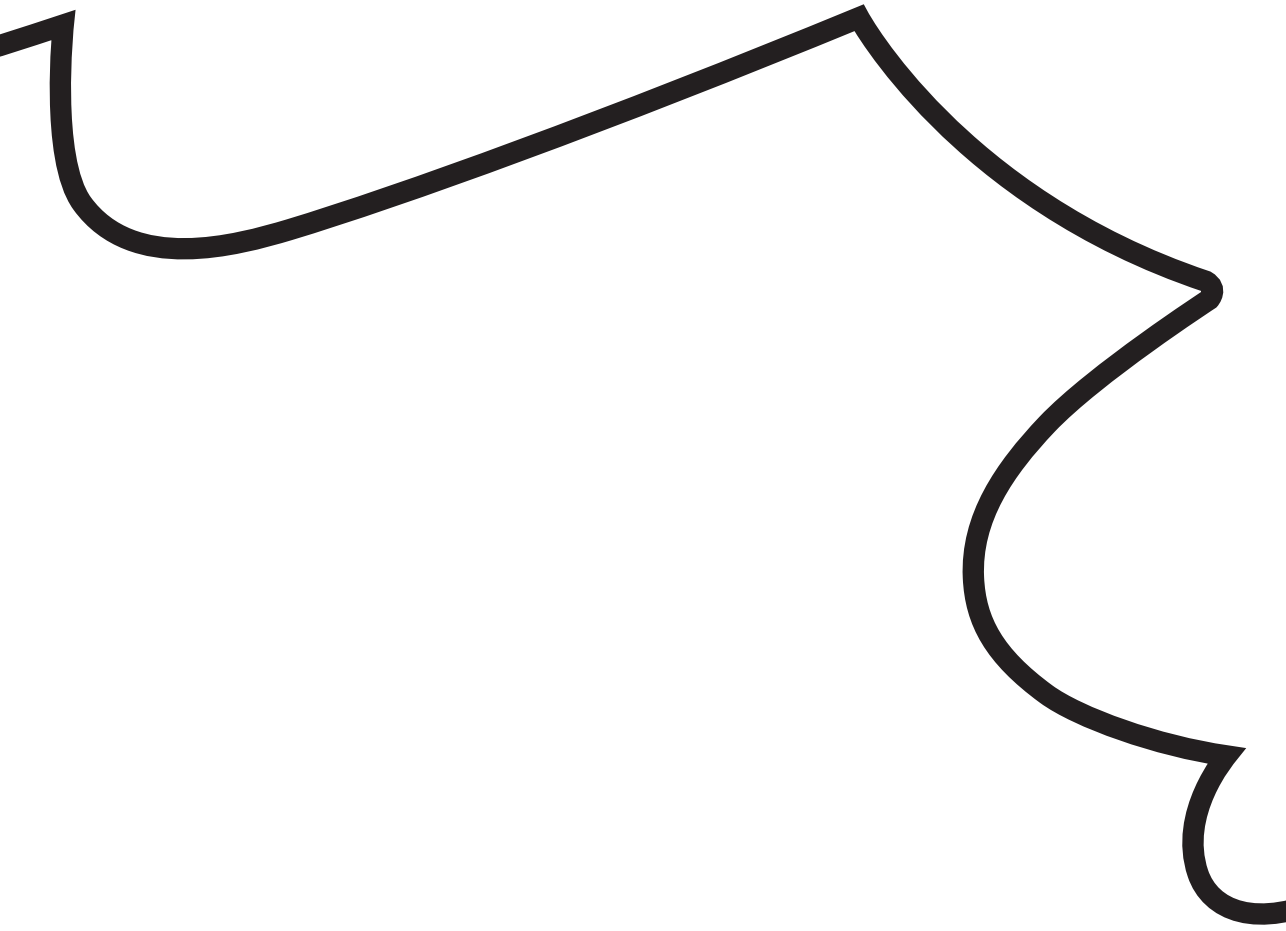
NUTRITIONAL INFORMATION

# Improving information provision on nutrition and cancer

For cancer survivors and health professionals

**Merel R. van Veen**

CANCER SURVIVORS



# PROPOSITIONS

1. **Healthy lifestyle adherence must be screened for and supported in all curatively treated cancer patients.**
   (this thesis)

2. **A lack of knowledge and false beliefs about nutrition and cancer go hand in hand.**
   (this thesis)

3. **Nutritionists must always adhere to all dietary recommendations.**

4. **Unsupervised access to medical test results harms patients.**

5. **Every GP must actively discuss end-of-life wishes with their patients.**

6. **Data-analysis should never be conducted by one single person.**

7. **Social media should be used more in spreading the evidence-based 'healthy lifestyle'-message.**

Propositions belonging to the thesis, entitled;

## Improving information provision on nutrition and cancer

For cancer survivors and health professionals

**Merel R. van Veen**
Wageningen, 18 September 2019

# Improving information provision on nutrition and cancer

For cancer survivors and health professionals

*Merel R. van Veen*

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# Improving information provision on nutrition and cancer

For cancer survivors and health professionals

*Merel R. van Veen*

**Thesis**

Submitted in fulfillment of the requirements for the degree of *doctor*
at Wageningen University
by the authority of the Rector Magnificus
Prof. dr. A.P.J. Mol,
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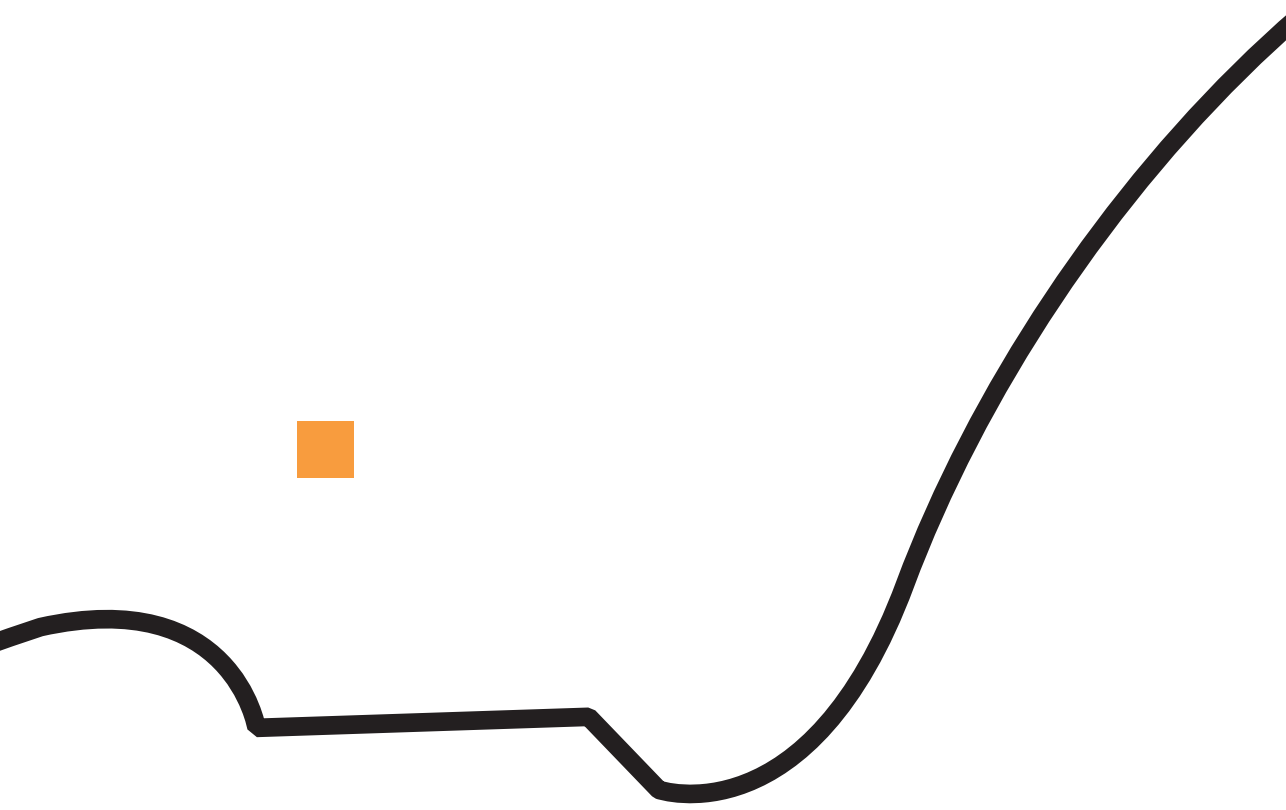
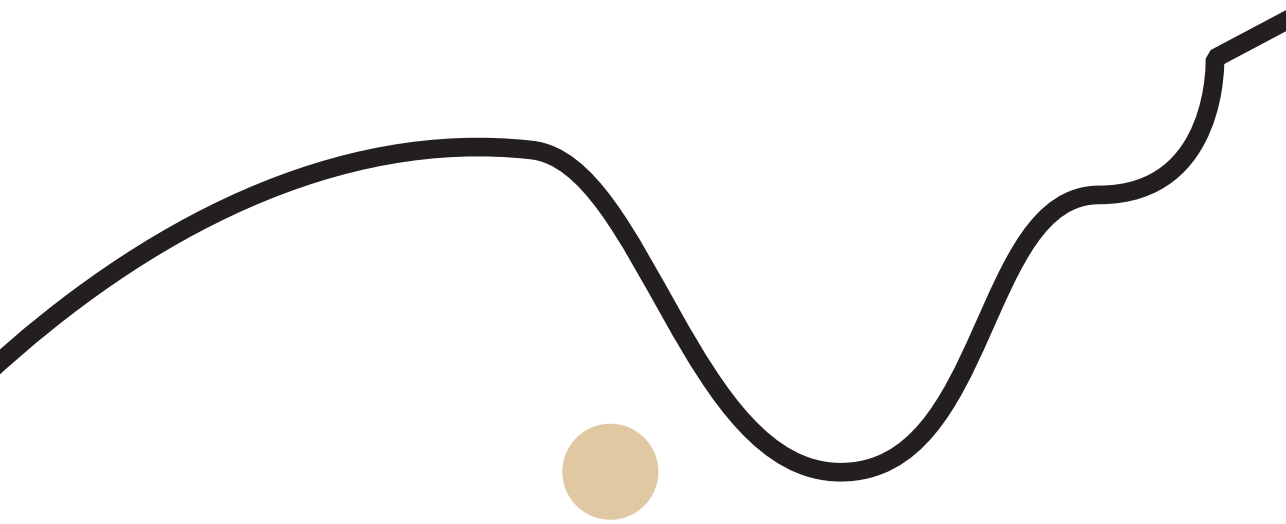
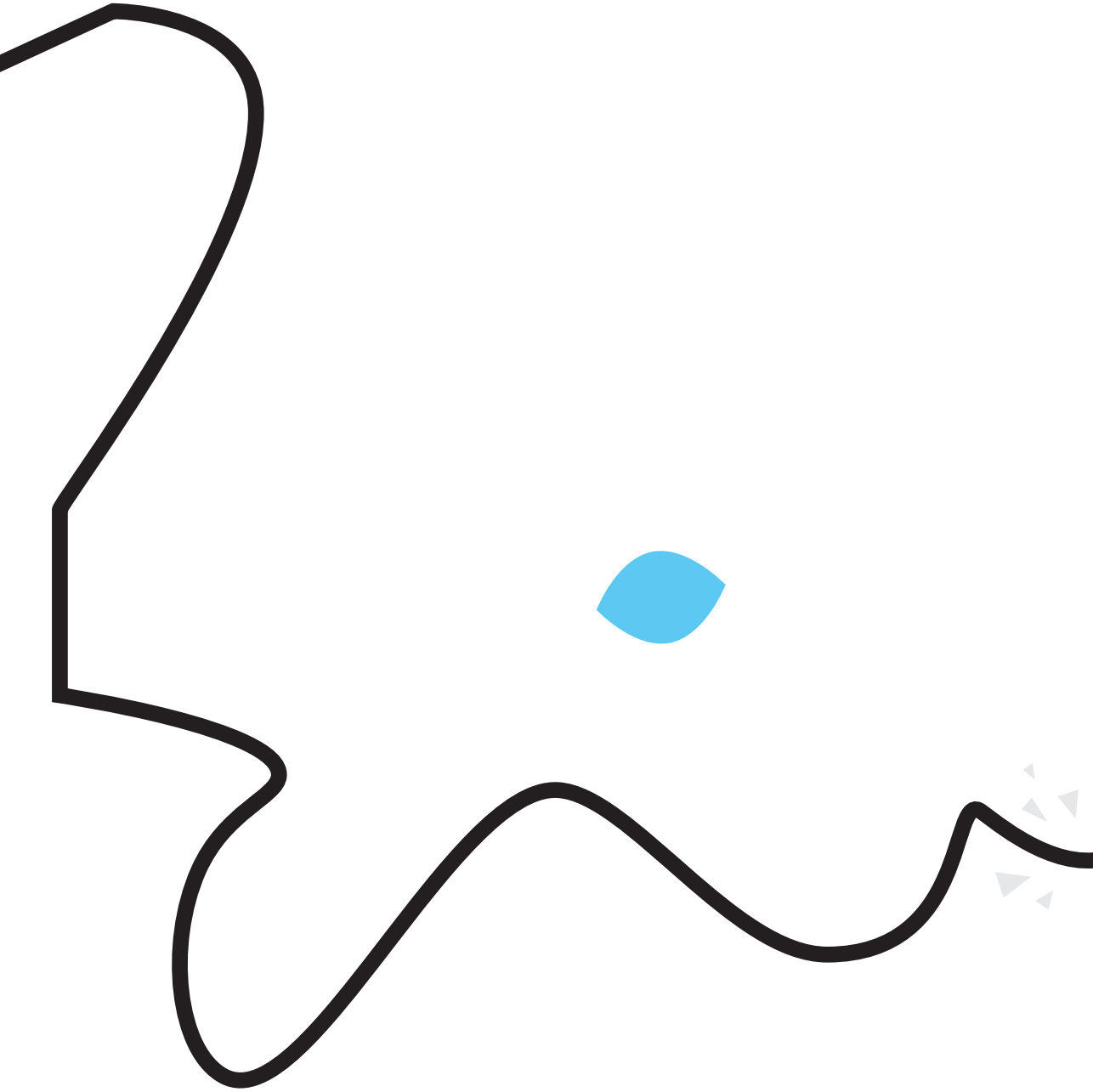


# CHAPTER 1:

## General introduction





## BACKGROUND

The number of cancer survivors is growing rapidly in high income countries, due to an increasing incidence [1] of cancer. Earlier detection and higher survival rates because of improved treatment [2] and increasing incidence. In 2018, there were an estimated 18.1 million incident cancer cases worldwide [3] and many continue to live for a long period of time. In the period 2011–2015, 64% of cancer survivors was still alive five years after diagnosis [1]. Globally, in 2012 approximately 32.6 million people were living with cancer [4].

### Definition of cancer survivor

In 1986, the American National Coalition for Cancer Survivorship (NCCS) created the term 'cancer survivor' to describe the broad experience on the cancer continuum – living with, through and beyond a cancer diagnosis. This term covered health issues related to the treatment, as well as late and long-term effects; psychological, financial, emotional, spiritual and social challenges [5]. Later this definition was sharpened to 'people who are living with a diagnosis of cancer, including those who have recovered from the disease'. This definition is also used by the World Cancer Research Fund/ American Institute of Cancer Research (WCRF/AICR) [6]. Some institutes also include family members, friends and caregivers in the definition of cancer survivors [7]. In this thesis, the definition is used as stated by WCRF/AICR. In the Netherlands, a cancer survivor is often called a cancer patient. In this thesis, both terms are used interchangeably.

## NUTRITION AND CANCER RECOMMENDATIONS FOR CANCER PREVENTION

Based on more than 10,000 epidemiological studies, animal and in-vitro experiments, the major diet- and nutrition-related factors in the etiology of cancer are known. Numerous reports and guidelines have been written and are widely available, aiming at the prevention of cancer [8, 9]. General recommendations for the prevention of cancer include maintaining a healthy bodyweight, being physically active, eating wholegrains, vegetables, fruits and beans, limit 'fast foods', limit red and processed meat, limit sugar sweetened drinks, limit alcohol consumption and don't rely on supplements. Furthermore the diet should be a plant rich diet, low in energy dense foods, meat and added sugars, not rely on dietary supplements, and you should breastfeed your baby if you can [8]. There is ample evidence that diet can influence the incidence of the most frequently occurring types of cancer, including breast and colorectal cancer [8]. Although adhering to the guidelines concerning a healthy weight, a healthy diet

and sufficient physical activity does reduce cancer risk [10, 11], two-thirds of people think they can do little to prevent cancer [12]. This is in spite of the fact that these guidelines are actively addressed by both national and international organizations in their campaigns for the general public [13, 14].

### Nutritional recommendations after a cancer diagnosis

Several recommendations are available, providing advice on the diet of cancer survivors during or after treatment [8, 9, 15, 16]. Optimal nutrition after a cancer diagnosis may increase survival and could reduce the risk of recurrence and the risk of developing a secondary tumor or other comorbidities. A healthy diet might limit side effects and complaints resulting from cancer and its treatment, and improve recovery and quality of life [15–21]. Recommendations for cancer survivors during treatment focus on relieving symptoms, and making sure the patient is in a good nutritional status to undergo treatments [15]. Cancer survivors who finished treatment are advised to adhere to the recommendations for the prevention of cancer [8].

### Adherence to nutritional recommendations

Adherence to nutritional recommendations for the prevention of cancer is found to be low to moderate [19, 22–25]. This may be caused by the idea that little can be done to prevent cancer [12], practical reasons such as 'a lack of time to eat healthy', 'a lack of money to eat healthy' and taste preferences [26], but starts with shortcomings in the nutritional information provision.

## NUTRITIONAL INFORMATION PROVISION AND NEEDS

A high percentage of cancer survivors and their relatives do not receive nutritional information and are therefore unfamiliar with nutritional guidelines, available information, and nutritional information resources [27–33]. This may lead to unmet nutritional information needs, unfavorable changes in their dietary behavior, uncertainty what to do or continuation of an unhealthy diet.

Cancer survivors welcome nutritional guidance from healthcare professionals [34]. Although oncology nurses are in a favorable position to provide advice [29], nurses are generally not trained in providing nutritional advice, and may therefore have insufficient knowledge to be able to provide such advice [35]. Doctors are also not trained in providing nutritional advice and only part of cancer survivors is referred to a dietician.

During the last decades a shift in information sources and ways of providing information has occurred. An increasing number of cancer patients seek information themselves on the internet [36], without consulting a healthcare professional to check the correctness of the information.

Although most cancer survivors use the internet for their cancer care and are comfortable using a computer, less than half of them are comfortable in evaluating online information for healthcare decisions [37]. Cancer survivors may suffer from cancer information overload and therefore have problems with determining what information on the internet is from a trustworthy source [38]. Therefore, it is important that a reliable website on nutrition and cancer is developed and is widely available for survivors.

## AIM AND OUTLINE OF THE THESIS

The overall aim of this thesis is to improve the nutritional information provision for cancer survivors, the general public and health professionals.

The thesis starts with describing the importance of adherence to the WCRF/AICR recommendations for cancer prevention for the health-related quality of life of colorectal cancer survivors. As the percentage of cancer survivors adhering to these guidelines is disappointing, possibly due to misbeliefs about the role of nutrition in cancer and lack of nutritional information provision, **chapter 3** focuses on the association between nutritional information provision and colorectal cancer survivors' beliefs on nutrition and cancer. **Chapter 4** aims to investigate the association between nutritional information provision and dietary changes in cancer survivors. Because oncology nurses often are the center of information provision, the aim of **chapter 5** is to assess what percentage of oncology nurses perceived themselves to have insufficient knowledge to provide advice on nutrition and/or physical activity to their patients and which characteristics were associated with oncology nurses' perception of having insufficient knowledge. To directly provide cancer survivors with reliable nutritional information and to support oncology nurses and other healthcare professionals in giving nutritional advice to cancer survivors, we developed a website to fight fiction and support facts about nutrition and cancer. **Chapter 6** describes the development of this website providing evidence-based information about nutrition and cancer.

In the final chapter of the thesis, **chapter 7**, the main findings of the studies are summarized and discussed. This general discussion puts the findings into perspective and gives implications for daily practice and suggestions for future research.

