, JR, MS). Summaries of the interviews were made using the transcripts. Member checks were done in a random subset of 18 HCPs. These HCPs were asked to check the summary of their interview for accuracy, completeness, and whether the information was interpreted correctly. Four respondents replied with small corrections and adjustments to the summary, 14 respondents agreed with the summary.

Data analysis

A thematic analysis was conducted as described in Braun and Clarke [34]. Transcripts were subsequently disentangled and divided into fragments and open-coded. Codes were categorized by subthemes and main themes. Relationships between the subthemes were explored, to eventually cover the subthemes under the overall themes. The codes, subthemes, and themes were discussed by MS, JR, and AK until consensus was reached on all the themes and structured in a code tree. The constant comparison method was used in order to understand the differences, as well as similarities, between HCPs and within each of the HCP professions. The main results were discussed in the research team (MS, JR, AK, and MW) to enhance the robustness of the findings.

Results

All oncologists, specialized nurses, and dieticians worked in 5 different hospitals: 1 academic and 4 peripheral hospitals. All but one of the GPs worked at group practices: 9 GPs worked in a village practice and 7 GPs worked in a city practice. For further demographic characteristics of the HCPs, see Table 1.

The results of the interviews are described in four themes: (I) HCPs information provision concerning weight gain, nutrition and physical activity; (II) Exchange of information between HCPs; (III) HCPs perspectives on responsibility of executing care about weight gain; (IV) HCPs perspectives on their possibilities to optimize care about weight gain.

I. HCPs information provision concerning weight gain, nutrition and physical activity

GPs and dieticians experienced a different role in information provision compared to the other HCPs. GPs said they have

very little contact with their patients during and after treatment in the hospitals. Some GPs mentioned that letters about diagnosis and treatment of women are sent too late from the hospital, which contributed to the loss of contact with their patients. On the few occasions they did speak to their breast cancer patients they did not want to burden the women with discussions on weight gain because they had already had a hard time during breast cancer treatment. They only provided information on nutrition and physical activity to breast cancer patients with weight gain in combination with other health problems, such as high blood pressure. In their opinion, dealing with the issue of weight gain would be more important after the women had finished chemotherapy. GPs stated that information provision depends on the personal wishes of patients. In that case, they would refer women to a dietician or a physiotherapist.

Prior to, and during chemotherapy, oncologists said they provide women with initial information about chemotherapy and its possible side-effects, but not in detail. They were of the opinion that the nurse practitioners oncology have more time available to inform women about these effects:

“The nurse practitioner is actually their first contact. So that is the person who will particularly focus on side effects if they [the patients] have a question...”
(Oncologist)

Nurses confirmed that they provide more detailed information. They clarify the information given by the oncologists and answer the patient’s questions such as: “What do I need to eat?” and “What do I need to avoid?” Nurses did not consider it necessary to enforce restrictions during treatment concerning dietary intake and supplements:

“We advise the patients to just eat normal foods, it will be just fine, enough vegetables and a variety of fruit.....When

Table 1 Demographic characteristics of the participating health professionals

Characteristics	General Practitioners <i>N</i> = 16	Oncologists <i>N</i> = 6	Specialized nurses* <i>N</i> = 6	Dieticians <i>N</i> = 6
Age, mean (range) y	46 (32–63)	47.6 (40–63)	48.5 (33–60)	33.8 (26–38)
Gender				
Male	7	3	–	–
Female	9	3	6	6
Workplace:				
Hospital: oncology dept.		6	4	
Surgical dept.		–	2	
All departments				6
GPs: practices in a village	9			
Practices in a city	7			

* Specialized nurses include: mamma care nurses (*n* = 2), nurse practitioner oncology (*n* = 4)

they want to eat unhealthy, it is also allowed” (Nurse practitioners oncology).

Nurses of the surgical departments, however, said they did not consider discussing nutrition:

“For us it is not an important topic to bring up. We think it is more important the patient feels well, has sufficient energy.....” (Mamma Care nurse surgical department).

Especially oncologists stated that the only information they gave about nutrition was based on their common sense because it is not part of their training. They said they do not have sufficient knowledge about nutrition for expert advice to their patients. Most of the oncologists actually said they are not concerned about the long term health risks of weight gain during and after chemotherapy. They considered it as neither important nor relevant to discuss it with women during the therapy:

“I do not often ask patients about their weight gain or what they eat during CT. Is it really necessary, at that moment, for them to eat healthy...?” (Oncologist).