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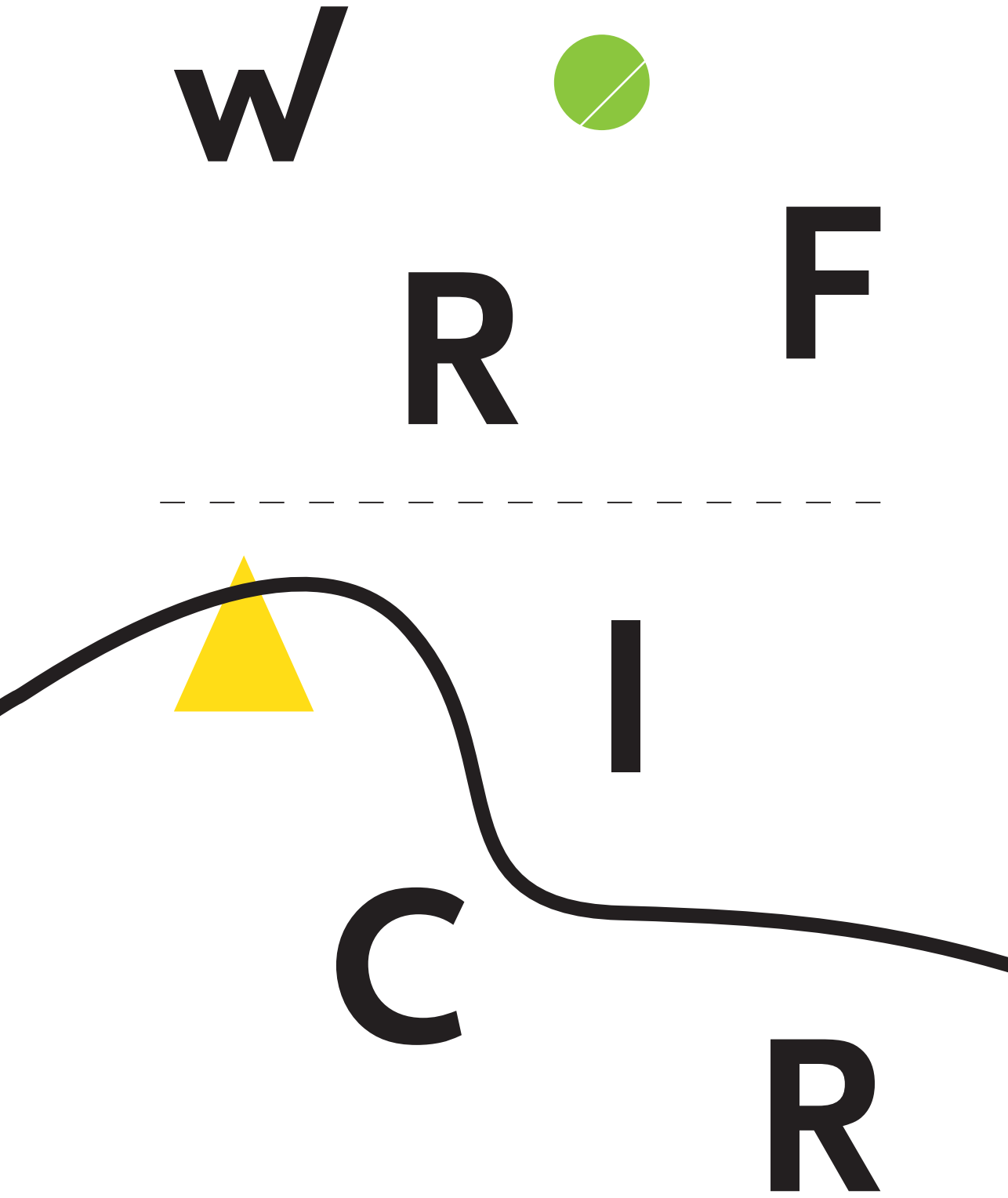
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# CHAPTER 2:

## Adherence to the World Cancer Research Fund/ American Institute for Cancer Research recommendations for cancer prevention is associated with better health–related quality of life among long-term colorectal cancer survivors: results of the PROFILES registry

Merel R. van Veen, Floortje Mols, Martijn J.L. Bours, Matty P. Weijenberg, Ellen Kampman, Sandra Beijer

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## ABSTRACT

Since colorectal cancer (CRC) survivors often suffer from long-term adverse health effects of the cancer and its treatment, having a negative impact on their health-related quality of life (HRQL), this study focuses on the association between adherence to WCRF/AICR recommendations and HRQL among CRC survivors. In a cross-sectional PROFILES registry study in 1096 CRC survivors (mean time since diagnosis 8.1 years), WCRF/AICR adherence scores (range 0–8, with a higher score for better adherence) were calculated, and HRQL was assessed using the EORTC QLQ-C30. Associations between adherence scores and HRQL scores were investigated using linear regression analyses. Additionally, associations with adherence to guidelines for body mass index (BMI) (normal weight, overweight and obese), physical activity (PA) (score 0/1) and diet (score < 3, 3 – < 4 and > 4) were evaluated separately. Mean adherence score was 4.81 ± 1.04. Higher WCRF/AICR scores were associated with better global health status (β 1.64; 95%CI 0.69/2.59), physical functioning (β 2.71; 95%CI 1.73/3.68), role functioning (β 2.87; 95%CI 1.53/4.21), cognitive functioning (β 1.25; 95%CI 0.19/2.32), social functioning (β 2.01; 95%CI 0.85/3.16) and fatigue (β – 2.81; 95%CI – 4.02/– 1.60). Adherence versus non-adherence PA was significantly associated with better physical, role, emotional and social functioning, global health status and less fatigue. Except for the association between being obese and physical functioning (β – 4.15; 95%CI – 47.16/– 1.15), no statistically significant associations with physical functioning were observed comparing adherence to non-adherence to BMI and dietary recommendations. Better adherence to the WCRF/AICR recommendations was positively associated with global health status, most functioning scales and less fatigue among CRC survivors. PA seemed to be the main contributor.



**KEYWORDS:**
Colorectal cancer survivors; health related quality of life; WCRF guidelines; dietary guidelines; physical activity; body composition

## INTRODUCTION

In 2007, the World Cancer Research Fund/American Institute for Cancer Research (WCRF/AICR) launched the diet and physical activity recommendations for cancer prevention [1]. Cancer survivors, defined as people who are living with a diagnosis of cancer, including those who have recovered from the disease [1], or in other words those who finished treatment and are disease-free, are encouraged to follow these recommendations to reduce risk of recurrence and improve survival.

Colorectal cancer (CRC) survivors often suffer from long-term adverse health effects of cancer and its treatment [2]. This can have a negative impact on health-related quality of life (HRQL). Two systematic reviews showed that CRC survivors had a lower physical functioning and more fatigue and psychological problems, including depression, anxiety and distress than the general population [3, 4]. Because of the increasing numbers of CRC survivors, investigating possibilities to increase HRQL is very important.

Several studies showed an association between adherence to general non-cancer-specific dietary guidelines, such as the Healthy Eating Index or the Mediterranean diet, and higher levels of HRQL in cancer survivors, including CRC survivors [5, 6, 7]. In addition, previous studies have demonstrated that CRC survivors who met the public health exercise guidelines reported better quality of life (QL) and fatigue scores than CRC survivors who did not meet these guidelines [8, 9]. Although adherence to general dietary or exercise guidelines showed positive associations with HRQL, the association between adherence to the cancer-specific WCRF/AICR recommendations on diet, physical activity and body weight/composition and HRQL have only been investigated in female cancer survivors in general [10], in breast cancer survivors [11] and in a small cross-sectional study ($n$=145) in CRC survivors [12]. These studies showed that better adherence to the WCRF/AICR recommendations was associated with better HRQL [10, 11, 12]. However, due to the relatively small numbers in these studies, it was not possible to evaluate which specific recommendations had the highest impact among CRC survivors (diet, physical activity or body composition). The aim of the present study was to investigate the association between adherence to the WCRF/AICR recommendations and HRQL for all recommendations together and for physical activity, body composition and diet separately in a large cohort of CRC survivors.

## SUBJECTS AND METHODS

### Study design

This study was part of an ongoing longitudinal study investigating HRQL in CRC patients. All CRC patients stage I–IV, diagnosed between January 2000 and June 2009 from the southern area of the Netherlands, were sampled via the Netherlands Cancer Registry (NCR). The Patient Reported Outcomes Following Initial Treatment and Long-term Evaluation of Survivorship (PROFILES) registry was used to collect the data [13]. Ethical approval for the study was obtained from the local certified Medical Ethics Committee of the Maxima Medical Centre Veldhoven, the Netherlands (approval number 0822). All participants gave informed consent. Data from this longitudinal study are (partly) available online for non-commercial scientific research, subject to study question, privacy and confidentiality restrictions, and registration (www.profilesregistry.nl).

### Data collection

CRC patients were invited for participation via a letter from their (former) attending physician. The letter included a link to a secure website, a login name and a password, so that interested patients could provide consent and complete questionnaires online. Those who preferred written communication could return a postcard after which they received our paper-and-pencil informed consent form and questionnaire. Non-respondents were sent a reminder letter and paper-and-pencil questionnaire within 2 months. Patients were reassured that nonparticipation had no consequences for their follow-up care or treatment. The NCR provided information on cancer diagnosis and cancer treatment history, such as year of diagnosis, stage and localization of cancer and having a stoma.

### Study population

The CRC study started in December 2010 and respondents received subsequent HRQL questionnaires in December 2011, December 2012 and January 2014. In August 2013, data on the adherence to WCRF/AICR recommendations were collected once. A complete overview of the selection of patients can be found on our website under 'data & documentation'; www.dataarchive.profilesregistry.nl/study_units/view/22. In the current paper, we present data on the adherence to WCRF/AICR recommendations and data regarding HRQL of the subsequent measurement in January 2014. Patients with unverifiable addresses, with cognitive impairment, who died prior to the start of the study or were terminally ill, with stage 0/carcinoma in situ and those already included in our 2009 CRC study or another study ($n$=69), were excluded [14]. One thousand six hundred twenty-five participants were invited for the data collection in

August 2013, see Fig. 1. Between August 2013 and January 2014, 78 (4.8%) participants died or discontinued participation, resulting in 1547 survivors who were invited for the questionnaire on HRQL in January 2014. Figure 1 gives an overview of the number of non-responders and excluded patients. Of the 1625 CRC survivors who were invited in August 2013, 1096 were included in the present study (67.4% of invited participants in August 2013) (Fig. 1).



### Health-Related Quality of Life (HRQL)

The validated European Organization for Research and Treatment of Cancer–Quality of Life Questionnaire (EORTC QLQ)-C30 was used to assess HRQL and fatigue [15, 16]. For CRC patients, previous research concludes that a healthy lifestyle is mainly associated with functioning scales (i.e. physical, emotional, social, cognitive and role functioning) and fatigue [5, 17]. Therefore, only functioning scales, fatigue and global health status were included in the analysis. All items were scored on a 4-point Likert scale ranging from 'not at all' to 'very much', except for the items regarding global health status which were scored from 1 (very poor) to 7 (excellent). All scores were linearly transformed to a scale ranging from 0 to 100 points [15, 18]. Higher scores on functioning scales represent better functioning, while a higher score on the fatigue scale corresponds to more fatigue.

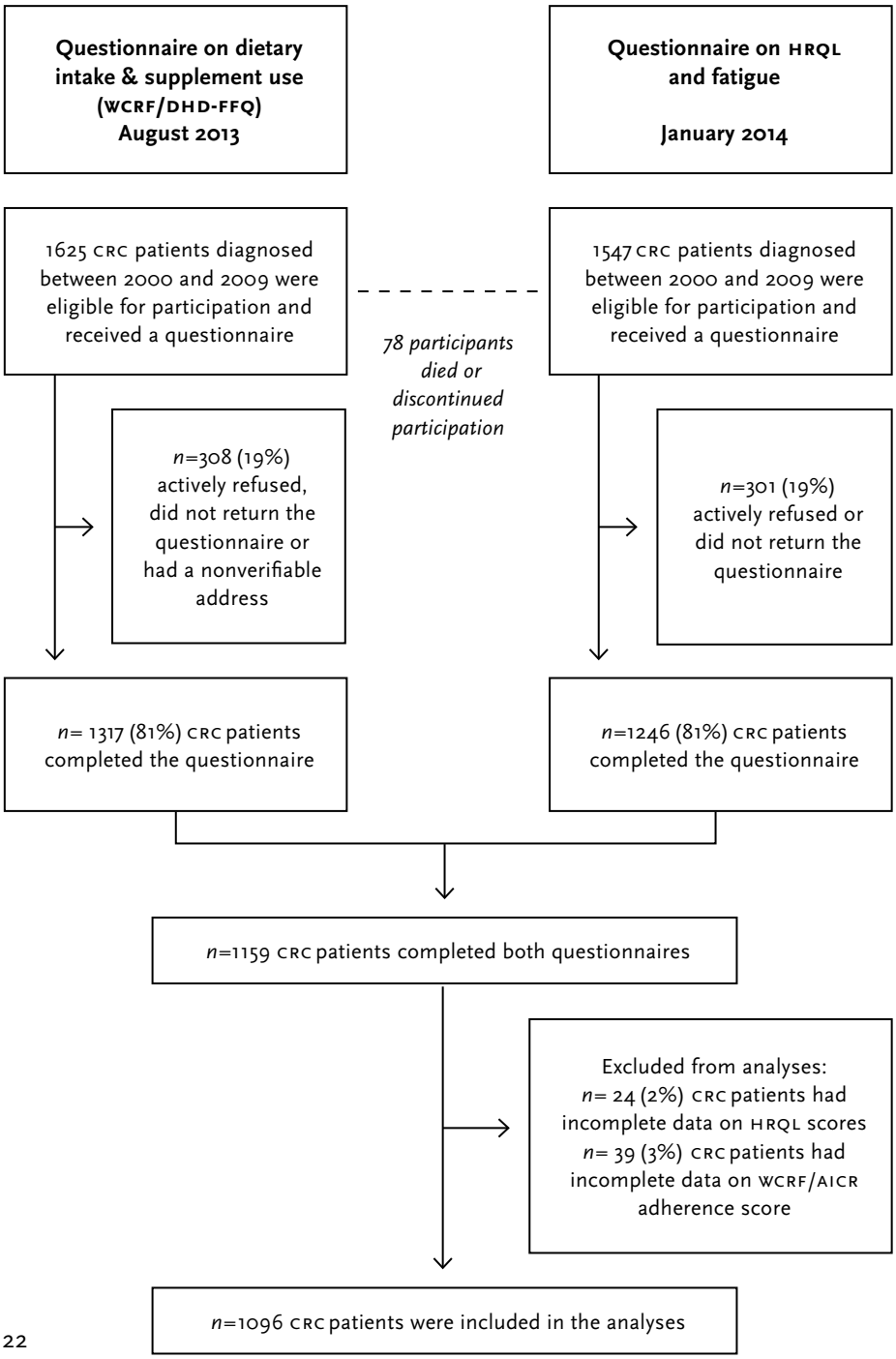
Changes in scores were considered clinically relevant if the mean difference was 5–14 points for physical functioning, 5–11 points for social functioning, 3–9 points for cognitive functioning, 6–19 points for role functioning and 5–13 point for fatigue [19]. For emotional functioning no cut-offs were defined [19].

### Adherence to the WCRF/AICR recommendations

Adherence to the eight WCRF/AICR recommendations was determined, six recommendations about healthy diet, one about body fatness and one about physical activity. The scoring of adherence to the WCRF/AICR recommendations is described extensively by Winkels et al. [20] and Romaguera et al. [21].

With regard to a healthy diet, in 2007, the WCRF/AICR published the following recommendations: 'foods and drinks that promote weight gain: avoid high-calorie foods and sugary drinks', 'plant-based foods: eat more grains, vegetables, fruit and beans', 'animal foods: limit red meat and avoid processed meat', 'alcoholic drinks: for cancer prevention, don't drink alcohol', 'preservation, processing & preparation: eat less salt and avoid mouldy grains & cereals' and 'dietary supplement use: for cancer prevention, don't rely on supplements'. To assess adherence to the recommendations concerning healthy diet, the Dutch Healthy Diet-Food Frequency Questionnaire (DHD-FFQ) was used [22]. The original DHD-FFQ consists of 34 items. To compensate for items that were missing in the DHD-FFQ but are incorporated in the WCRF/AICR recommendations,

**Figure 2:** HRQL scores by WCRF/AICR adherence scores (*n*=1096).



additional questions on intake of meat, processed meat and sugary beverages were added to the questionnaire, from now on called WCRF/DHD-FFQ. The WCRF/DHD-FFQ consists of 40 items on intakes of bread, fruit, vegetable, potatoes, milk, cheese, meat products, fish, cookies, pastries, crisps, soup, fats and oils, take-away food, pizza, sugary drinks, alcoholic beverages and discretionary salt.

Adherence to the recommendation regarding body fatness was determined based on body mass index (BMI) by calculating weight (kg)/height (m)$^2$. Weight and height were self-reported. BMI was categorised as normal weight ($18.5 < BMI < 25$ kg/m$^2$), overweight ($25 > BMI < 30$ kg/m$^2$) or obesity ($BMI > 30$ kg/m$^2$).

Physical activity was assessed using the Short Questionnaire to Assess Health-Enhancing Physical Activity (SQUASH) which contains questions about multiple activities referring to a normal week in the past month. Results were converted to time spent in light, moderate and vigorous activities, which were then converted to activity scores [23]. When this total activity score was 5 or more, representing the number of activities of at least 30 min per week, persons were categorised as adherent to the physical activity recommendation. If one of the recommendations was met, participants received 1 point for that recommendation.

When a recommendation was not met, 0 or 0.5 points were allotted according to the available cut-off values. The total score had a range of 0–8; a higher score means better adherence to the recommendations [20].

## Analysis and statistical methods

Responders were compared to non-responders. The CRC survivors were categorised into three groups, based on tertiles of WCRF/AICR adherence scores following the sample distribution. Chi-square (categorical variables) and one-way ANOVA (continuous variables) were used to test for differences in baseline characteristics.

To assess the association between WCRF adherence scores and HRQL, linear regression models were used both for the tertiles and for the continuous adherence scores. The following variables were tested whether they changed the regression coefficient by at least 10% [24]: gender, age, comorbidities, smoking status, years since diagnosis, tumour localization, tumour stage, having a stoma, chemotherapy and radiotherapy; and for the analyses of the individual components diet, physical activity and BMI. Gender (male/female), age (continuous), comorbidities (no comorbidities, 1 comorbidity, >2 comorbidities) and smoking (current, former, never) changed the regression coefficient ≥ 10% and were included in the multivariable model. For the analyses of the individual components, diet and BMI changed by > 10% when physical activity was added to the model, therefore physical activity was added to the multivariable model. Dummy variables were created for WCRF/AICR adherence score tertiles, smoking status and comorbidities.

Functioning scales, global health status and fatigue were also examined separately in relation to each of the three components of the adherence score (BMI (normal weight, overweight and obese), physical activity (score 0/1) and diet (low adherence (score < 3 points), moderate adherence (score 3–< 4 points) and high adherence (> 4 points)). To evaluate the effect of the separate components of adherence scores on the functioning scales, global health status and fatigue beyond the effects of the other components, the analysis of each component was adjusted for the other components. A p value < 0.05 was regarded as statistically significant. All analyses were conducted using the Statistical Package for Social Sciences (SPSS) version 23.0 (IBM).

## RESULTS

### General characteristics of the study population

Respondents of our study were most often male, > 65 years old, had two or more comorbidities, were former smokers, had a mean time since diagnosis of 8.1 years, had a colon tumour, stage II, and did not receive chemotherapy or radiotherapy (Table 1). When comparing the non-respondents and excluded respondents to the included respondents, non-respondents and excluded respondents did not differ from respondents (data not shown).

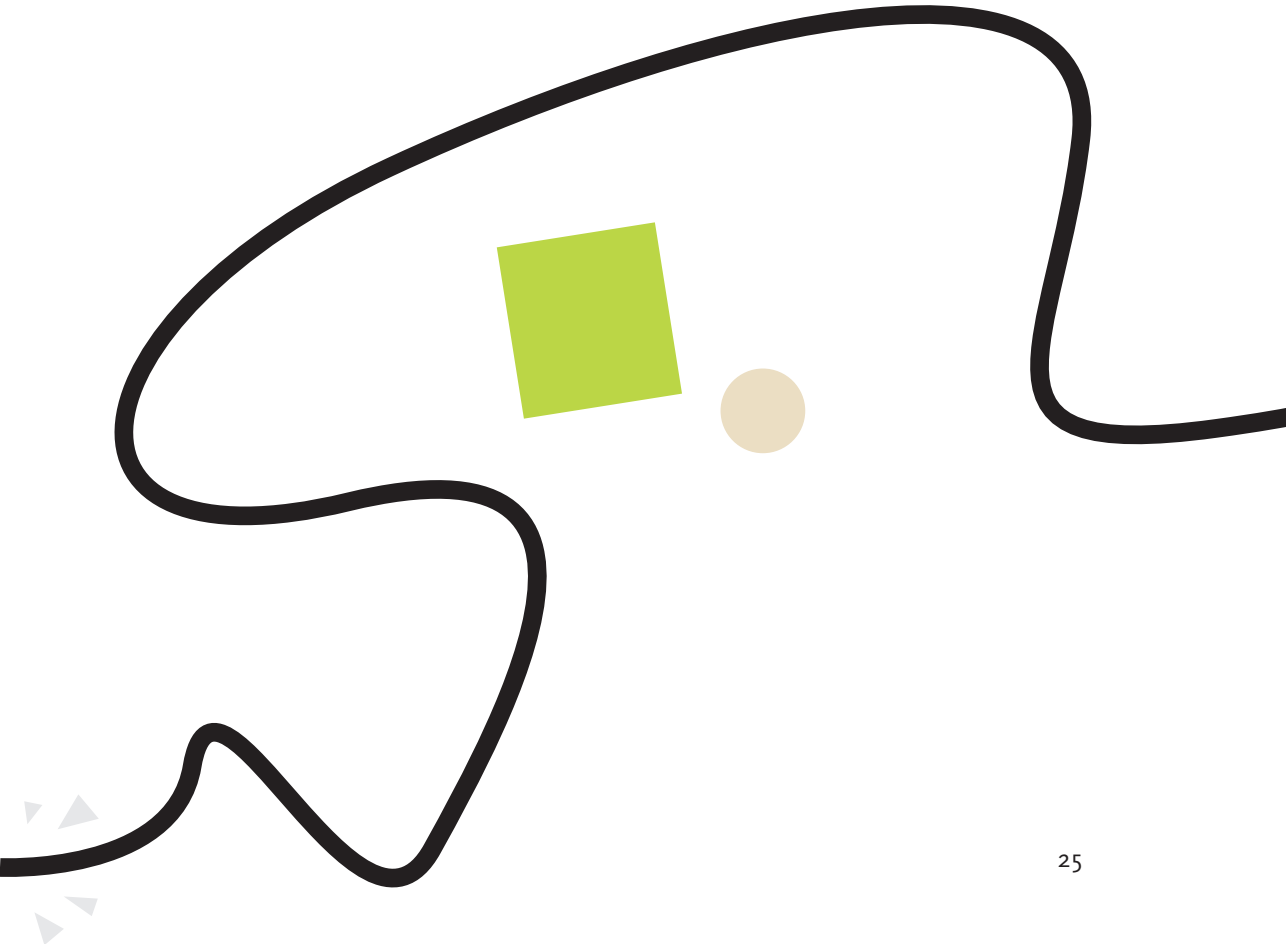
The mean total WCRF/AICR adherence score was 4.81 ± 1.04 of a total of 8 points (range 1.33–8.00).

Higher WCRF/AICR adherence scores were more common among women compared to men. The highest WCRF/AICR adherence scores were found among survivors who never smoked, among older participants and among participants who did not receive chemotherapy (Table 1). Years since diagnosis, tumour localization and stage, having a stoma, comorbidities and receiving radiotherapy, were evenly distributed among the tertiles of WCRF/AICR adherence scores. Thirty-four percent of respondents adhered to the BMI recommendation: 'maintain body weight within the normal range from age 21; BMI 18.5 <25 kg/m$^2$', 75% adhered to the physical activity recommendation: 'be moderately physically active, equivalent to brisk walking, for at least 30 min every day' and the mean dietary adherence score was 3.48 ± 0.87 of a total of 6 points (range 0.5–6.0). Fifty-eight percent adhered to the recommendation 'foods and drinks that promote weight gain: avoid sugary drinks' with adherence = no sugary drinks, 10% adhered to 'plant-based foods: at least five portions/servings (at least 400 g) of a variety of non- starchy vegetables of fruits every day' with adherence = a mean fruit and vegetable intake > 400 g/day and dietary fibre > 17 g/day, 8% to 'meat products: people who eat red meat to consume less than 500 g/week, very little, if any, to be processed' with adherence = red/processed meat < 500 g/week of which processed meat < 3 g/day, 73% to 'alcoholic drinks: If alcoholic drinks are consumed,

limit consumption to no more than two drinks a day for men, and one drink a day for women', 12% to 'preservation, processing & preparation: Limit consumption of processed foods with added salt to ensure an intake of <6 g (2.4 g sodium) a day' and 75% to the recommendation on 'dietary supplement use: Dietary supplements are not recommended for cancer prevention'.

Higher HRQL scores were seen among men (physical, role, emotional functioning and global health status), for younger participants (< 65 years old) (physical and emotional functioning), CRC survivors without comorbid conditions (for physical, role, emotional, cognitive, social functioning and global health status and fatigue) and those who never smoked (emotional functioning and global health status). For years since diagnosis, tumour localization, tumour stage, having a stoma, receiving chemotherapy and radiotherapy, no significant differences in HRQL was found (data not shown).

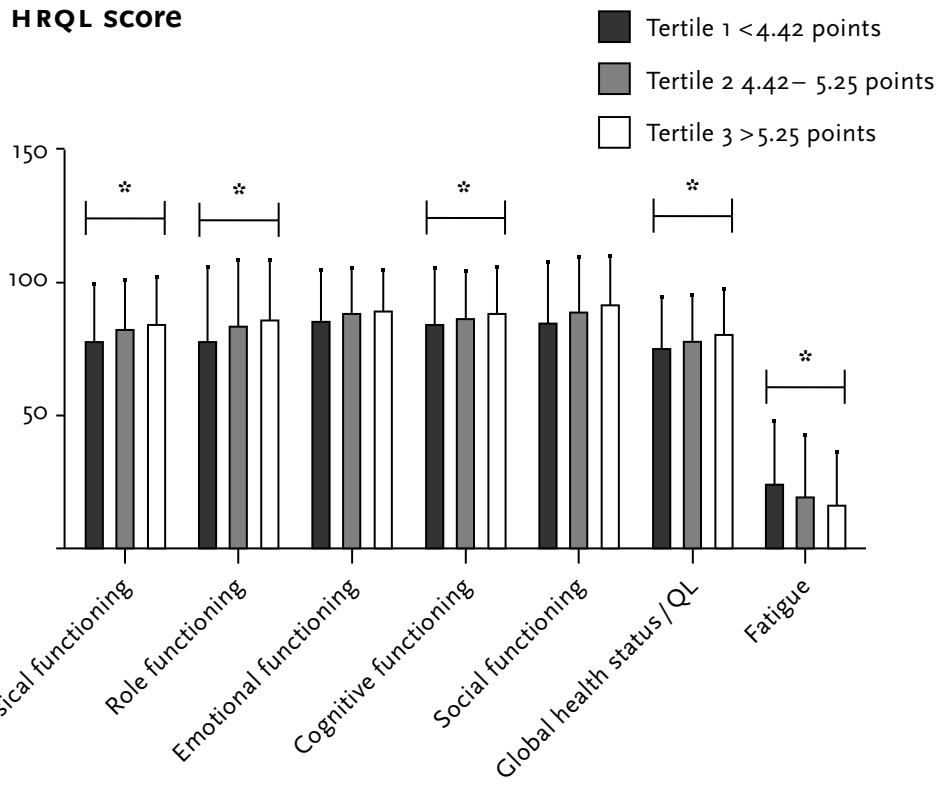




## Health-Related Quality of life

Survivors with the highest WCRF/AICR adherence scores (tertile 3; >5.25 points) had the highest mean physical functioning scores (84.8 ± 17.2 vs. 78.3 ± 21.3) and role functioning scores (86.5 ± 21.7 vs. 78.3 + 27.7) and the lowest mean scores on fatigue (16.6 ± 19.7 vs. 24.7 ± 23.7), compared to survivors with the lowest WCRF/AICR adherence scores (tertile 1; <4.42 points; see Fig. 2). Although small, these differences are considered clinically relevant [19].

**Figure 2:** HRQL scores by WCRF/AICR adherence scores (*n*=1096).




** Small clinically relevant difference between tertile 1 and tertile 3.*

**Table 1:** Socio-demographic and clinical characteristics for the three tertiles of WCRF/AICR adherence scores (*n*=1096).

| | | Total population | Tertile 1 WCRF adherence score | Tertile 2 WCRF adherence score | Tertile 3 WCRF adherence score |
|---|---|---|---|---|---|
| | | | <4.42 points | 4.42 – 5.33 points | >5.33 points |
| | | *n* (%) | *n* (%) | *n* (%) | *n* (%) |
| **N** | | 1096 (100%) | 360 (33%) | 365 (33%) | 371 (34%) |
| **Gender*** | Male | 635 (58%) | 227 (63%) | 229 (63%) | 179 (48%) |
| | Female | 461 (42%) | 133 (37%) | 136 (37%) | 192 (52%) |
| | Missing | 0 | 0 | 0 | 0 |
| **Age*** | Mean age (years ± SD) | 70.8 ± 9.2 | 69.7 ± 9.5 | 70.9 ± 9.1 | 71.7 ± 8.9 |
| | <65 years | 264 (24%) | 102 (28%) | 89 (24%) | 73 (20%) |
| | >65 years | 832 (76%) | 258 (72%) | 276 (76%) | 298 (80%) |
| | Missing | 0 | 0 | 0 | 0 |
| **Comorbidities** | 0 | 261 (24%) | 76 (21%) | 85 (23%) | 100 (27%) |
| | 1 | 306 (28%) | 96 (27%) | 102 (28%) | 108 (29%) |
| | ≥2 | 495 (45%) | 183 (51%) | 163 (45%) | 149 (40%) |
| | Missing | 34 (3%) | 5 (1%) | 15 (4%) | 14 (4%) |
| **Smoking*** | Current | 85 (8%) | 33 (9%) | 26 (7%) | 26 (7%) |
| | Former | 667 (61%) | 237 (66%) | 224 (61%) | 206 (56%) |
| | Never | 322 (29%) | 83 (23%) | 106 (29%) | 133 (36%) |
| | Missing | 22 (2%) | 7 (2%) | 9 (3%) | 6 (2%) |

| | | | | | |
|---|---|---|---|---|---|
| **Years since diagnosis** | Mean time since diagnosis (SD) | 8.1 ± 2.8 | 8.1 ± 2.8 | 8.2 ± 2.8 | 7.9 ± 2.8 |
| | <5 years | 116 (11%) | 39 (11%) | 32 (9%) | 45 (12%) |
| | >5 years | 980 (89%) | 321 (89%) | 333 (30%) | 326 (88%) |
| | Missing | 0 | 0 | 0 | 0 |
| **Tumour localization** | Colon | 634 (58%) | 204 (57%) | 211 (58%) | 219 (59%) |
| | Rectum | 462 (42%) | 156 (43%) | 154 (42%) | 152 (41%) |
| | Missing | 0 | 0 | 0 | 0 |
| **Tumour stage** | Stage I | 348 (32%) | 111 (31%) | 112 (31%) | 125 (34%) |
| | Stage II | 372 (34%) | 108 (30%) | 129 (35%) | 135 (37%) |
| | Stage III | 318 (29%) | 119 (33%) | 101 (28%) | 98 (26%) |
| | Stage IV | 26 (2%) | 10 (3%) | 12 (3%) | 4 (1%) |
| | Missing | 31 (3%) | 12 (3%) | 11 (3%) | 8 (2%) |
| **Stoma** | Yes | 168 (15%) | 58 (16%) | 46 (13%) | 64 (17%) |
| | No | 928 (85%) | 302 (84%) | 319 (87%) | 307 (83%) |
| | Missing | 0 | 0 | 0 | 0 |
| **Chemotherapy*** | Yes | 329 (30%) | 128 (36%) | 113 (31%) | 88 (24%) |
| | No | 767 (70%) | 232 (64%) | 252 (69%) | 283 (76%) |
| | Missing | 0 | 0 | 0 | 0 |
| **Radiotherapy** | Yes | 370 (34%) | 125 (35%) | 119 (33%) | 126 (34%) |
| | No | 726 (66%) | 235 (65%) | 246 (67%) | 245 (66%) |

*$p<0.05$

Multivariable linear regression models (Table 2) showed that compared to the lowest tertile (< 4.42 points), the second (4.42–5.25 points) and the third tertile (> 5.25 points) of the WCRF/AICR adherence score were significantly associated with higher scores on physical, role and social functioning and a lower level of fatigue. The highest tertile of the adherence score was significantly associated with higher scores on emotional functioning, cognitive functioning and global health status compared to the lowest tertile. For an increase in the continuous score of adherence to the WCRF/AICR recommendations, significant associations were found for better physical functioning, role functioning, cognitive functioning, social functioning and global health status and less fatigue.



**Table 2:** The association between overall WCRF/AICR adherence score and HRQL and fatigue using multivariable linear regression (*n*=1096).

| HRQL | WCRF Adherence Scores | | | |
|---|---|---|---|---|
| | **Tertile 1** | **Tertile 2** | **Tertile 3** | **Continuous** |
| | <4.42 points | 4.42 – 5.25 points | >5.25 points | |
| **Physical Functioning** | REF | 3.88 (4.42, 6.33)* | 6.94 (4.46, 9.42)* | 2.71 (1.73, 3.68)* |
| **Role Functioning** | REF | 4.76 (1.40, 8.12)* | 7.49 (4.09, 10.89)* | 2.87 (1.53, 4.21)* |
| **Emotional Functioning** | REF | 2.35 (-0.06, 4.75) | 3.34 (0.90, 5.77)* | 0.85 (-0.11, 1.81) |
| **Cognitive Functioning** | REF | 1.90 (-0.77, 4.57) | 3.48 (0.78, 6.17)* | 1.25 (0.19, 2.32)* |
| **Social Functioning** | REF | 3.56 (0.67, 6.44)* | 6.12 (3.21, 9.04)* | 2.01 (0.85, 3.16)* |
| **Global health status / QL** | REF | 1.68 (-0.70, 4.07) | 4.33 (1.92, 6.74)* | 1.64 (0.69, 2.59)* |
| **Fatigue** | REF | -3.87 (-6.90, -0.84)* | -7.65 (-10.72, -4.59)* | -2.81 (-4.02, -1.60)* |

**Results are expressed as β (95% confidence interval (CI)). All models were adjusted for age, gender, comorbidities, and smoking. An increase in functioning scores and global health status indicates an improvement in HRQL. A decrease in fatigue scores indicates an improvement in fatigue.** *$p<0.05$

Multivariable linear regression models showed that adherence to the physical activity recommendation was associated with better physical, role, emotional and social functioning, better global health status and less fatigue (Table 3). Being overweight was not significantly associated with different HRQL and fatigue scores compared to participants with a healthy weight. However, being obese was significantly associated with lower physical functioning compared to healthy weight respondents. Adherence to the dietary recommendations was not associated with the different functioning scales, global health status or fatigue.

## DISCUSSION

Higher adherence to the WCRF/AICR recommendations was associated with better physical functioning, role functioning, social functioning and global health status and less fatigue among CRC survivors. Physical activity seemed to be the main component of the WCRF/AICR recommendations contributing to the observed associations. Being obese was associated with worse physical functioning. Diet was not associated with the different functioning scales, global health status and fatigue.

Previous studies showed an association between higher adherence to the non-cancer-specific Healthy Eating Index or the Mediterranean diet and higher levels of HRQL in cancer survivors, including CRC survivors [5, 6, 7]. Our study did not show an association between the specific dietary recommendations of the WCRF/AICR and HRQL, however when looking at the total adherence WCRF/AICR recommendations score, an association between level of adherence and HRQL was found in CRC survivors similar to the association with the Healthy Eating Index or the Mediterranean diet [5, 6, 7]. Our study only found an inverse association between being obese and physical functioning. Our findings are in line with the results of Inoue-Choi who showed that higher adherence to the WCRF/AICR recommendations, especially to the physical activity recommendations, was significantly associated with higher physical and mental component summary scores (SF-36) in a population of female cancer survivors with different cancer types [10]. Our results are also in line with the results of Breedveld-Peters et al. who found that higher adherence to the total set of WCRF/AICR recommendations was associated with better physical functioning and less fatigue in a small group ($n$=145) of CRC survivors in the Netherlands [12].

Of all recommendations, physical activity was most strongly associated with most functioning scales: physical, role, emotional and social functioning; global health status and fatigue in our study. When investigating the crude model, diet was associated with physical functioning. However, when we adjusted for physical activity, as discussed in the 'Subjects and Methods' section, the association was no longer

**Table 3:** The association between HRQL and fatigue and physical activity, diet and BMI using multivariable linear regression ($n$=1096).

| | | Physical Functioning | Role Functioning | Emotional Functioning | Cognitive Functioning | Social Functioning | Global health status / QL | Fatigue |
|---|---|---|---|---|---|---|---|---|
| **Physical activity** | *0* | REF | REF | REF | REF | REF | REF | REF |
| | *1* | 10.30 (8.01; 12.59)* | 10.50 (7.31; 13.67)* | 2.75 (0.45; 5.06)* | 2.49 (-0.07; 5.04) | 6.20 (3.45; 8.95)* | 6.27 (4.02; 8.53)* | -7.43 (-10.32; -4.54)* |
| **Diet** | *0 – <3* | REF | REF | REF | REF | REF | REF | REF |
| | *3 – <4* | 0.42 (-1.98; 2.82) | 1.55 (-1.79; 4.89) | 1.05 (-1.38; 3.47) | 1.52 (-1.53; 3.83) | 1.64 (-1.25; 4.54) | 1.96 (-0.41; 4.33) | -2.87 (-5.91; 0.16) |
| | *> 4* | 0.09 (-2.45; 2.64) | 0.38 (-3.17; 3.92) | 0.39 (-2.18; 2.96) | 1.71 (-1.14; 4.55) | 0.70 (-2.37; 3.77) | 0.26 (-2.25; 2.78) | -3.12 (-6.34; 0.10) |
| **BMI** | *Normal weight* | REF | REF | REF | REF | REF | REF | REF |
| | *Over-weight* | -0.24 (-2.46; 1.98) | 0.29 (-2.80; 3.37) | 0.97 (-1.27; 3.20) | -0.58 (-3.06; 1.90) | 0.22 (-2.45; 2.89) | 1.74 (-0.45; 3.93) | -0.49 (-3.23; 2.32) |
| | *Obese* | -4.15 (-7.16; -1.15)* | 1.73 (-5.91; 2.46) | -0.92 (-3.95; 2.11) | -2.80 (-6.15; 0.55) | -1.93 (-5.54; 1.69) | -0.29 (-3.25; 2.67) | 2.81 (-0.98; 6.60) |

**Results are expressed as β (95% confidence interval (CI)). All models were adjusted for age, gender, comorbidities, and smoking. An increase in functioning scores and global health status indicates an improvement in HRQL. A decrease in fatigue scores indicates an improvement in fatigue.** *$p<0.05$

significant. This indicates that physical activity indeed was the main component of the WCRF/AICR associated with a better HRQL and not diet.

For fatigue, there is ample evidence that physical activity has a positive influence [25]. This is also in line with the US National Comprehensive Cancer Network guidelines for managing fatigue [26]. Two observational studies recommended that CRC survivors should meet the public health exercise guideline (>150 min of moderate to strenuous intensity exercise or >60 min of strenuous intensity exercise per week), since CRC survivors who meet these standards had a higher quality of life than other survivors who did not meet these exercise guidelines [8, 14]. However, to be able to be physically active, a healthy diet and body weight are important. This is supported by our finding that being obese was negatively associated with physical functioning. Therefore, it remains important to focus on the triad of physical activity, diet and body weight when targeting CRC survivors, as was also suggested by Blanchard et al. [27].

The differences found in functioning scales when comparing respondents with the highest WCRF/AICR adherence scores (> 5.25) to those with the lowest scores (< 4.42) are subtle but nevertheless clinically meaningful, meaning that these differences are noticeable in daily clinical practice [19].

The present study was the first study investigating the associations between adherence to the cancer-specific WCRF/AICR recommendations and HRQL, in a large group of male and female CRC survivors. Major strengths of our study are the large sample size that made it possible to investigate the association between diet, physical activity and body fatness on HRQL separately, and the registry-based character of the study. However, there are also some limitations. First, selection bias may limit the generalizability of our findings. The present study covers CRC stage I–IV, with a mean time since diagnosis of 8.1 years. Patients with a worse prognosis or worse health might be less likely to participate in the study, might have more problems to complete the follow-up questionnaires or might have already died. Although our included participants were older and more often former smokers than the excluded participants, our study population may consist of more healthy CRC survivors possibly with different associations between a healthy lifestyle and HRQL. Absolute HRQL scores of our CRC survivors should be interpreted cautiously and are not generalizable for the whole population of CRC survivors. Second, data in our study were self-reported by survivors, which might have led to underreporting (body weight) and overreporting (physical activity, consumption of vegetable and fruits) due to social desirable answers [28, 29, 30, 31]. Self-reporting of nutritional intake may lead to differential misclassification: obese participants might underreport their intake more than non-obese participants and elderly might be more eager to present themselves in a favourable way, giving a social desirable answer, hence their higher WCRF/AICR scores 32. Also non-differential misclassification might have occurred, probably leading to higher WCRF/AICR adherence

scores. However, only one respondent had a total score of 8 points and the percentage survivors adhering to specific recommendations e.g., more plant-based foods, less red meat was often low, demonstrating how hard it is for CRC survivors and for the general public to adhere to the WCRF/AICR recommendations. Third, 75% of respondents reported to meet the guidelines for physical activity. This might be an overestimation, due to the nature of measuring physical activity: by means of a questionnaire (SQUASH) and not by the use of activity trackers. Fourth, the scoring of fatigue and other functioning scales by use of the EORTC QLQ-C30 may not be the best way to determine HRQL, especially fatigue, so many years after treatment. However, the EORTC QLQ-C30 is the most common questionnaire to determine HRQL in cancer survivors. Hence, it makes it easy to compare our results to the work of others.

Finally, due to the study design, with 6 months between the questionnaire on adherence to the WCRF recommendations and the questionnaire on HRQL in a cohort with a mean time since diagnosis of 8.1 years, we cannot draw conclusions whether the association between HRQL and adherence to the WCRF/AICR recommendations reflects a causal relation or reverse causation which means that survivors who have a better HRQL easier adhere to the WCRF/AICR recommendations.