In the hospitals HCPs monitored weight changes as side-effect of chemotherapy, but based on the guidelines the focus was towards weight loss and hardly on weight gain. Although Mamma care nurses said they sometimes met women who do experience problems with weight gain, they did not undertake action:

“I cannot refer these women to a dietician or someone..... It is a matter of two, three kilograms mostly, that is not an enormous weight gain”. (Mamma care nurse).

According to most of the HCPs, women deal with weight gain in two different ways: (1) women are unhappy with the gained kilograms: they dislike the fat around their belly and they need to buy bigger clothes which negatively impacts their self-image, or (2) women do not worry at all about the extra kilos and seem to accept it. This is why some oncologists found it difficult to talk about it and struggled how they should deal with women with weight gain:

“I have the impression that weight and nutrition to them, as far as I can see ...is not a big issue...it is up to the patient whether they experience a few kilos more as a problem. The question is whether you should discuss this when women are overwhelmed with surgery, irradiation, and chemotherapy... ? (Oncologist).

Dieticians experienced few or no possibilities at all to support women with weight gain:

“We only see patients on the basis of the guideline focused on undernutrition, we hardly see patients with involuntary weight gain. I think it is a group which falls between two stools...” (Dietician).

All HCPs said they always discussed physical activity and advise women to stay physically active during and after chemotherapy. But they were not aimed at actually supporting patients in these activities. In their opinion physical activity contributes to feeling healthy and well, even though they understand that women are less physically active because of having cancer and being fatigue. HCPs did not associate a lack of physical activity with weight gain.

II Exchange of information between health care professionals

In weekly multidisciplinary breast cancer meetings in the hospital, most of the oncology patients were discussed with all HCPs involved in breast cancer. None of the HCPs mentioned consultation about weight issues, nutrition, or physical activity as an item for these meetings. GPs stated, although they were regularly invited, it was difficult to attend these meetings because they often take place during practice consultations hours, it costs too much time, and their input is minor because the discussion about the treatment is very technical. Dieticians were not invited. Dieticians discussed the patients they advised about nutrition only with the referring HCP. Oncologists, specialized nurses, and dieticians, however, were not aware of the content of each other’s exact advice concerning nutrition and physical activity to women with breast cancer.

III HCPs’ perspectives on responsibility of executing care about weight gain

GPs said their role during treatment could be different. During diagnosis all GPs were involved in breast cancer care when suspicious mammograms were detected, or when women themselves found a lump in their breasts. During treatment some GPs also experienced a supportive role as sparring partner for the patient. According to GPs, some patients still need support after treatment. However, they did not actively invite women for consultation although they continue to feel responsible for their patients.

Dieticians mainly see patients with weight loss, because weight gain is not described in the guidelines. Patients with weight gain are barely referred, and dieticians experienced a lack of time to call up patients with weight gain themselves. In their opinion, personal guidance by them of patients with weight gain during chemotherapy is recommended.

IV HCPs' perspectives on their possibilities to optimize care about weight gain

All HCPs were asked about ideas to optimize care for patients with breast cancer experiencing weight gain. They proposed strategies to prevent or reduce weight gain, such as physical activity or exercise programs. In addition, half of the oncologists suggested that nutrition and the adverse effects of chemotherapy must become part of their training and they suggested that the Dutch Association for Oncologists needs to emphasize this, for example, by making it part of the yearly conference:

“...I think, perhaps there needs to be more attention to nutrition and weight gain- also in our specialist training. I cannot remember that we were taught about the effects of nutrition, at any time at all” (Oncologist)

Nurse practitioners oncology recommended more time for informing women with breast cancer about the possibility of weight gain and to monitor them during and after chemotherapy. One of them proposed a standardized screening to monitor not only weight loss, but also weight gain, by adding questions to the Short Nutritional Assessment Questionnaires (SNAQ) used in most of the hospitals in the Netherlands. All oncologists agreed it is mainly the responsibility of the nurse practitioners oncology. Dietitians recommend consultations for patients with breast cancer in non-hospital dietitian practices, presuming that such consultations are easier to organize outside the hospitals.

Discussion

In this qualitative study, we found that information about weight gain, nutrition, and physical activity was hardly provided by HCPs to women with breast cancer treated with (neo)adjuvant chemotherapy. Oncologists and nurses did not routinely provide information about weight gain and nutrition partially due to lack of knowledge and time. All HCPs said they stress the importance to stay physically active to their patients, but they do not explain how. Most of the HCPs were not concerned and seemed not aware of the long-term health risks as a consequence of weight gain during and after CT treatment. In their opinion, weight gain was just a matter of a few kilos and not an important issue during treatment. They all believed that it is better that women themselves address their weight gain after CT.