## CONCLUSION

Higher adherence to the WCRF/AICR recommendations was associated with better physical, role, cognitive and social functioning, better global health status and less fatigue among CRC survivors. Physical activity seemed to be the main contributor to higher scores on most functioning scales and global health status and lower scores on fatigue in CRC survivors.

Because CRC survivors with the highest adherence to the WCRF/AICR recommendations also report the highest HRQL, we recommend to investigate whether increasing the adherence in CRC survivors indeed results in better HRQL. However, previous research as well as the present study has shown that it is very difficult to motivate cancer survivors to positively change their lifestyle [12, 20]. Even Lynch syndrome carriers, with a very high inherited risk of developing CRC [33], from whom we hoped that they would be extremely motivated to change their lifestyle, were shown to adhere to those recommendations only in a slightly better manner than CRC survivors without Lynch syndrome. Adhering to the WCRF/AICR recommendations can be challenging for CRC survivors. Thus, trials aiming to increase adherence should not only focus on the effects better adherence has on cancer outcomes but also on tools to stimulate and motivate CRC survivors to follow the recommendations to the best of their abilities.

**ACKNOWLEDGEMENTS**

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**COMPLIANCE WITH ETHICAL STANDARDS**

**CONFLICT OF INTEREST**

The authors declare that they have no conflict of interest.

**RESEARCH INVOLVING HUMAN PARTICIPANTS**

Ethical approval for the study was obtained from the local certified Medical Ethics Committee of the Maxima Medical Centre Veldhoven, the Netherlands (approval number 0822).

**INFORMED CONSENT**

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

**DATA**

We have control over all primary data, we agree to allow the journal to review our data if requested.

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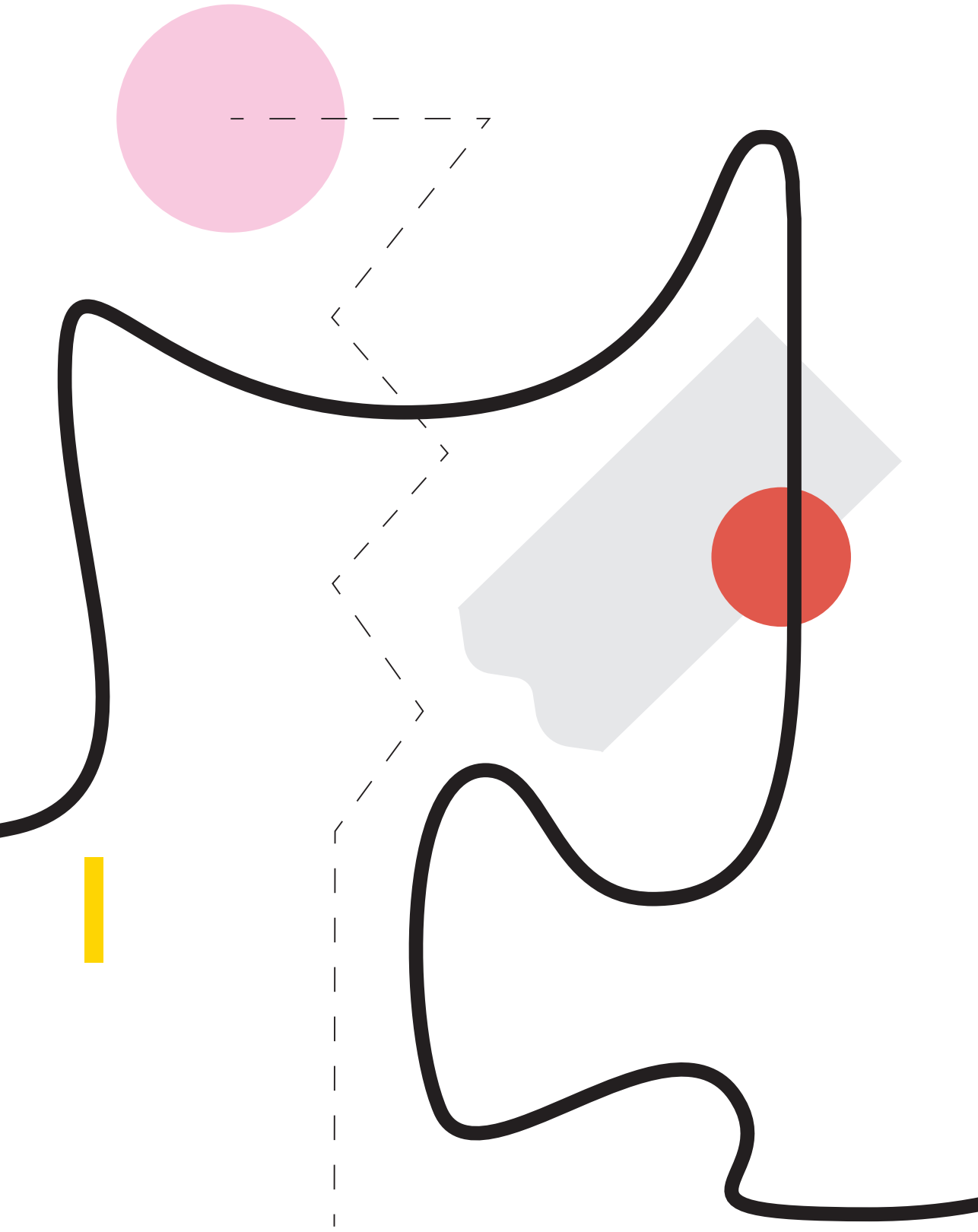

# CHAPTER 3:

## Colorectal cancer survivors' beliefs on nutrition and cancer; correlates with nutritional information provision

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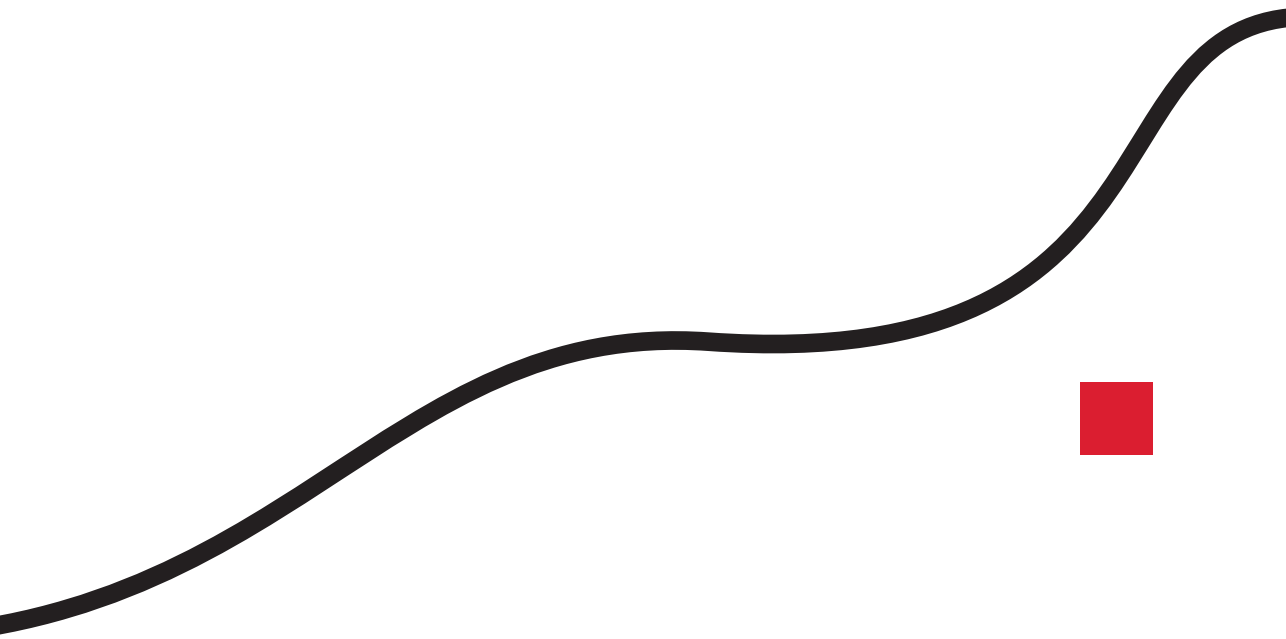


## ABSTRACT

**PURPOSE:** To investigate CRC survivors' beliefs on nutrition and cancer and the association with nutritional information provision by (kind and number) of health professionals and to inquire about foods that CRC survivors believed either had a positive or negative influence on their cancer.

**METHODS:** A total of 326 CRC survivors of an ongoing prospective cohort study filled out questionnaires 1 month after surgery on whether they had received nutritional information from health professionals. Also, their beliefs that nutrition influences (1) feelings of well-being, (2) complaints after treatment, (3) recovery and (4) cancer recurrence were investigated. Prevalence ratios were calculated (using Cox proportional hazard regression analysis) to study associations between information provision and the four beliefs adjusted for age, gender and cancer stage.

**RESULTS:** Sixty-two percent of respondents received information about nutrition from one or more health professionals. Most respondents who received information strongly believe nutrition influences feelings of well-being (59%) and recovery after cancer (62%). Compared with those who did not receive information, respondents who received information from three professionals showed the strongest beliefs on the influence of nutrition on complaints after treatment (PR 3.4; 95% CI 1.6–7.4), recovery after treatment (PR 2.0; 95% CI 1.2–3.3) and recurrence (PR 2.8; 95% CI 1.3–6.2).

**CONCLUSION:** Nutritional information provision by health professionals positively influences the beliefs of CRC survivors on the influence of nutrition on cancer outcomes: stronger beliefs occur when respondents received information from three health professionals.

## INTRODUCTION

Colorectal cancer (CRC) is the third most common cancer worldwide [1]. Due to the ageing of the population, implementation of screening programs and ongoing advancements in treatment, incidence and survival rates of CRC have increased over the past years [2], resulting in an increase in CRC survivors [3]. A person is characterized as a cancer survivor from the moment of diagnosis until the person deceases [4].

Before, during and after treatment, CRC survivors often suffer from nutrition-related symptoms such as changes in defecation, intestinal cramps, lack of appetite and unintended weight gain or weight loss [5, 6], which have a negative impact on quality of life [7, 8]. Dietary guidelines to alleviate these symptoms are available [6, 7, 9] and it is important that CRC survivors are able to access and follow this information in order to change their diet to improve their quality of life.

In addition, prospective cohort studies in cancer survivors have shown that higher adherence to the World Cancer Research Fund/American Institute for Cancer Research (WCRF/AICR) guidelines for cancer prevention [10] is associated with lower mortality in CRC survivors [11, 12] and better health-related quality of life [13, 14]. A healthy diet low in fat, meat and refined grains, combined with a high level of physical activity, has been shown to be associated with lower recurrence and mortality rates and a decreased risk of comorbid conditions in cancer survivors in general [11, 13, 15] and specifically in CRC survivors [16, 17].

Although the diagnosis of cancer is seen as a teachable moment [18], an event which presents a good opportunity for learning something about a particular aspect of life, only a minority of CRC survivors change their diet after diagnosis. Results from a cross-sectional study in 1458 CRC survivors showed that only 36% of CRC survivors reported that they had changed their diet after diagnosis [19]. Another cross-sectional study in 1196 CRC survivors found that 32% of CRC survivors intended to adopt a healthier diet; however, only 25% changed their diet after diagnosis of CRC. This study also found that CRC survivors' adherence to the WCRF/AICR guidelines for cancer prevention was low, with 9% adhering to the recommendation for fruit and vegetable intake, and 12% adhering to more than six out of eight recommendations [20].

It is unknown why only few CRC survivors change their diet after diagnosis and why low adherence to healthy lifestyle recommendations persists even after a cancer diagnosis. One hypothesis is that CRC survivors think they already follow a healthy diet, as was seen by Anderson et al., where cancer survivors were sceptical that poor diet caused cancer, because people believed their diets were healthy before onset [21].

Another hypothesis is that CRC survivors do not believe nutrition can have an effect on cancer and cancer outcomes, possibly due to poor nutritional information provision. Two studies among CRC survivors found that only 17–19% of survivors received advice on nutrition or supplement use [17, 18].

The aim of the current study is (1) to investigate CRC survivors' beliefs on nutrition and cancer and their association with information provision on nutrition by health professionals, (2) to investigate the association between the kind and number of health professionals and the strength of beliefs and (3) to categorize foods that CRC survivors believed either had a positive or negative influence on their cancer.

## METHODS

### Study design and study population

The PROCORE study, started in 2016, is a prospective population based study, in which newly diagnosed CRC survivors are recruited before the start of treatment and followed via the PROFILES-registry (Patient Reported Outcomes Following Initial treatment and Long term Evaluation of Survivorship) [22] until 2 years after diagnosis. Ethical approval for the study was obtained from the certified Medical Ethics Committee of Medical Research Ethics Committees United (approval number NL51119.060.14). All respondents gave informed consent. Data from this longitudinal study will be available online for non-commercial scientific research, subject to study question, privacy and confidentiality restrictions and registration (www.profilesregistry.nl). For this specific paper, data from baseline (e.g. pre-treatment) and data from 4 weeks after surgery were used.

Respondents were recruited from four Dutch hospitals: the Catharina Hospital in Eindhoven, Maxima Medical Centre in Veldhoven, Elkerliek Hospital in Helmond and Elisabeth-TweeSteden Hospital in Tilburg. Inclusion criteria were the diagnosis of CRC stage I–IV and being 18 years or older. Exclusion criteria were ever being diagnosed with a different carcinoma, except for basal cell carcinoma of the skin; having cognitive limitations or being unable to read or write Dutch, which did not allow them to independently fill out a questionnaire.

### Data collection

CRC patients were identified by the research nurses or case managers (depending on hospital). They informed patients about the study and asked them to participate, before start of the treatment. Patients received an information package from the nurse or case manager, including a letter, a patient information leaflet, an informed consent form and a questionnaire. The informed consent and questionnaire could be send back to the PROFILES registry in two separate envelopes. Patients could indicate if they wanted

to receive the follow-up questionnaires in digital form via the PROFILES registry, or on paper. Patients were reassured that nonparticipation had no consequences for their follow-up care or treatment.

A total of 595 people recently diagnosed with CRC were invited to participate in the PROCORE study. Of those, 403 people filled out the baseline questionnaire. Of these respondents, 344 underwent surgery for their CRC and were sent the second questionnaire, which was filled out by 326 survivors.

#### QUESTIONNAIRES

For the current research question, data was obtained from the baseline survey and from the survey 4 weeks after surgery. The baseline survey before surgery consisted of self-designed questions on general characteristics, including age, height, usual body weight, body weight at the moment of diagnosis, highest level of education (elementary school, high school, vocational education, bachelor degree), smoking (current smoker, non-smoker, former smoker) and on alcohol consumption (current drinker (with mean intake), former drinker, never). The questionnaire 4 weeks after surgery consisted of self-designed questions on nutritional information provision by health professionals, and patients' beliefs that nutrition influences feelings of well-being, complaints after treatment, recovery and cancer recurrence. Depending on the question, answers could be indicated on an ordinal Likert scale with four options (not at all, a little, some, a lot), on a scale from 0 to 10, or could be answered with 'yes' or 'no'. Two open-ended questions were included asking the respondents to mention foods, diets or supplements they believed to either positively or negatively affect cancer.

Patients' sociodemographic and clinical information was retrieved from the Netherlands Cancer Registry (NCR), including gender, diagnosis and tumour staging.

### Data analyses

Personal and disease-related characteristics, percentage of respondents who received nutritional information and percentage of respondents who strong, intermediate or do not believe that nutrition can influence feelings of well-being, complaints after treatment, recovery after treatment and cancer recurrence were described for the total group of respondents ($n$=326; Tables 1 and 2). To investigate whether strong believers on one belief are also strong believers on the other beliefs, the characteristics of the study population were also split out by the belief of the influence of nutrition on well-being using the following categories: no belief of an influence (score 0–2, $n$=63), an intermediate belief (score 3–6, $n$=78) and a strong belief (score 7–10, $n$=71). Differences between the 'no belief', 'intermediate belief' and 'strong belief' groups were analysed using Chi-square test.

Furthermore, the association between the kind and number of health professionals and the strength of beliefs was investigated.

For the different health professionals, the Likert scale option 'none' was recoded into received information 'no' and a little/some/a lot into 'yes'. Usual body weight and body weight and height at the moment of diagnosis were used to calculate weight change before diagnosis and body mass index (BMI) at diagnosis. For survivors < 70 years old, a BMI 20–25 was considered a healthy BMI, for survivors ≥70 years old, a BMI 22–28 was considered a healthy BMI [23, 24]. The Global Leadership Initiative on Malnutrition (GLIM) states for survivors > 70 years old, a BMI < 22 is a low body mass index, which results in a higher risk for a mild to moderate deficit in muscle mass [23]. BMI 22.01–28 corresponded to not undernourished in people aged > 70, as stated by the team of the SNAQ RC [24].

To evaluate the association between the dependent variables having strong beliefs on the influence of nutrition on feelings of well-being (yes/no), complaints after treatment (yes/no), recovery after treatment (yes/no) and cancer recurrence (yes/no), and (1) having received nutritional information (yes/no), and (2) the number of health professionals providing nutritional information, prevalence ratios (PR) and 95% confidence intervals were calculated. Cox proportional hazard regression analysis was used with the time variable set at 1 for each respondent. Having a strong belief corresponded to a score of 7–10 (scale 0–10) and having no strong belief corresponded to a score of 0–2 (scale 0–10). Analyses were adjusted for age and gender. Educational level (elementary school/high school; vocational education; bachelor degree or higher), smoking status (current, former or non-smoker), comorbidities (0, 1 or ≥ 2), stage (I, II, III or IV) and BMI at diagnosis (underweight, normal weight, overweight or obese) were evaluated as possible confounding factors and were included if they changed the PR by at least 10%. For strong beliefs that nutrition influences complaints and recurrence, cancer stage changed the PR with > 10%. Therefore, the Cox proportional hazard regression analyses were adjusted for age, gender and cancer stage.

Foods that respondents believed either had a positive or negative influence on their cancer were categorized.

Analyses were performed using SPSS (version 23) and $p < 0.05$ was considered statistically significant.

**Table 1:** General characteristics of the total group of respondents (*n*=326) and split in three groups based on the score for 'belief that nutrition influences feelings of well-being'.

| | | | Score 0-2 | Score 3-6 | Score 7-10 |
|---|---|---|---|---|---|
| | | **Respondents** (*n*=326) | **No belief influence** (*n*=63) | **Intermediate belief influence** (*n*=78) | **Strong belief influence** (*n*=171) |
| **N** | | *n* (%) | *n* (%) | *n* (%) | *n* (%) |
| **Gender** | Male | 198 (61%) | 42 (67%) | 41 (53%) | 107 (63%) |
| | Female | 128 (39%) | 21 (33%) | 37 (47%) | 64 (37%) |
| **Age** | Years (mean ± SD) | 67.2 (8.9) | 68.8 (8.4) | 66.9 (9.2) | 66.2 (8.8) |
| | <70 years | 191 (59%) | 32 (51%) | 43 (55%) | 112 (65%) |
| | ≥70 Years | 135 (41%) | 31 (49%) | 35 (45%) | 59 (35%) |
| **Highest level of education*** | Elementary school/ High school | 108 (33%) | 28 (44%) | 30 (38%) | 17 (10%) |
| | Vocational education | 130 (40%) | 20 (32%) | 30 (38%) | 94 (55%) |
| | Bachelor degree or higher | 81 (25%) | 11 (17%) | 18 (23%) | 51 (30%) |
| | Missing | 7 (2%) | 4 (6%) | 0 (0%) | 9 (5%) |
| **Alcohol consumption** | Never | 59 (18%) | 14 (22%) | 14 (18%) | 28 (16%) |
| | Former drinker | 14 (4%) | 1 (2%) | 4 (5%) | 8 (5%) |
| | Yes | 234 (72%) | 46 (73%) | 57 (73%) | 123 (72%) |
| | Mean intake (glasses per week) (SD) | 10 (9) | 7.3 (6) | 9.3 (10) | 10.6 (10) |
| | Missing | 19 (6%) | 2 (3%) | 3 (4%) | 12 (7%) |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| **BMI at diagnosis (kg/m2)** | Mean ± SD* | 26.6 | (4.1) | 27.5 | (4.0) | 26.3 | (4.5) | 26.5 | (3.9) | |
| | Underweight | 24 | (7%) | 4 | (6%) | 10 | (13%) | 8 | (5%) | |
| | Normal weight | 127 | (39%) | 23 | (37%) | 31 | (40%) | 69 | (40%) | |
| | Overweight | 113 | (35%) | 19 | (30%) | 19 | (24%) | 69 | (40%) | |
| | Obese | 58 | (18%) | 17 | (27%) | 16 | (21%) | 23 | (14%) | |
| | Missing | 4 | (1%) | 0 | (0%) | 2 | (3%) | 2 | (1%) | |
| **Weight change before diagnosis** | > 5% weight loss | 63 | (19%) | 5 | (8%) | 14 | (18%) | 54 | (32%) | |
| | > 0% to ≤ 5% weight loss | 66 | (20%) | 15 | (24%) | 17 | (22%) | 62 | (36%) | |
| | Stable weight | 181 | (56%) | 41 | (65%) | 42 | (54%) | 93 | (54%) | |
| | Weight gain | 14 | (4%) | 1 | (2%) | 5 | (6%) | 6 | (4%) | |
| | Missing | 4 | (1%) | 1 | (2%) | 0 | (0%) | 3 | (2%) | |
| **Comorbidities** | 0 | 68 | (21%) | 15 | (24%) | 20 | (26%) | 31 | (18%) | |
| | 1 | 91 | (28%) | 21 | (33%) | 19 | (24%) | 48 | (28%) | |
| | ≥2 | 166 | (51%) | 27 | (43%) | 39 | (50%) | 91 | (53%) | |
| **Stage** | I | 85 | (26%) | 16 | (25%) | 18 | (23%) | 48 | (28%) | |
| | II | 78 | (24%) | 16 | (25%) | 13 | (17%) | 43 | (25%) | |
| | III | 92 | (28%) | 15 | (24%) | 28 | (36%) | 48 | (28%) | |
| | IV | 10 | (3%) | 1 | (2%) | 5 | (6%) | 4 | (2%) | |
| | Missing[&] | 61 | (19%) | 15 | (24%) | 14 | (18%) | 28 | (16%) | |
| **Tumour location** | Colon | 222 | (68%) | 39 | (62%) | 55 | (71%) | 119 | (70%) | |
| | Rectum/Rectum sigmoid | 76 | (23%) | 15 | (24%) | 18 | (23%) | 40 | (24%) | |
| | Missing[&] | 28 | (9%) | 9 | (14%) | 5 | (6%) | 12 | (7%) | |

[&] *Cancer registry is not yet complete, so these respondents are not registered yet.*

**p<0.05 between the three groups of beliefs.*

## RESULTS

As can be seen in Table 1, the oldest respondents and respondents with a lower level of education had the least belief on the influence of nutrition on feelings of well-being. Respondents with a high intake of alcohol, respondents with the highest levels of weight loss and with the most comorbidities had the strongest belief. Respondents with a strong belief on the influence of nutrition on feelings of well-being had more often received information from one or more health professionals (Table 2) and were less often obese than survivors who believed there was no influence (Table 1).

A total of 125 respondents (38%) did not receive information about nutrition from their healthcare professionals (Table 2). Of the respondents who received information about nutrition (*n*=201, 62%), 41% received information from one health professional (41% from a nurse, 36% from a dietician and 23% from a doctor), 37% of two health professionals (72% from a doctor and nurse, 11% from a doctor and dietician and 17% from a nurse and dietician) and 21% of three health professionals. No differences were seen in ratings of the different beliefs and whether the information was provided by a doctor, a nurse or a dietician.

Respondents, who received nutritional information from a health professional, had stronger beliefs on the feelings of well-being, the influence of nutrition on recurrence of cancer, recovery after treatment and complaints, compared with respondents who received no nutritional information (Figure 1 and Table 3). People, who had strong beliefs on the influence of nutrition on well-being, also had strong beliefs about the influence of nutrition on the recovery after treatment, recurrence after cancer and complaints.

People, who received no information from health professionals, had the least beliefs nutrition influences well-being, complaints, recovery after treatment or recurrence. People, who received information from more health professionals, had stronger beliefs (Figure 2 and Table 3).

Ninety-one respondents (28%) believe there are nutrients and diets that can positively influence the course of the disease the CRC. Nutrients and diets mentioned by respondents to have a positive influence were a healthy diet with plenty of fruits and vegetables (*n*=43), fibres (*n*=10), supplements (*n*=9), curcumin (*n*=8), protein-rich foods (*n*=7), fresh products (*n*=4), cannabidiol (*n*=3), little meat (*n*=2) and a diet that influences the immune system (*n*=2).

A total of 114 respondents (35%) believe there are nutrients and diets that can negatively influence the disease. Nutrients and diets mentioned by respondents to have a negative influence were too much fat (*n*=37), red and processed meat (*n*=31), alcohol (*n*=24), sugar (*n*=20), additives (*n*=8), burned foods (*n*=6), processed foods (*n*=6), salt (*n*=5), an unhealthy diet (*n*=4), fibre (*n*=1), protein (*n*=1) and vitamins (*n*=1) (data not shown).

**Table 2:** Information provision and beliefs on the influence of nutrition of the total group of respondents (*n*=326) and split in three groups based on the score for 'belief that nutrition influences feelings of well-being'.

| | | | Score 0-2 | Score 3-6 | Score 7-10 |
|---|---|---|---|---|---|
| | | **Respondents** (*n*=326) | **No belief influence** (*n*=63) | **Intermediate belief influence** (*n*=78) | **Strong belief influence** (*n*=171) |
| **N** | | *n* (%) | *n* (%) | *n* (%) | *n* (%) |
| **Information provision*** | Yes | 201 (62%) | 24 (38%) | 56 (72%) | 119 (70%) |
| | No | 125 (38%) | 39 (62%) | 22 (28%) | 52 (30%) |
| **Number of health professionals*** | 0 | 125 (38%) | 39 (62%) | 22 (28%) | 52 (30%) |
| | 1 | 83 (26%) | 13 (21%) | 23 (30%) | 46 (27%) |
| | 2 | 75 (23%) | 7 (11%) | 20 (26%) | 47 (28%) |
| | 3 | 43 (13%) | 4 (6%) | 13 (17%) | 26 (15%) |
| **Beliefs recovery after treatment*** | 0-2 | 74 (24%) | 49 (78%) | 13 (17%) | 12 (7%) |
| | 3-6 | 69 (22%) | 10 (16%) | 36 (46%) | 23 (14%) |
| | 7-10 | 169 (54%) | 4 (6%) | 29 (37%) | 135 (79%) |
| **Beliefs recurrence of cancer*** | 0-2 | 123 (40%) | 53 (84%) | 27 (35%) | 42 (25) |
| | 3-6 | 113 (36%) | 9 (14%) | 38 (49%) | 66 (39%) |
| | 7-10 | 75 (24%) | 1 (2%) | 13 (17%) | 60 (36%) |
| **Beliefs complaints*** | 0-2 | 133 (43%) | 61 (97%) | 29 (37%) | 43 (25%) |
| | 3-6 | 92 (30%) | 2 (3%) | 43 (55%) | 47 (28%) |
| | 7-10 | 85 (27%) | 0 (0%) | 6 (8%) | 79 (47%) |

**p<0.05 between the three groups of beliefs.*

**Figure 1:** Nutritional information provision (yes/no) and beliefs that nutrition can influence feelings of well-being, complaints, recovery after treatment and recurrence of cancer.

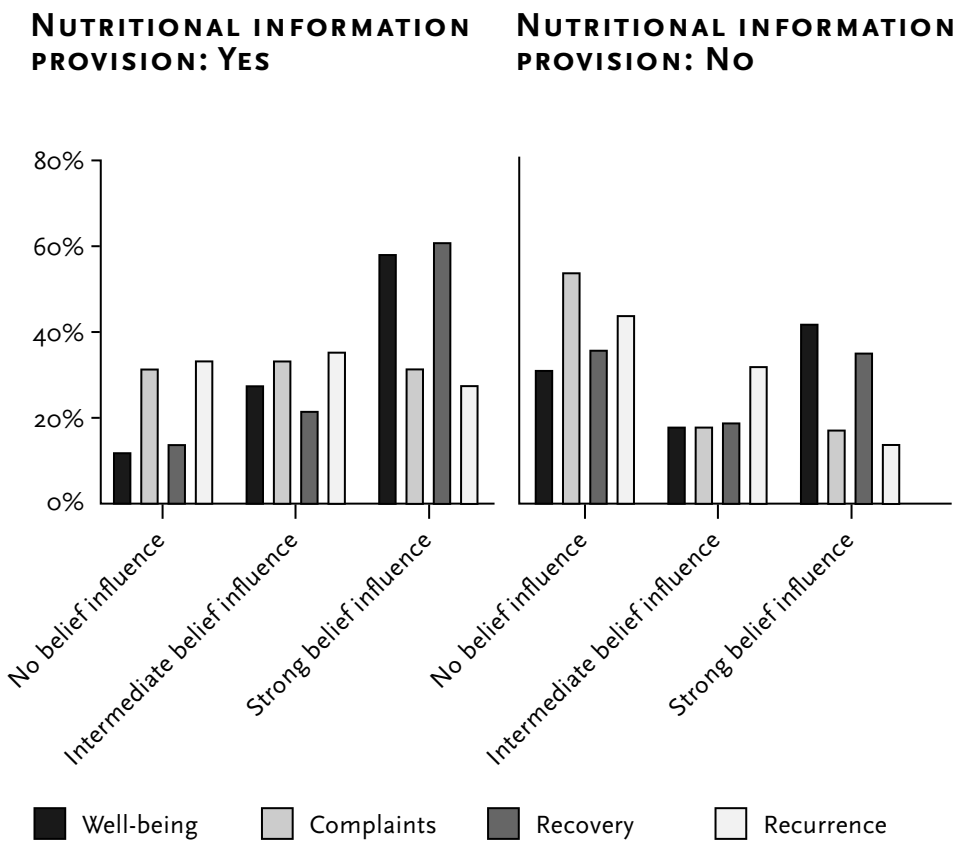
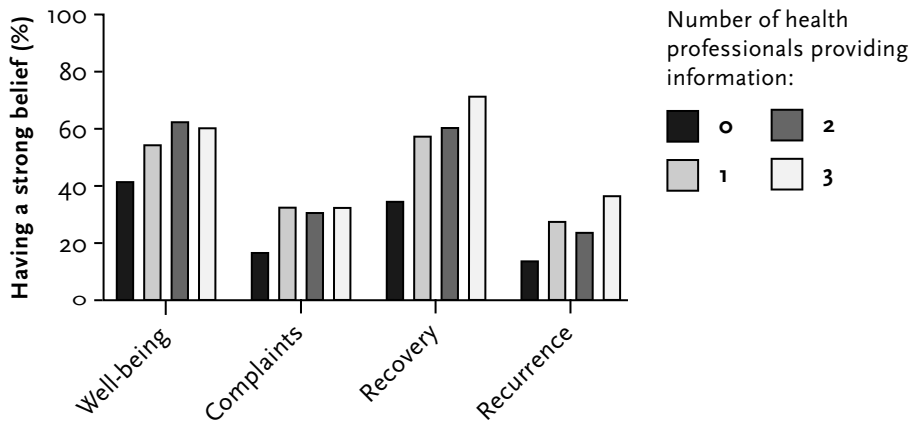


**Table 3:** Association between having strong beliefs and having received nutritional information or the number of health professionals providing nutritional information.

| | | **Prevalence ratio's (95% CI) of having a strong belief that nutrition influences** | | | |
|---|---|---|---|---|---|
| | | Well-being | Complaints | Recovery after treatment | Recurrence |
| **Received nutritional information** | No | (1) | (1) | (1) | (1) |
| | Yes | 1.5 (1.1-2.2) | 2.6 (1.4-4.7) | 1.7 (1.1-2.5) | 1.97 (1.00-3.89) |
| **Number of health professionals providing nutritional information** | 0 | (1) | (1) | (1) | (1) |
| | 1 | 1.4 (0.9-2.2) | 2.5 (1.3-5.0) | 1.5 (0.9-2.4) | 1.6 (0.7-3.6) |
| | 2 | 1.57 (1.01-2.44) | 2.2 (1.1-4.5) | 1.67 (1.05-2.67) | 1.7 (0.8-3.9) |
| | 3 | 1.61 (0.97-2.68) | 3.4 (1.6-7.4) | 2.0 (1.2-3.3) | 2.8 (1.3-6.2) |

*All adjusted for age, gender and cancer stage.*

**Figure 2:** The number of health professionals providing information and the % of respondents having a strong belief.



## DISCUSSION

Most respondents who received information strongly believe nutrition influences feelings of well-being and recovery after treatment. No differences were found in the ratings of the different beliefs and whether the information was provided by a doctor, a nurse or a dietician. Nevertheless, it did matter how many health professionals provided nutritional information: survivors who received information from three health professionals had more often strong beliefs than those who received information from one health professional.

Weaver et al. [25] described that experiments in psychology showed that an opinion is likely to be more widely shared the more different group members express it. Participants had stronger beliefs when the same opinion was expressed once by each of three different group members than when it was expressed once by one group member [25]. In a previous study of our research group, we found that the preferred way of receiving information in a group of cancer survivors was from multiple health professionals: (oncology) nurses, dieticians and doctors, at four or more times [26]. The wish for repeated information provided by different health professionals as expressed in the previous study matches the association found in the current study. Since 59% of respondents received information from two or more health professionals in the present study, it is important to provide uniform information, to have a maximal effect of repetition, as is also supported by Weaver et al. [25].

No association was seen between the strength of beliefs and the kind of health professional who provided the information. No previous literature was found on this association. In a best-worst discrete choice experiment by Wright et al., CRC survivors expressed the wish to receive dietary information in a hospital by a bowel cancer nurse, which was preferred beyond information from a dietician or a general nurse [27]. In a survey among 175 CRC survivors, 93% indicated they wanted a conversation with their doctor about survivorship information. Sixty-six percent had received information about diet and exercise to keep them healthy, and of these people 94% found the information useful [28]. Focus groups with CRC survivors showed that they wish to receive lifestyle support in hospital, offered by a gastro-intestinal oncology nurse, an oncology dietician and/or a stoma nurse specialist. Oncologists were also mentioned to be suitable to offer or to refer to lifestyle support [29]. A survey held among young cancer survivors (mean age 20 years) showed the preferred sources of dietary information were websites and health professionals, without mentioning what kind of health professional [30]. In the Netherlands, every cancer survivor meets with the doctor and oncology nurse. Nutritional counselling by a dietician is only possible after referral.

The beliefs on foods that can positively or negatively influence the disease are mostly correct. There is indeed evidence that a diet rich in fruits, vegetables and fibres can positively influence cancer outcomes, and too much fat, red and processed meat, alcohol, much sugar, burned foods and an unhealthy diet may negatively influence the risk of cancer recurrence [31]. However, supplements, curcumin and cannabidiol do not positively influence the disease to our current knowledge. The use of supplements during chemotherapy or radiotherapy may even be counter-effective, since anti-oxidants may counteract the oxidative effect of chemotherapy and radiotherapy [32, 33].

A large part of the present study population is overweight or obese at diagnosis, which is in line with other studies [5], who also show that weight gain during and after cancer treatment in specific cancer types (e.g. breast and colorectal cancer) is very common. The conventional belief that weight gain is good and weight loss is bad during and after cancer treatment may not be in place [34].

The present study is one of the first studies investigating the association between nutritional information provision and patients' beliefs on nutrition and cancer. Previous studies often focused on a broad range of topics on information provision to cancer survivors, such as environmental pollution, stress [35, 36], but not on patients' beliefs on nutrition in association with information provision. Major strengths of our study are the link with the Netherlands Cancer Registry and the structured way of sending out questionnaires by the PROFILES registry. In this way, clinical information can be extracted from the Cancer Registry, instead of having to ask for this information in a questionnaire, the latter being more prone to errors. The assessment of information provision by different health professionals is another strength, not focusing on one type of health professional.

There were also some limitations. Due to the short time between the questionnaire and the writing of this manuscript, not all clinical data was registered in the Netherlands Cancer Registry. There is always a delay between the diagnosis of cancer and appearance in the Netherlands Cancer Registry. In the current study, this led to a number of missing values in tumour location and stage. Second, survivors have been actively recruited by oncology nurses and could not be recruited if they were already participating in another study. This may have led to the inclusion of a specific survivor population, because of the inclusion criteria of the other studies. The age and sex distribution of our study population indeed shows that we have a specific survivor population, since our population included more men (61% vs. 56%) and younger patients (59% vs. 50% < 70 years old) compared with the Netherlands Cancer Registry population of 2016 [2]. Recruitment took place in four hospitals, which is a selection of peripheral hospitals in the region. A third limitation is that the authors did not know what kind of nutritional information was given to the cancer survivors by the health professionals. It might be possible that not all advice given was according to the latest insights and knowledge.

Other studies did report about the provided advice: participants reported to have received the advice to gain weight by eating whatever they liked, and that they were not discouraged to eat unhealthier foods. This was in contrast with the advice that should have been provided in this study. Also, exercise was not encouraged by nurses in this study, while this was part of the study programme. Patients with a stoma had been told to eat bland low-fibre foods, which is not in line with the dietary guidelines [6, 37, 38]. Another limitation is that our study was based on cross-sectional data, so nothing can be concluded about causal relationships between the provision of nutritional information and changes in beliefs on the effect of nutrition on cancer recurrence, recovery, feelings of well-being and complaints. A last limitation is the relatively short study duration, of 4 weeks. In this timeframe, shortly after diagnosis, most advice will be on surgical recovery, on nutritional needs related to a stoma and digestion problems [37]. In the weeks and months after the completion of acute treatments, nutritional needs may include advice on protein intake, weight loss or weight gain, diarrhoea, xerostomia, anorexia and food aversion [6].



## CONCLUSION AND RECOMMENDATIONS

The current study shows that it is important for cancer survivors to receive information about nutrition and cancer, since it might positively influence cancer survivors' beliefs on the effect of nutrition on cancer recurrence, recovery, feelings of well-being and complaints. Repeating the information by different health professionals is important in strengthening correct beliefs on nutrition and cancer. The beliefs on foods that can positively or negatively influence the disease are mostly correct.

Future research should focus on whether it is more important to have the same message repeated by one health professional several times, or that the same message is spread by different health professionals. We speculate that in patient care, several health professionals should bring the same message to the patient, to confirm the information already given. This might be the solution in altering nutritional beliefs and thereby altering nutritional behaviour of CRC survivors. To make sure that every health professional brings the same message, it is important to make one person (e.g., a dietician) responsible for keeping the other health professionals up to date about evidence- or practice-based nutritional advices and changes in these advices. Furthermore, the dietician must take the lead in arranging the procedure concerning nutritional screening (when and by whom), which basic advice can be given and by whom and when patients need to be referred. All given dietary advice and used information sources must be registered in the patient file. In this way, all health professionals can refer to this information source and inform the survivor in a uniform manner.

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**COMPLIANCE WITH ETHICAL STANDARDS**

**CONFLICT OF INTEREST**
The authors declare that they have no conflict of interest.

**RESEARCH INVOLVING HUMAN PARTICIPANTS**
Ethical approval for the study was obtained from the certified Medical Ethics Committee of Medical Research Ethics Committees United (approval number NL51119.060.14).

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

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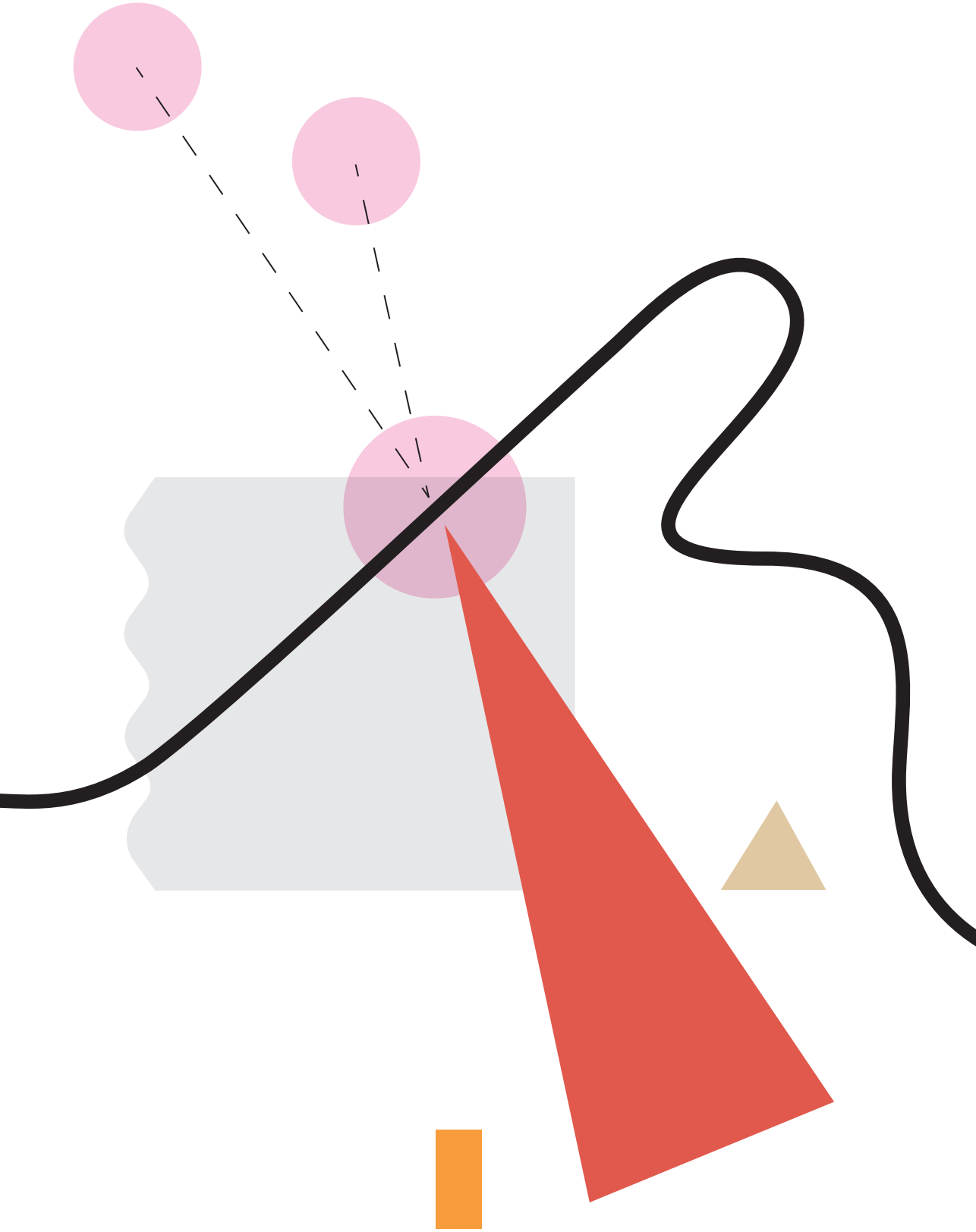

# CHAPTER 4:

## Nutritional information provision to cancer patients and their relatives can promote dietary behaviour changes independent of nutritional information needs

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## ABSTRACT

We investigated whether obtaining nutritional information influences reported changes in dietary behaviour in cancer survivors and their relatives and whether nutritional information needs influence this association.