GPs hardly provided information about nutrition, weight gain or physical activity because they were mostly involved during diagnose phase. Dietitians rarely had the opportunity to provide women information about nutrition

and weight gain because only in case of weight loss, patients were referred to them.

HCPs rarely informed breast cancer patients about weight gain, nutrition, and physical activity because they believe during treatment is not the best time to bring up such information. This confirms the results of previous research of Coa et al. [35] involving oncologists and nurses. HCPs also thought the issue concerning weight gain, as a side-effect of CT, was less important than how the cancer patients perceived it to be. Although even minimal weight gain can lead to adverse health effects [4, 5, 10], a weight gain of one to three kilograms is not considered as a topic that needs the attention of HCPs. On the other hand, some HCPs experienced that women with breast cancer struggled with questions and problems about nutrition and weight gain and needed information. These findings are in line with the reported unmet needs by breast cancer patients in several studies [17, 19–22], such as a lack of information on managing side effects, the things they can do to help themselves to get well, and about dealing with lack of energy and tiredness caused by chemotherapy [36, 37]. No specific questions were however included in these studies about changes in dietary intake, nutrition and weight gain, as side effects of chemotherapy [38].

Knowledge about nutrition and weight gain is not part of the training of HCPs and also not part of the guidelines for breast cancer patients used by them. They do not feel supported by the existing guidelines [33, 39] and therefore they do not know what to tell their patients. Only the study of Cappiello et al. [20] reported that information is often not given due to a lack of knowledge. McCaughan et al. [40] identified that doctors feel that addressing problems such as recurrence of cancer is more important than spending time on providing information about weight gain in breast cancer survivors.

Despite growing evidence there is a considerable variance in HCPs' beliefs about the benefits of lifestyle changes in patients with breast cancer with respect to cancer related outcomes. Some studies already show that interventions targeting weight gain are effective among women with breast cancer [31, 41]. This suggests that if HCPs discuss weight gain and perhaps more often refer women with breast cancer to dietitians and physiotherapists, it would probably contribute to reduce weight gain in women with breast cancer preventing long-term health risks associated with weight gain. Unfortunately, our study confirms that dietitians hardly see breast cancer patients with weight gain because the focus is much more on weight loss as described in the current used guidelines. During the period of interviewing, the HCPs used the Dutch breast cancer guidelines for breast cancer care in hospitals [39], and for GPs [33]. These guidelines, and also the guidelines used in the UK and US [42, 43], do not include information on weight gain as adverse effects of chemotherapy, despite growing evidence [7–11]. In the new Dutch guidelines 2017, involuntary weight gain (BMI > 25; weight gain

>5% or > 3 kg since diagnosis; middle waist > 88 cm) is now included, but only in the diagnostic phase not during treatment [44]. In the new ESPEN guidelines also increased level of physical activity in cancer patients is recommended [45]. Adapting existing guidelines with information about treatment of weight gain, nutrition, and also physical activity is necessary to bring to the attention of HCPs in order to deliver good quality oncology care.

Strengths and limitations

Strengths of this study were the method of coding which corresponds to the thematic approach from Braun & Clarke [34]. Two independent researchers performed coding on four of the transcripts, adding to the reliability of this study. All the data was discussed in a large research team to ensure the quality of both the data collection and the analysis.

In addition, random member checks were carried out to ensure the validity and representativeness of the results. Some interviews were very short because HCPs had little time and two of them were even called away during the interview. All interviews were sufficiently in depth except probably these two. Nevertheless, the results give a good picture of what is happening in practice.

Conclusions

Despite the increasing evidence on the health risks associated with chemotherapy-induced weight gain in women with breast cancer, to date, HCPs provide little information regarding nutrition and physical activity on how to prevent and/or reduce weight gain. More knowledge about the health risks associated with chemotherapy induced weight gain and how to combat these issues through nutrition and physical activity needs to be made readily available to the HCPs and must be a part of their education and training. Existing patient guidelines should include information on how to prevent and/or reduce weight gain through self-management of nutrition intake and physical activity during and post chemotherapy. Screening should not only include weight loss but weight gain as well, which could help HCPs in their efforts to provide information to the patients to prevent and/or reduce long-term consequences of chemotherapy.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study.

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