We included 239 cancer survivors and their relatives, recruited from an online panel of cancer survivors and relatives. This panel completed a survey about their experiences with nutritional information provision by healthcare professionals and the media in the period after diagnosis, their information needs regarding nutrition and cancer and whether they changed their dietary behaviour since diagnosis.

The survey showed that 56% of respondents obtained nutritional information, mostly during treatment. Respondents who obtained nutritional information more often reported to have altered their dietary behaviour after diagnosis. This association was not altered by having information needs. The reported changes in dietary behaviour were coherent with the recommendations of the World Cancer Research Fund: respondents reported to choose less products that promote weight gain, increased intake of plant foods, and decreased meat and alcohol use.

Respondents who obtained nutritional information more often changed their dietary behaviour, regardless whether they had nutritional information needs. This might be an indication that healthcare professionals should provide nutritional information not only to those expressing a need for nutritional information.

## INTRODUCTION

Optimal nutrition after cancer diagnosis may reduce the risk of cancer recurrence, the development of comorbidities, limit side-effects and complaints resulting from cancer and cancer treatment and improve recovery [1–3]. Unfortunately, a high percentage of cancer survivors and their relatives do not receive nutritional information and are therefore unfamiliar with nutritional guidelines, available information, and nutritional information resources [4–10]. This may lead to unfavourable changes in their dietary behaviour or continuation of an unhealthy diet.

However, less literature is available describing the association between nutritional information provision by healthcare professionals and changes in dietary behaviour in the period of cancer treatment and thereafter. One study using a web based, computer tailoring intervention for cancer survivors providing information on, among others, healthy diet showed positive changes in a person's dietary behaviour, possibly due to better nutritional information provision [11]. Other studies mainly focused on the association between unmet nutritional information needs and dietary changes, showing unmet needs in the fields of weight management, nutrition-related side effects of chemotherapy and healthy eating [10, 12, 13]. An information need is a recognition that your knowledge is inadequate to satisfy a goal that you have [14]. It refers to the intrinsic needs of a cancer survivor or his/her relative to retrieve information. The need for nutritional intervention depends on one's (unhealthy) dietary habits and is independent of one's information needs. Unmet nutritional information needs are present in 40-70% of cancer survivors in the whole trajectory of cancer survivorship [5, 8, 12, 15–17]. A study in colorectal cancer survivors showed that although colorectal cancer survivors generally made healthy dietary changes in the period of diagnosis and treatment, they also started using supplements. Cancer survivors in this study who had received dietary information were more likely to have favourably changed their dietary behaviour [18]. Another study showed that cancer survivors (all common cancers) reporting unmet nutritional information needs on how to make positive dietary changes were more likely to use supplements with mega-doses of vitamins than cancer survivors without unmet needs. Using mega-doses vitamin supplements might be undesirable especially during cancer treatment [13]. According to the guidelines of the World Cancer Research Fund (WCRF), the aim should be to meet nutritional needs through diet alone, hence not using dietary supplements unless there are deficiencies that cannot be solved with nutrition alone [19].

Insight should be gained in whether nutritional information provision can positively change dietary habits of cancer survivors and whether this is influenced by having nutritional information needs or not. Therefore, the aims of the present study were 1. to investigate the proportion of cancer survivors and their relatives who

obtained information regarding nutrition and cancer, who had nutritional information needs and who made dietary changes; 2. to assess the association between nutritional information provision and dietary changes, and 3. whether this association is influenced by having nutritional information needs. With the results of this study we hope to get a starting point to improve future nutritional information provision for cancer survivors.

## METHODS

### Study population

The study population consisted of cancer survivors and their relatives having an account on the website kanker.nl, from now on mentioned as 'panel'. This panel subscribed themselves to kanker.nl and indicated they are willing to answer surveys via kanker.nl. Inclusion criteria were >16 years old, being able to read and write in Dutch, being a cancer survivor, a 'partner of', 'child of', or 'brother/sister of'. No information was available on whether a respondent is a cancer survivor or a relative, due to privacy restrictions of kanker.nl. Therefore, no difference will and can be made between cancer survivors and relatives of cancer survivors in this study. Informed consent was obtained from all individual participants included in the study by kanker.nl when the survivors and their relatives became panel members.

### Data collection

1,006 members of the panel received a link to the online questionnaire via email, using SurveyMonkey [20]. The questionnaire was online available for three weeks. A reminder was sent after two weeks.

#### QUESTIONNAIRE

The questionnaire consisted of questions regarding personal characteristics, dietary changes, nutritional information needs and nutritional information provision.
The questions regarding personal characteristics included age, gender, type of cancer involved (lung; breast; prostate; colon; other gastro-intestinal; head and neck; urinary tract; female sex organs and other types of cancer), stage of treatment (start/during treatment; recovery; >5 years after treatment; palliative phase/deceased) and highest level of education (primary school/secondary education; lower vocational training; high vocational training/university). The questions regarding nutritional information provision focused on whether the respondent obtained information (yes/no), from which information sources (oncology nurse, dietician, doctor, media, brochures and leaflets), frequency (1x, 2-3x, >4x) and time point of nutritional information provision (at diagnosis, start of treatment, recovery phase, every phase), preferred information sources (oncology nurse, dietician, doctor, media, brochures and leaflets), nutritional

information needs (yes/no), whether nutritional information needs were met (yes/no), and changes in dietary behaviour (yes/no and kind of changes).

### Data analysis

Open questions were categorized to include them in the data analyses. Descriptive statistics were used to describe the personal characteristics, nutritional information needs, information provision and changes in dietary behaviour. Mean and SD were reported for age; numbers and percentages were reported for all other descriptives. Independent samples t-tests (for age) and Pearson's Chi-square tests (for all other variables) were used to analyse differences between personal characteristics of respondents who did and did not obtain nutritional information.

Reported adherence to five WCRF/AICR recommendations [19, 21] on 'foods and drinks that promote weight gain', 'use of plant foods', 'meat products', 'alcoholic drinks' and 'supplements' were classified as either being favourable or non-favourable changes, for respondents who obtained and did not obtain nutritional information. Adherence to the WCRF recommendations for 'body fatness', 'physical activity' and 'preservation, processing and preparation of foods' could not be assessed, since no data of our respondents were available on these topics. Prevalence ratios (PR) were calculated to study the association between nutritional information obtained (yes/no) and changes in dietary behaviour (yes/no), whether this association changed by having information needs (yes/no) and to study the association between frequencies of obtained information and changes in dietary behaviour (yes/no). To calculate this ratio, we used Cox proportional hazard regression analysis with the time variable set at 1 for each participant. Age, gender, educational level (primary school/secondary education; lower vocational training; higher vocational training/university) and type of cancer (lung, breast, prostate, head and neck, colorectal and other gastro-intestinal cancers) were evaluated as possible confounding factors and were included if they changed the PR by at least 10%. Only type of cancer changed the PR with ~10%. Statistical analyses were conducted using SPSS for Windows, version 23. A $p$-value $<0.05$ was considered statistically significant.

## RESULTS

### Study population

The study population consisted of 239 members of the panel who filled out the questionnaire (response rate 24%). The mean age was 56 years (range 19 – 79) (Table 1) and the majority of the study population was female (59%) and finished higher vocational training/university (45%). Many respondents reported that they or their relatives were treated for breast cancer (24%) or prostate cancer (9%) and were recovering after completing treatment at the time the questionnaire was filled out.

**Table 1:** Socio-demographic and clinical characteristics of the panel (*n*=239) divided in respondents who did (*n*=133) and did not obtain information (*n*=106).

| | | **Total population** | **Information obtained** | | ***p*-value** |
|---|---|---|---|---|---|
| | | | **No** | **Yes** | |
| | | (*n*=239) | (*n*=106) | (*n*=133) | |
| **N** | | *n* (%) | *n* (%) | *n* (%) | |
| **Age (mean ± SD)** | | 55.7 ± 11.2 | 57.9 ± 11.2 | 53.9 ± 10.9 | <0.01 |
| **Gender** | Male | 85 (36%) | 43 (43%) | 42 (33) | 0.10 |
| | Female | 142 (59%) | 56 (57%) | 86 (57%) | |
| **Education** | Primary school/ secondary education | 25 (11%) | 15 (14%) | 11 (8%) | 0.06 |
| | Lower vocational training | 105 (44%) | 51 (48%) | 57 (41%) | |
| | High vocational training/ university | 108 (45%) | 40 (38%) | 69 (50%) | |
| **Type of cancer** | Lung cancer | 14 (6%) | 5 (5%) | 9 (7%) | <0.01 |
| | Breast cancer | 58 (24%) | 28 (26%) | 30 (23%) | |
| | Prostate cancer | 22 (9%) | 19 (18%) | 3 (2%) | |
| | Colorectal cancer | 17 (7%) | 4 (4%) | 13 (10%) | |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | Gastro-intestinal[1] | 17 | (7%) | 3 | (3%) | 14 | (11%) | <0.01 |
| | Head and neck cancer[2] | 11 | (5%) | 0 | (0%) | 11 | (7%) | |
| | Urinary tract cancer[3] | 13 | (9%) | 9 | (9%) | 4 | (3%) | |
| | Cancer of the female sex organs[4] | 12 | (5%) | 6 | (6%) | 6 | (5%) | |
| | Others[5] | 75 | (31%) | 32 | (30%) | 43 | (32%) | |
| **Stage of treatment** | At the start/ during treatment | 75 | (31%) | 36 | (40%) | 39 | (30%) | 0.59 |
| | After treatment/ recovery stage | 109 | (46%) | 49 | (46%) | 60 | (46%) | |
| | Five years (or more) after treatment | 35 | (15%) | 12 | (11%) | 23 | (17%) | |
| | Palliative phase/ deceased | 19 | (8%) | 9 | (9%) | 10 | (8%) | |
| **Information needs** | No | 101 | (42%) | 68 | (64%) | 33 | (25%) | <0.01 |
| | Yes | 138 | (58%) | 38 | (36%) | 100 | (75%) | |
| **Information needs met** | No | NA | NA | NA | NA | 56 | (47%) | – |
| | Yes | NA | NA | NA | NA | 63 | (53%) | |
| **Changes in dietary behavior** | No | 91 | (38%) | 61 | (58%) | 30 | (23%) | <0.01 |
| | Yes | 148 | (62%) | 45 | (42%) | 103 | (77%) | |

[1] *Includes pancreatic cancer, small intestine cancer, bile duct cancer, stomach cancer, esophageal cancer*

[2] *Includes throat cancer, oral cavity cancer, nasal cancer, salivary gland cancer, tongue cancer, larynx cancer and nasal cavity cancer*

[3] *Includes bladder cancer and kidney cancer*

[4] *Includes cervical cancer, uterine cancer, ovarian cancer, vulvar cancer, vaginal cancer and ovum cancer*

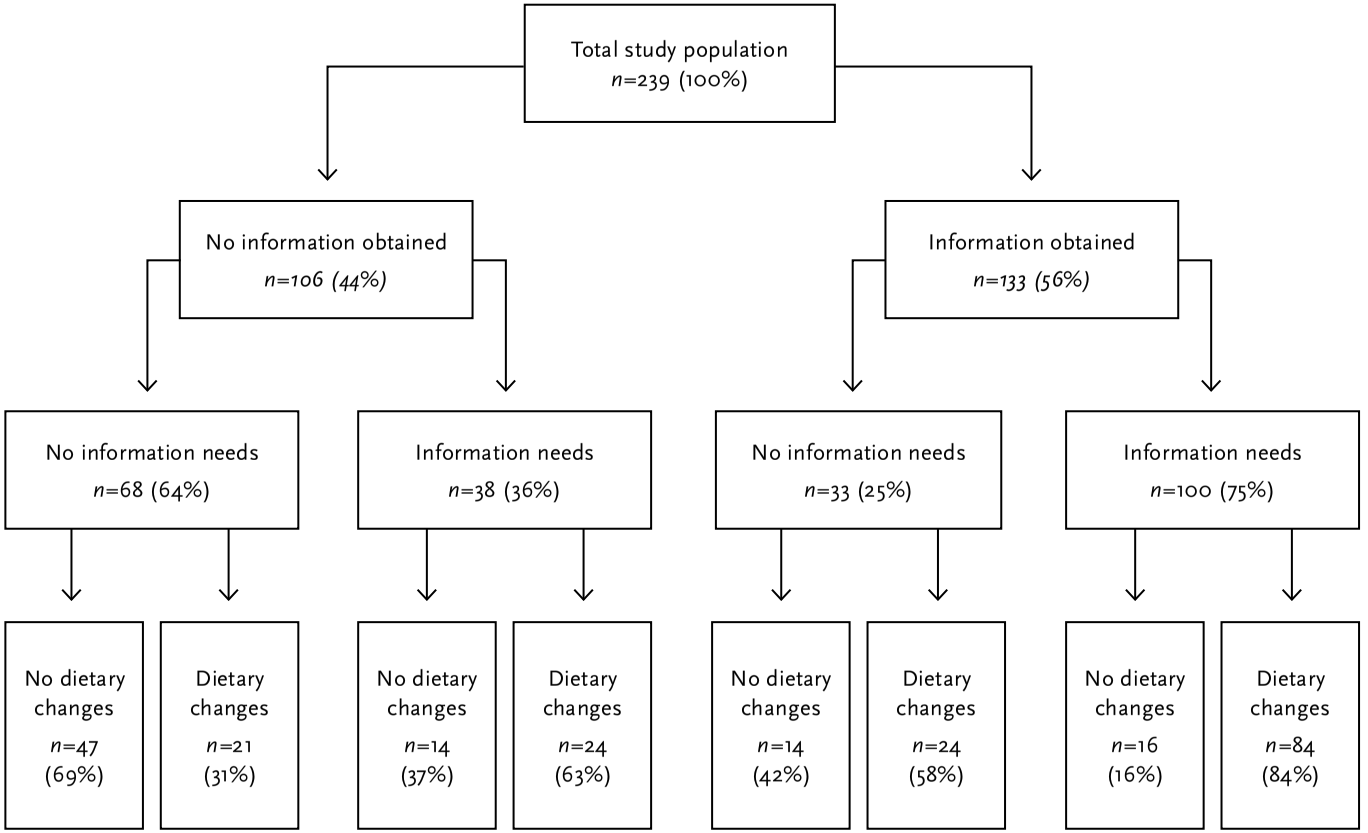
[5] *Includes skin cancer (melanoma, squamous cell carcinoma), brain cancer, acute myeloid leukaemia, chronic lymphatic leukaemia, Hodgkin lymphoma, non-Hodgkin lymphoma, multiple myeloma, Waldenströms disease, skin lymphoma, chronic myeloid leukaemia, bone cancer, chondrosarcoma, neuroendocrine tumour, osteosarcoma, eye cancer, thyroid cancer, soft tissue tumour, adrenal cancer and multiple cancers*

NOTE: percentages may not always add up to 100 due to rounding.

Respondents who obtained nutritional information were significantly younger (53.9 vs 57.9 years, $p$ <0.01), and more often treated for colorectal, other gastro-intestinal and head and neck cancer than respondents who did not obtain information. Respondents who obtained nutritional information more often reported to have nutritional information needs than those who did not obtain nutritional information (75 vs 36%; $p$ <0.01). Information on the non-responders was not available due to the privacy statement of kanker.nl.

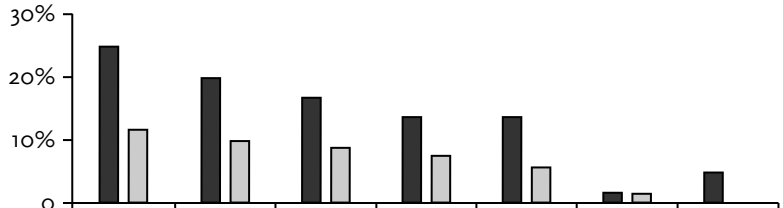
Respondents who obtained information more often changed their dietary pattern than respondents who did not obtain information (77% vs 42%; $p$ <0.01) (Figure 1).

**Figure 1:** Nutritional information provision, information needs and dietary changes.



The respondents who obtained information regarding nutrition reported to have changed their dietary behaviour by choosing less food products that promote weight gain (25%); increasing plant food intake (20%); decreasing meat intake (17%); decreasing alcohol intake (14%); increasing supplement use (14%); choosing more food products that promote weight gain (5%) and decreasing supplement intake (2%) (Figure 2). The respondents who obtained no information regarding nutrition reported less changes in their dietary behaviour. 12% chose less food products that help promote weight gain; 10% increased their plant food intake; 9% decreased their meat intake; 8% decreased their alcohol intake; 6% increased their supplement use and 2% decreased their supplement intake (Figure 2).

**Figure 2:** Adherence to WCRF guidelines (%) for respondents who obtained information (*n*=133) and those who obtained no information (*n*=106).




| | Less products that promote weight gain | Increase plant food | Decrease meat | Decrease alcohol | Increase supplement use | Decrease supplement use | More products that promote weight gain |
|---|---|---|---|---|---|---|---|
| Obtained information (%) | 25 | 20 | 17 | 14 | 14 | 2 | 5 |
| Obtained no information (%) | 12 | 10 | 9 | 8 | 6 | 2 | 0 |

The sources of information most mentioned were the dietician (50%), (oncology) nurses (42%) and the media, including television, radio and the Internet. Most respondents obtained information during treatment (53%) and obtained information only once (59%) (Table 2).

**Table 2:** Adherence to WCRF guidelines (%) for respondents who obtained information (*n*=133) and those who obtained no information (*n*=106).

| | | Information obtained | | Preferred way of receiving information | |
|---|---|---|---|---|---|
| | | *n* | (%) | *n* | (%) |
| **Information sources** | Dietician | 67 | (50%) | 59 | (44%) |
| | (Oncology) nurse | 56 | (42%) | 60 | (45%) |
| | Doctor | 33 | (25%) | 49 | (37%) |
| | Media[a] | 48 | (36%) | 32 | (24%) |
| | Brochures and leaflets | 44 | (33%) | 53 | (40%) |
| **Moment of receiving information** | Diagnosis | 20 | (15%) | 15 | (11%) |
| | Start of treatment | 44 | (33%) | 40 | (30%) |
| | During treatment | 71 | (53%) | 40 | (30%) |
| | Recovery phase | 31 | (23%) | 27 | (20%) |
| | Every phase | - | | 61 | (46%) |
| **Frequency of receiving information** | 1x | 78 | (59%) | 6 | (5%) |
| | 2-3x | 36 | (27%) | 45 | (34%) |
| | ≥4x | 2 | (2%) | 72 | (54%) |

[a] *Including television, radio and internet*

Respondents preferred to obtain information via the (oncology) nurses (45%), dietician (44%) or via brochures and leaflets (40%) at diagnosis, during and after treatment and at four times or more in every phase of treatment.

Respondents who reported to have obtained information, were more likely to have made dietary changes (PR 1.7; 95% CI 1.2-2.5) (Table 3).

**Table 3:** Prevalence ratios for nutritional information obtained and changes in dietary behaviour, with and without nutritional information needs; and for the frequency of obtained information and changes in dietary behaviour.

| | Information obtained | | |
|---|---|---|---|
| | No | Yes | |
| Prevalence of having made adjustments in dietary behavior* | 1 (ref) | **1.7(1.2-2.5)** | |
| Prevalence of having made adjustments in dietary behavior and having information needs* | 1 (ref) | 1.4 (0.9-2.1) | |
| | Frequency of information obtained | | |
| | 0 | 1x | >2x |
| Prevalence of having made adjustments in dietary behavior* | 1 (ref) | **1.5 (1.0-2.2)** | **1.9 (1.2-3.0)** |

* *Adjusted for type of cancer.*

*Bold values are prevalence rations that are statistically significant.*

When also taking information needs into account, the association between obtained information and dietary changes was slightly less strong and no longer significant (PR 1.4; 95% CI 0.9-2.1). Respondents who obtained information twice or more were more likely to have made dietary changes (PR 1.9; 95% CI 1.2-3.0) than those who obtained information once (PR 1.5; 95% CI 1.0-2.2).

## DISCUSSION

The survey showed that 56% of the respondents obtained nutritional information and that respondents who obtained nutritional information more often reported to have altered their dietary behaviour, whether they had nutritional information needs or not. The reported changes in dietary behaviour were mostly according to the recommendations of the WCRF.

In the present study, respondents who obtained information were younger, more often had colorectal, gastro-intestinal and head and neck cancer, were more often female and higher educated than those who did not obtain information. This is in line with the literature, where age, gender and education were reported as being of influence in obtaining information [2, 4, 6, 8–10, 22–24]. The respondents with mentioned tumour types obtaining more information is in line with expectations, since survivors with these tumour types encounter more nutritional problems than for example prostate cancer survivors [25].

Respondents who obtained information were more likely to have changed their dietary behaviour, in comparison with respondents who did not obtain information. This is in line with the study of Bours et al, where cancer survivors who had received dietary information were more likely to have changed their diet than those who did not receive nutritional information [18]. Changes in dietary behaviour were comparable for the study of Bours et al and the present study: respondents reported to use less products that promote weight gain, less meat, and more plant foods. Changes in dietary behaviour in the present study were also comparable to a study in Hawaiian cancer survivors who did not receive advice: respondents reported an increase in plant foods, a decrease in meat intake, sugar and alcohol after diagnosis of cancer. However, in this Hawaiian population many survivors who changed their diet also reported an increased intake of herbal and vitamin supplements, many with unproven effects. Increasing nutritional information provision by healthcare professionals may prevent the use of unproven and possibly harmful supplements [26].



Respondents who obtained information reported more positive behaviour changes than respondents who did not obtain information. Readiness for lifestyle change should be taken into account when providing nutritional information, since each stage of change requires different behaviour change techniques [27–29]. This result might indicate that providing nutritional information is beneficial for improving dietary behaviour of cancer survivors. However, the observed effect could also be due to a high interest of respondents in nutrition, or respondents giving social desirable answers. The latter is less likely, since respondents also described negative changes in dietary behaviour, while no answer categories were provided.

Furthermore, respondents indicate they would like to receive nutritional information via healthcare professionals, with no preference for whether the information was provided by an oncology nurse, a dietician or their doctor. This is in line with the literature, where prostate cancer survivors [30] and cancer survivors in general [31] also describe healthcare professionals to be their preferred source of nutritional information. Also, timing and frequency of nutritional information provision is important for respondents. They indicated they would like to receive information at diagnosis,

during and after treatment. In the current study most cancer survivors who obtained information, obtained this only once. However, when asking for the preferred situation, respondents would like to obtain information on four or more occasions. This is a large contrast between the actual and the ideal situation and indicates that respondents should be informed about nutrition more often. This is enforced by the finding that respondents who obtained information twice or more, more often reported to have made dietary changes than those who obtained information only once. This finding needs to be addressed by policy makers and should be highlighted to healthcare professionals, since physicians often underestimate nutritional problems [32] and might not discuss nutritional topics with cancer survivors.

Respondents who obtained information made positive changes in their dietary behaviour, independent of whether they had information needs or not. This is reflected in the absence of an effect on the prevalence ratio when the need for nutritional information was included in the model. It is therefore important that healthcare professionals provide nutritional information to all cancer survivors, regardless whether they express a need for nutritional information. We advise to start nutritional information provision early in the trajectory of cancer treatment and not to wait for questions from cancer survivors.

The present study is one of the first studies investigating the association between nutritional information provision and changes in dietary behaviour. Previous studies often focused on a broad range of topics on information needs and information provision to cancer survivors while the present study specifically focuses on nutrition and nutritional information needs which is an important addition to the available literature.

However, this study also has some limitations. The response rate of our study was low. Non-response may have influenced our results, possibly leading to an overestimation of obtaining nutritional information in our study population. When especially persons interested in nutrition responded to the questionnaire, these respondents may also more often ask for information leading to a higher number of respondents who obtained nutritional information.

Furthermore, extrapolation of our results to the general cancer population is not possible, since the respondents of the present study were younger and more often female than the general Dutch cancer survivor population [33]. Also, respondents of our study are both cancer survivors and their relatives.

In addition, the members of the internet panel included in this study are people who have signed up to fill out surveys. Hence, this population may be more willing to express their opinion and be more information conscious than the population of cancer survivors and their relatives in general.

In conclusion, the present study showed that respondents who obtained nutritional information more often reported to have positively altered their dietary behaviour compared to respondents who did not obtain information, whether they had nutritional information needs or not. This indicates that all cancer survivors with an unhealthy lifestyle and their relatives should receive nutritional information regardless of their nutritional information needs, preferably provided by healthcare professionals on several occasions. Nutritional information provision as part of the overall information provision, provided to every cancer survivor, might probably promote positive dietary changes. This could be achieved by implementing nutritional advice in the treatment program of cancer survivors.


## ACKNOWLEDGEMENT

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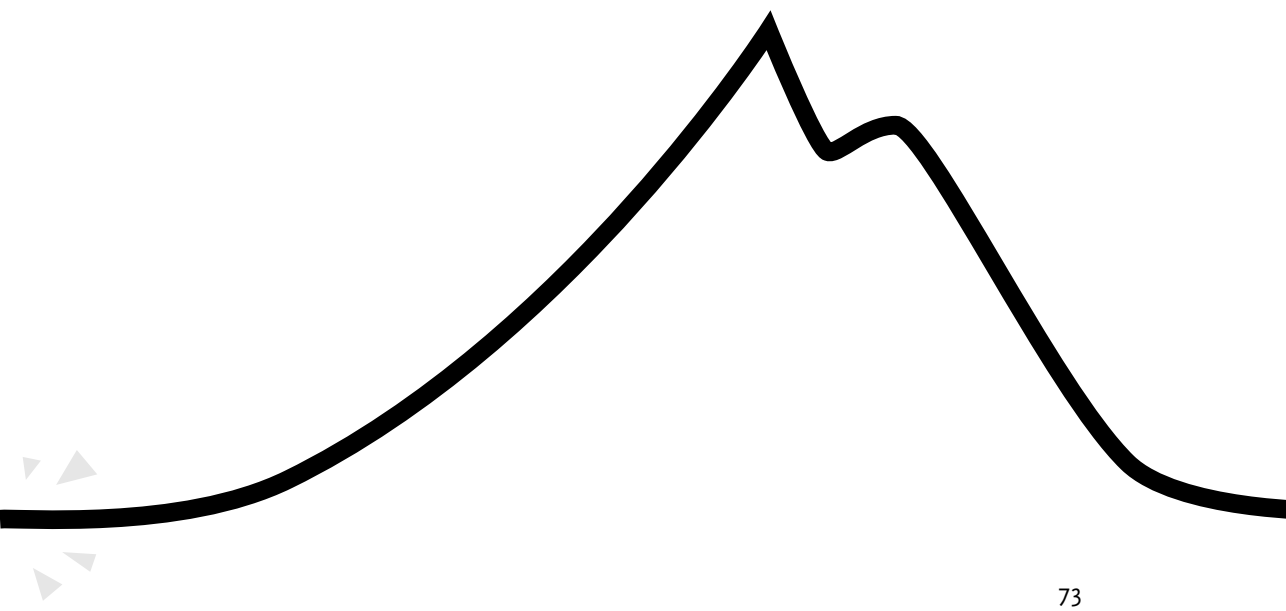

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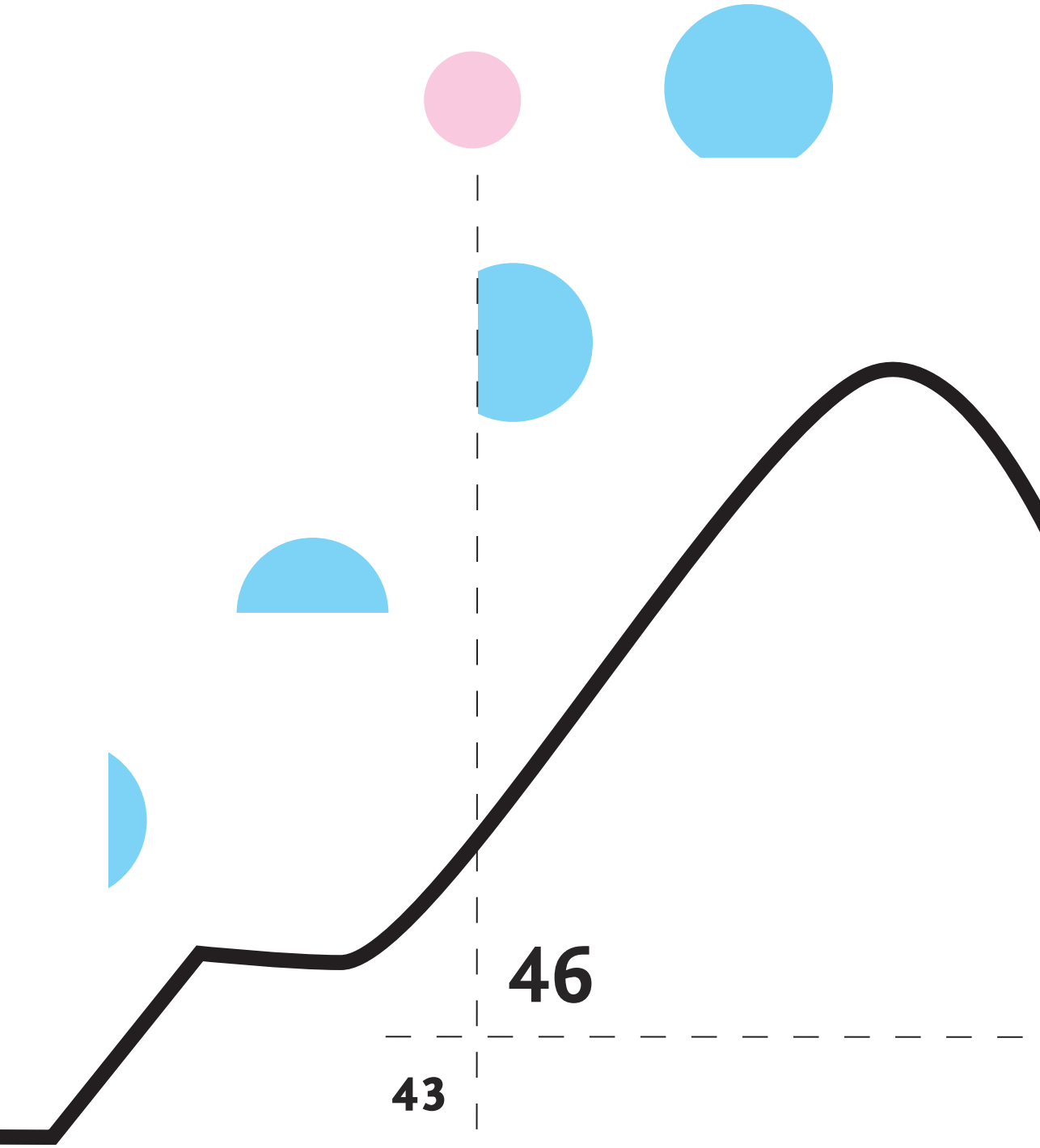
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# CHAPTER 5:

## Improving oncology nurses' knowledge about nutrition and physical activity for cancer survivors

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## ABSTRACT

**PURPOSE/OBJECTIVES:** To assess what percentage of oncology nurses perceived themselves as having insufficient knowledge to provide advice on nutrition and/or physical activity (PA), which characteristics were associated with nurses' perception, and whether the content and information sources differed among those nurses.

**DESIGN:** A cross-sectional study.

**SETTING**: A web-based survey among oncology nurses in the Netherlands.

**SAMPLE:** 355 oncology nurses provided advice on nutrition; of these, 327 provided advice on PA.

**METHODS:** From May to July 2013, oncology nurses were invited to complete an online questionnaire. Pearson's chi-squared tests and uni- and multivariate logistic regression analyses were conducted.

**MAIN RESEARCH VARIABLES:** Oncology nurses' perception of having sufficient or insufficient knowledge to be able to provide advice on nutrition and PA, the content of the advice, and the information sources on which the advice was based.

**FINDINGS:** 43% of oncology nurses perceived themselves as having insufficient knowledge to provide advice on nutrition, and 46% perceived insufficient knowledge to provide advice on PA. Factors associated with perceiving insufficient knowledge on nutrition were being aged younger, having lower education, and providing counselling during treatment only. Those nurses were more likely to suggest taking oral nutritional supplements or visiting a dietitian and were less likely to provide information on fluid intake. Nurses perceiving insufficient knowledge about PA used oncology guidelines less often.

**CONCLUSIONS:** Almost half of the oncology nurses providing advice on nutrition and PA perceived themselves as having insufficient knowledge to be able to provide such advice. In particular, younger oncology nurses and oncology nurses with an intermediate vocational education may benefit most from education about these topics.

**IMPLICATIONS FOR NURSING:** Educational training for oncology nurses should include nutrition and PA. Oncology nurses should collaborate with dietitians to discuss what information should be provided to patients by whom, and specific PA advice should be provided by a physical therapist.

## INTRODUCTION

Oncology nurses play a key role in the provision of information for cancer survivors, defined as people who are living with a diagnosis of cancer, including those who have recovered from the disease [1]. Oncology nurses frequently meet with cancer survivors from diagnosis until follow-up after treatment, generally having more time to spend with survivors than oncologists. Therefore, they have ample opportunities to provide information and advice and to answer questions that may arise throughout the treatment process and thereafter [2, 3] on appropriate nutrition and physical activity (PA) [4, 5].

According to guidelines [6, 7], oncology nurses should also be involved in detecting and referring cancer survivors in need of dietary and PA support. In case of risk for malnutrition, unintentional weight loss or gain, nutritional complaints, or impaired PA, oncology nurses can provide advice on nutrition and PA themselves or refer more complex cases to an oncology dietitian, an oncology physiotherapist, or a clinical or accredited exercise physiologist [7].

Nutrition and PA advice should be provided from prediagnosis until follow-up after treatment [1, 8–11]. However, Stevinson and Fox [12] demonstrated that advice on PA and the use of exercise is rarely provided to patients with cancer.

Although cancer survivors need information on appropriate nutrition and PA, and oncology nurses are in a favourable position to provide advice [13], nurses are generally not trained in providing advice on these topics and, therefore, may perceive themselves as having insufficient knowledge to be able to provide such advice [14, 15]. To what extent oncology nurses perceive themselves as having insufficient knowledge about nutrition and PA and whether this perception influences the content of the advice about nutrition and PA they provide are unknown. Also unknown are on what information sources oncology nurses base their advice and whether oncology nurses who perceive themselves as having insufficient knowledge use different information sources than oncology nurses who perceive themselves as having sufficient knowledge. This is of interest because oncology nurses are the healthcare providers who patients see most during treatment. Patients rely on the information they receive from oncology nurses. In addition, oncology nurses may be the major provider of nutritional information to patients with cancer [5]. If oncology nurses perceive themselves as having insufficient knowledge on nutrition and PA – and, therefore, maybe providing inappropriate advice – this may unintentionally harm the patient. To be able to help oncology nurses feel confident about the nutrition and PA advice they provide, adjusting training programs on nutrition and PA may be necessary. Before this is done, more information is needed on oncology nurses and information provision on nutrition and PA.

The aims of the current study were to assess what percentage of oncology nurses perceived themselves as having insufficient knowledge to provide advice on nutrition and/or PA to their patients, which characteristics were associated with oncology nurses' perception of having insufficient knowledge, and whether the content of the nutrition and/or PA advice and the information sources on which this advice was based differed between nurses who perceived themselves as having insufficient knowledge and those who perceived themselves as having sufficient knowledge.

## METHODS

A cross-sectional survey study was conducted among oncology nurses. Nurses had to be working in oncology health care to be included. In the current study, all nurses working with cancer survivors are referred to as oncology nurses. Ethical approval was not required.

### Data Collection

From May to July 2013, 3,564 oncology nurses were invited to complete an online questionnaire. SurveyMonkey® was used to compose and distribute the online questionnaire. A hyperlink to this questionnaire was distributed via direct mailing or via a newsletter through different oncology nursing networks in the Netherlands: the Dutch Oncology Nursing Society, the Nationwide Group of Specialized Oncology Nurses, and various networks of oncology nurses of the Netherlands Comprehensive Cancer Organisation. The number of oncology nurses who were invited for participation is estimated by summing the members of the different Dutch oncology networks and deleting oncology nurses who were members of more than one oncology network.
The questionnaire included questions on general characteristics of the oncology nurses, such as age, gender, education level (intermediate vocational, higher vocational, university), type of organization (hospital, other), and the number of years of work experience with cancer survivors (5 years or less, 6–15 years, 16–25 years, 25 years or more). Timing of counselling was assessed by the following question: "During which stage(s) in the treatment process do you see cancer survivors as part of your job?" Responses were during diagnosis and treatment, during treatment only, during treatment and after care, or during the whole trajectory.

Provision of advice on nutrition and PA was assessed by the questions, "Do you provide advice about nutrition to cancer survivors?" and "Do you provide advice about PA to cancer survivors?" Both had a 'yes' or 'no' response. Having sufficient knowledge on nutrition or PA was assessed by the following 'yes' or 'no' questions: "Do you perceive to have sufficient knowledge to provide advice on nutrition to cancer survivors?" and "Do you perceive to have sufficient knowledge to provide advice on

PA to cancer survivors?" The population for analysis consisted of oncology nurses who positively answered at least one of the questions on information provision and also provided an answer to the appropriate question on sufficient knowledge. The questionnaire included open-ended questions on the content of the advice and on the information sources on which the nutrition and PA advice was based.

### Data Analyses

Independent sample t tests were used to analyse differences between included and excluded nurses. Descriptive statistics were used to describe characteristics of oncology nurses and to describe the proportion of oncology nurses who did and did not report having sufficient knowledge about nutrition and/or PA. Univariate logistic regression analyses were conducted to investigate associations between characteristics of the oncology nurses and perceiving to have insufficient versus sufficient knowledge to provide advice on nutrition and/or PA. Each of these analyses was conducted with 'having sufficient knowledge (yes/no)' as the dependent variable, and one of the characteristics – age, gender, education level, type of organization, timing of counselling, and number of years of work experience – as the independent variable. Variables were included only if at least 80% of the cells in the cross tabulation had an expected cell frequency of 5 or more. In addition, multivariate logistic regression analyses were conducted with all characteristics that were statistically significantly ($p < 0.05$) associated with having sufficient knowledge (yes/no) in the univariate logistic regression analyses. To be included in the final multivariate regression model, a characteristic had to be statistically significantly ($p < 0.05$) associated with the perception of insufficient versus sufficient knowledge after backwards selection.

Answers to the open-ended questions (e.g., on information sources and on content of the advice) were categorized according to the content of the answers. Differences between oncology nurses perceiving themselves as having sufficient and insufficient knowledge were analysed using Pearson's chi-squared test. Statistical analyses were conducted using SPSS®, version 23.0.



## RESULTS

### Sample Characteristics

Of the 3,564 oncology nurses who were invited to participate in the current study, 486 (14%) filled in the online questionnaire. After removal of 26 duplicates and 2 nurses who did not fit the definition of an oncology nurse, 458 valid questionnaires remained. The questionnaires of oncology nurses with missing values on the questions, "Do you provide advice about nutrition/PA to cancer survivors?" and "Do you perceive to have sufficient knowledge to provide advice on nutrition/PA to cancer survivors?"

were excluded. After exclusion, the study population consisted of 355 oncology nurses who reported that they provide advice about nutrition to cancer survivors, of whom 327 also reported advising about PA.

Most oncology nurses in the current study were female, had completed higher vocational education, were currently employed in a hospital, and had counselled patients with cancer for 15 years or less. See Table 1 for an overview of the characteristics of the study population.

Oncology nurses who were excluded from the analyses on nutritional advice were younger (44 years versus 47 years, $p = 0.023$) and less educated (66% versus 76% higher vocational education, $p < 0.001$) than oncology nurses who were included in the study population. For nurses giving advice on PA, excluded nurses were less educated (67% versus 76% higher vocational education, $p < 0.001$) and less often counselled patients during the whole trajectory (33% versus 57%, $p = 0.003$) than oncology nurses who were included in the study population.

## Oncology Nurses Who Reported Insufficient Knowledge

Of the oncology nurses providing advice on nutrition, 153 (43%) reported insufficient knowledge on nutrition, and 149 (46%) providing advice on PA reported insufficient knowledge on PA.

Older oncology nurses were more likely to perceive themselves as having sufficient knowledge on nutrition (odds ratio [OR] 1.03; 95% confidence interval [CI] [1.01, 1.06]). Less educated nurses (intermediate vocational education versus university) (OR 0.36; 95% CI [0.14, 0.89]) and nurses providing counselling during treatment only versus counselling during the whole trajectory (OR 0.52; 95% CI [0.29, 0.94]) were less likely to perceive sufficient knowledge on nutrition.

Multivariate logistic regression analysis showed that younger age and intermediate vocational education remained associated with having insufficient knowledge on nutrition after backward selection. None of the characteristics were associated with having insufficient knowledge on PA.

## Content of Nutrition and Physical Activity Advice

An overview of the content of the nutrition and PA advice oncology nurses reported providing is displayed in Tables 2 and 3. Oncology nurses most often reported that their nutritional advice was to adhere to nutritional guidelines. Other frequently reported advice was to visit a dietitian, to consume small portions during the day, and to consume an energy-enriched diet. Oncology nurses who perceived insufficient knowledge more frequently advised patients to visit a dietitian ($p = 0.03$), more frequently advised patients to take oral nutritional supplements ($p < 0.01$), and less often provided information about fluid intake ($p = 0.04$) than oncology nurses who perceived sufficient knowledge.

Oncology nurses most often reported that their PA advice was to promote PA in general. Other reported PA advice included to meet PA guidelines by being physically active 30 minutes per day, five times a week; to visit a physical therapist; and to attend a Dutch cancer rehabilitation program [16]. No differences in the content of the PA advice were found between nurses who perceived insufficient knowledge on PA and those who perceived sufficient knowledge.

**Table 1:** Characteristics of oncology nurses providing advice on nutrition (*n*=355) and physical activity (*n*=327).

| | | Nutrition (*n*=355) | | | | | |
|---|---|---|---|---|---|---|---|
| | | **Total** | | **Insufficient knowledge** | | **Sufficient knowledge** | |
| | | *n* | (%) | *n* | (%) | *n* | (%) |
| **Age [median (min-max)]** | | 47 | (23 - 65) | 44 | (23 - 65) | 47 | (3 - 64) |
| **Gender** | Female | 337 | (94.9%) | 146 | (95.4%) | 191 | (94.6%) |
| | Male | 18 | (5.1%) | 7 | (4.6%) | 11 | (5.4%) |
| **Educational level** | University | 34 | (9.6%) | 10 | (6.5%) | 24 | (11.9%) |
| | Higher vocational education | 271 | (76.3%) | 116 | (75.8%) | 155 | (76.7%) |
| | Intermediate vocational education | 50 | (14.1%) | 27 | (17.6%) | 23 | (11.4%) |
| **Organisation** | Other | 34 | (9.6%) | 12 | (7.8%) | 22 | (10.9%) |
| | Hospital | 321 | (90.4%) | 141 | (92.2%) | 180 | (89.1%) |
| **Work experience with oncology patients** | > 25 years | 14 | (5.3%) | 5 | (4.4%) | 9 | (6.0%) |
| | ≤ 5 years | 103 | (39.0%) | 48 | (42.1%) | 55 | (36.7%) |
| | 6 – 15 years | 114 | (43.2%) | 46 | (40.4%) | 68 | (45.3%) |
| | 16 – 25 years | 33 | (12.5%) | 15 | (13.2%) | 18 | (12.0%) |
| **Timing of counselling** | The whole trajectory | 196 | (55.2%) | 75 | (49.0%) | 121 | (59.9%) |
| | Diagnosis & treatment | 61 | (17.2%) | 29 | (19.0%) | 32 | (15.8%) |
| | During treatment | 59 | (16.6%) | 32 | (20.9%) | 27 | (13.4%) |
| | Treatment & aftercare | 39 | (11.0%) | 17 | (11.1%) | 22 | (10.9%) |

REF=reference category; 95%CI= 95% Confidence Interval

| Physical activity (*n*=327) | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| **Odds ratio** | | **Total** | | | **Insufficient knowledge** | | **Sufficient knowledge** | | **Odds ratio** | |
| (95% CI) | | *n* | (%) | | *n* | (%) | *n* | (%) | (95% CI) | |
| **1.03** | **(1.01-1.06)** | 47 | (23 - 64) | | 46 | (23 - 64) | 47 | (23 - 62) | 1.01 | (0.98-1.03) |
| REF | | 310 | (94.8%) | | 138 | (92.6%) | 172 | (96.6%) | REF | |
| 1.0 | (0.46-3.17) | 17 | (5.2%) | | 11 | (7.4%) | 6 | (3.4%) | 0.44 | (0.16-1.21) |
| REF | | 36 | (11.0%) | | 11 | (7.4%) | 25 | (14.0%) | REF | |
| 0.56 | (0.26-1.21) | 253 | (77.4%) | | 120 | (80.5%) | 133 | (74.7%) | 0.49 | (0.23-1.03) |
| **0.36** | **(0.14-0.89)** | 38 | (11.6%) | | 18 | (12.1%) | 20 | (11.2%) | 0.49 | (0.19-1.27) |
| REF | | 33 | (10.1%) | | 16 | (10.7%) | 17 | (9.6%) | REF | |
| 1.44 | (0.69-3.00) | 294 | (89.9%) | | 133 | (89.3%) | 161 | (90.4%) | 0.88 | (0.14-1.80) |
| REF | | 13 | (5.3%) | | 8 | (7.2%%) | 5 | (3.7%) | REF | |
| 0.64 | (0.20-2.03) | 100 | (40.7%) | | 42 | (37.8%) | 58 | (43.0%) | 2.21 | (0.68-7.23) |
| 0.82 | (0.26-2.61) | 105 | (42.7%) | | 50 | (45.0%) | 55 | (40.7%) | 1.76 | (0.54-5.7) |
| 0.67 | (0.18-2.42) | 28 | (11.4%) | | 11 | (9.9%) | 17 | (12.6%) | 2.47 | (0.64-9.54) |
| REF | | 188 | (57.5%) | | 86 | (57.7%) | 102 | (57.3%) | REF | |
| 0.68 | (0.38-1.22) | 50 | (15.3%) | | 26 | (17.4%) | 24 | (13.5%) | 0.78 | (0.42-1.45) |
| **0.52** | **(0.29-0.94)** | 51 | (15.6%) | | 20 | (14.8%) | 29 | (16.3%) | 1.11 | (0.60-2.07) |
| 0.80 | (0.40-1.61) | 38 | (11.6%) | | 15 | (10.1%) | 23 | (12.9%) | 1.29 | (0.64-2.63) |

**Table 2:** Content of nutrition advice oncology nurses provide by group.

| **Nutritional advice (*n*=355)** | | | | | | |
|---|---|---|---|---|---|---|
| | **Total** | | **Insufficient knowledge** (*n*=153) | | **Sufficient knowledge** (*n*=202) | | ***p*-value** |
| | *n* | (%) | *n* | (%) | *n* | (%) | |
| **Advising about nutrition 'according to nutritional guidelines'** | 113 | (31.8%) | 50 | (32.7%) | 63 | (31.2%) | 0.76 |
| **To visit a dietician** | 81 | (22.8%) | **43** | **(28.1%)** | **38** | **(18.8 %)** | **0.03** |
| **To consume small portions during the day** | 75 | (21.1%) | 36 | (23.5%) | 39 | (19.3%) | 0.33 |
| **To consume an energy enriched diet** | 71 | (20.0%) | 26 | (17.0%) | 45 | (22.3%) | 0.21 |
| **To consume a protein enriched diet** | 34 | (9.6%) | 12 | (7.8%) | 22 | (10.9%) | 0.33 |
| **To take Oral Nutritional Supplements (ONS)** | 30 | (8.5%) | **21** | **(13.7%)** | **9** | **(4.5%)** | **<0.01** |
| **Providing information about fluids and drinking** | 19 | (5.4%) | **4** | **(2.6%)** | **15** | **(7.4%)** | **0.04** |
| **To maintain a stable body weight** | 17 | (4.8%) | 7 | (4.6%) | 10 | (5.0%) | 0.87 |
| **To provide brochures** | 15 | (4.2%) | 6 | (3.9%) | 9 | (4.5%) | 0.80 |

**Table 3:** Content of PA advice oncology nurses provide by group.

| | **Total** | | **Insufficient knowledge** (*n*=149) | | **Sufficient knowledge** (*n*=178) | | ***p*-value** |
|---|---|---|---|---|---|---|---|
| | *n* | (%) | *n* | (%) | *n* | (%) | |
| **To stimulate exercise in general** | 169 | (51.7%) | 79 | (53.0%) | 90 | (50.6%) | 0.65 |
| **To meet physical activity guidelines** | 51 | (15.6%) | 21 | (14.1%) | 30 | (16.9%) | 0.49 |
| **To visit a physical therapist** | 49 | (15.0%) | 23 | (15.4%) | 26 | (14.6%) | 0.83 |
| **To attend a Dutch cancer rehabilitation program [16]** | 36 | (11.0%) | 17 | (11.4%) | 19 | (10.7%) | 0.83 |
| **To find a balance between exercise and rest** | 34 | (10.4%) | 13 | (8.7%) | 21 | (11.8%) | 0.36 |

**Table 4:** Information sources on which oncology nurses reported to base their nutrition advice by group.

| **Nutrition (*n*=355)** | | | | |
|---|---|---|---|---|
| | **Total** | **Insufficient knowledge** (*n*=153) | **Sufficient knowledge** (*n*=202) | ***p*-value** |
| | *n* (%) | *n* (%) | *n* (%) | |
| **Dietician** | 214 (60.3%) | 90 (58.8%) | 124 (61.4%) | 0.62 |
| **Dutch cancer foundation*** | 102 (28.7%) | 40 (26.1%) | 62 (30.7%) | 0.34 |
| **The Internet** | 64 (18.0%) | 26 (17.0%) | 38 (18.8%) | 0.65 |
| **Guidelines** | 60 (16.9%) | 22 (14.4%) | 38 (18.8%) | 0.27 |
| **Internal brochures** | 49 (13.8%) | 17 (11.1%) | 32 (15.8%) | 0.20 |
| **Literature** | 27 (7.6%) | 8 (5.2%) | 19 (9.4%) | 0.14 |
| **Other materials**** | 79 (32.3%) | 27 (17.6%) | 52 (25.7%) | 0.06 |

* *Information sources, including leaflets and the website.*

** *Such as materials from previous training, information from industry, information from doctors, experiences from other patients, and common sense.*

**Table 5:** Information sources on which oncology nurses reported to base their physical activity advice by group.

| **Physical activity (*n*=327)** | | | | | | | |
|---|---|---|---|---|---|---|---|
| | **Total** | | **Insufficient knowledge** (*n*=149) | | **Sufficient knowledge** (*n*=178) | | ***p*-value** |
| | *n* | (%) | *n* | (%) | *n* | (%) | |
| **Dutch cancer rehabilitation program [16]** | 96 | (29.4%) | 46 | (30.9%) | 50 | (28.1%) | 0.58 |
| **Physical therapist** | 92 | (28.1%) | 39 | (26.2%) | 53 | (29.8%) | 0.47 |
| **Oncoline** | 61 | (18.7%) | **17** | **(11.4%)** | **44** | **(24.7%)** | **<0.01** |
| **Education** | 55 | (16.8%) | 19 | (12.8%) | 36 | (20.2%) | 0.07 |
| **Own experience** | 43 | (13.1%) | 18 | (12.1%) | 25 | (14.0%) | 0.60 |
| **Literature** | 39 | (11.9%) | 15 | (10.1%) | 24 | (13.5%) | 0.34 |
| **Brochures** | 25 | (7.6%) | 12 | (8.1%) | 13 | (7.3%) | 0.79 |

## Information Sources

Tables 4 and 5 provide an overview of information sources on which oncology nurses reported to base their nutrition and PA advice. The most frequently reported information sources included a dietitian, the Dutch Cancer Society's leaflets and website (www.kwf.nl/english/pages/the-organisation.aspx), and other materials (e.g., materials from previous training, information from the industry, information from doctors, experiences from other patients, common sense). No significant differences were found between information sources used by oncology nurses who perceived insufficient knowledge and those who perceived sufficient knowledge.

Information sources on which PA advice was based included the guidelines of a cancer rehabilitation program [16]; a physical therapist; education such as symposia, training via a medical doctor, and training to become a physical therapist; Oncoline (a website designed for the consultation of nationwide guidelines from the Netherlands for the field of oncology and palliative care) [7]; and oncology nurses' own experience.

## DISCUSSION

The current study showed that nearly half of the oncology nurses who reported providing advice on nutrition and PA perceived themselves as having insufficient knowledge to be able to provide such advice to cancer survivors. Younger oncology nurses, less educated nurses, and nurses who counselled cancer survivors during treatment only particularly reported insufficient knowledge on nutrition. The content of nutritional advice differed between oncology nurses with and without perceived sufficient knowledge on nutrition. Nurses with perceived insufficient knowledge were more likely to suggest taking oral nutritional supplements or visiting a dietitian and were less likely to give advice on drinking and fluids. Similar information sources were used among nurses with and without perceived sufficient knowledge on nutrition. None of the characteristics were associated with having perceived insufficient knowledge about PA. Regarding the content of advice on PA and information sources used, differences were found between oncology nurses with and without perceived insufficient knowledge on PA with regard to the use of Oncoline. Nurses who reported insufficient knowledge on PA less often used Oncoline as an information source.

A search of the literature revealed no studies on oncology nurses and their knowledge levels regarding giving advice on nutrition and PA. Therefore, the current study is the first relatively large study to report the effect of oncology nurses' perceived knowledge levels on information sources used, content of provided information, and characteristics of oncology nurses perceiving themselves as having sufficient or insufficient knowledge.

The response rate in the current study was comparable to Karvinen et al.'s [4] response rate (13.6% versus 13.8%) but lower than Stevinson and Fox's [12] response rate (62%). The higher response rate in Stevinson and Fox [12] may be explained by differences in sampling method. Stevinson and Fox used direct mailing, which likely leads to a higher response rate than using a combination of direct mailing and providing a link in a newsletter as in the current study. The current response rate could not be compared to Puhringer et al. [5] because they did not provide an estimate of eligible respondents.

The finding that oncology nurses reported providing advice on nutrition and PA even though they perceived insufficient knowledge to provide such advice is in line with other studies within and outside the field of oncology [4, 5, 14, 15]. In line with the current study, Karvinen et al. [4] showed that a lot of oncology nurses are unsure what to recommend to their patients regarding PA. In addition, Puhringer et al. [5] showed that a lack of expertise on nutrition was reported to be a common barrier for information provision on nutrition. The current findings seem to contradict this, because nearly half of the oncology nurses in the current study did provide advice on

nutrition and PA even though they perceived a lack of knowledge on these subjects. Earlier studies among nurses in other specialties showed that advice was provided despite a reported lack of knowledge and skills [17, 18]; for example, nurses in geriatric care and nurses from medical and surgical wards who received training on nutrition and afterwards felt they had achieved more insight into nutrition. When comparing the current study population with the results of a survey by Klemp, Frazier, Glennon, Trunecek, and Irwin[19], the authors found that the current study population had even higher information needs than Klemp et al.'s population. Klemp et al.'s survey of oncology nurses showed that 30% of respondents had a need for information to assist their patients on topics of health behaviours, such as diet and exercise. In the current study, 43% (nutrition) and 46% (PA) of nurses perceived themselves as having insufficient knowledge.

In contrast to the authors' finding that younger nurses more often reported insufficient knowledge to provide advice on nutrition, a study of palliative care nurses showed that older, more experienced nurses felt less equipped to properly care for their palliative patient group [15]. The association between younger age and insufficient knowledge observed in the current study may be explained by a lack of experience in younger oncology nurses. However, findings from the current study and Pfister et al.'s study suggest that work experience is not associated with perceiving insufficient knowledge.

No literature was found to explain the finding that less educated oncology nurses more often reported insufficient knowledge to provide advice on nutrition. Less educated oncology nurses may have received less training in nutritional topics than their more educated colleagues. However, this possible explanation is in contrast with the results of Klemp et al. [19], in which no association between knowledge deficits on diet and exercise and formal nursing training was found. The authors also speculated why nurses who provide counselling to patients with cancer during treatment only more often perceive insufficient knowledge. The occurrence of diverse and serious complaints and complications in the treatment phase may enhance the feeling of insufficient knowledge compared to the more general nutritional advice that needs to be given after treatment has finished.

In the current study, healthcare professionals, such as dietitians and physical therapists, were most often mentioned as information sources for knowledge on nutrition and PA. This is in line with a study among oncology healthcare professionals in Australia, which found that experienced colleagues were the preferred source of information [20].

The majority of the content of the advice on nutrition and PA as reported in the current study seems to be in line with nutritional and PA recommendations [1, 8–11, 21]. However, the advice to take oral nutritional supplements reported in the current

study is not according to guidelines. This finding is concerning, particularly because the authors found that nurses with a perceived lack of knowledge on nutrition more often provide advice to take these supplements [7, 21]. Oncology nurses should be taught to refer their patients to a dietitian if they suspect a need for oral nutritional supplements. A dietitian is the designated person to give advice on this. They have more knowledge about different types of nutritional supplements and can determine the specific needs of the patient. Previous research has demonstrated that educating oncology nurses can increase their knowledge about the importance of nutrition and its impact in oncology and their providing early and consistent interventions, such as nutritional advice, to prevent the incidence of malnutrition [22]. For example, in a study of nurses who followed a nutritional training program in which they gained knowledge on risk assessment, consequences of malnutrition, and the assessment of nutritional needs, they reported feeling an increased responsibility for nutritional care compared to the period before the training program (Bjerrum et al., 2012). In addition, educating oncology nurses will likely promote knowledge on nutrition and PA recommendations among cancer survivors [23].

Regarding the content of nutritional advice, the current study showed that nurses who reported insufficient knowledge more often advised their patients to visit a dietitian compared with nurses who perceived sufficient knowledge. Nurses who perceive insufficient knowledge to provide advice may be aware of their lack of knowledge and, therefore, refer patients to a dietitian more often. In addition, the current findings suggest that oncology nurses provide general PA advice. Because Garcia and Thomson [9] showed that advice on PA should be tailored to meet the individual needs of the patient, providing individually tailored PA advice seems more appropriate. Such tailored PA advice may be better provided by a physical therapist, suggesting that it would be more appropriate for oncology nurses to refer patients in need of information to physical therapists rather than to provide general PA advice themselves.

No literature has been found to explain the fact that no associations were found between perceived insufficient knowledge on PA and nurse characteristics and content of advice. A possible explanation for this may be that the PA advice oncology nurses provide is so basic and general that they are unlikely to perceive a lack of sufficient knowledge.

A strength of the current study was that data were collected nationwide in a large heterogeneous sample of oncology nurses with different education backgrounds and a large variety of number of years of work experience. However, the nurses who participated in the current study may not be representative of the population at large. The authors cannot make a comparison between the respondents and the nonrespondents because they have no information on the nonrespondents. Nurses who participated in the current study may have been more interested in nutrition and PA and,

therefore, may perceive sufficient knowledge on these topics more frequently. When this is the case, an even higher need exists for improving knowledge about nutrition and PA in oncology nurses because the number of oncology nurses with insufficient knowledge would be underestimated in the current study. Because the content of the advice was measured with a questionnaire, details are lacking on the precise content of the reported advice. For example, it is not precisely clear what oncology nurses meant by 'adhere to nutritional or PA guidelines' or 'an energy-enriched diet'. To gain more insight into the precise content of the advice provided by oncology nurses, qualitative data should be gathered (e.g., by means of semi-structured interviews). However, the current data on the content of the advice provide more insight into the topics nurses discuss with their patients. Another limitation was that the survey did not include questions about the frequency of providing advice on nutrition and PA. Whether advice on nutrition and PA is given routinely to every patient or only when it accidentally comes up is important.

### Implications for Nurses

The results of the current study indicate that improvement of knowledge about nutrition and PA in oncology nurses is needed. The current findings can be used as a starting point to educate oncology nurses on appropriate nutrition and PA advice for cancer survivors. The current study suggests that younger oncology nurses, less educated nurses, and nurses who counsel patients during treatment only should be particularly targeted for such education.

Nutrition and PA should become part of educational training for oncology nurses so that all future oncology nurses will be properly educated [24, 25]. For example, online education may provide an easy, accessible, and relatively cheap method of educating nurses. Research has demonstrated that nurses are already familiar with online education tools and have access to the Internet at work and at home, providing a viable method for reaching oncology nurses [19]. An option is to use an e-learning module for oncology healthcare professionals to improve knowledge on nutrition, PA, and cancer [26].

Some of the advice reported by oncology nurses in the current study preferably should be provided by a dietitian. For example, providing advice on oral nutritional supplements or an energy- or protein-enriched diet fits the expertise of a dietitian rather than the expertise of an oncology nurse. Therefore, it is important for oncology nurses to closely cooperate with oncology dietitians and to discuss what information should be provided by whom. Agreements about what advice belongs to the scope of oncology nurses need to be made and may be facilitated by using screening tools such as the Patient-Generated Subjective Global Assessment Short Form [27] and the Malnutrition Universal Screening Tool [28], as is recommended in the nutritional guidelines. For

example, agreement needs to be made about what cut-off points should be used for referral to a dietitian. Specific PA advice, adjusted to the patient's needs, should be given by a physical therapist. The authors recommend incorporating such criteria for referral to a dietitian or a physical therapist in educational materials.

## CONCLUSION

Nearly half of the oncology nurses who reported providing advice to their patients on nutrition and PA perceived insufficient knowledge to be able to provide such advice. Younger oncology nurses, oncology nurses with an intermediate vocational education, and nurses who counselled their patients during treatment only were less likely to have sufficient knowledge on nutrition. Therefore, these nurses should be educated. Additional research is needed to gain more knowledge on preferred education tools.
The authors gratefully acknowledge all of the oncology nurses who participated in the current study, the different nursing networks that distributed the questionnaire among their members, and Jan van Hoof for executing the survey.

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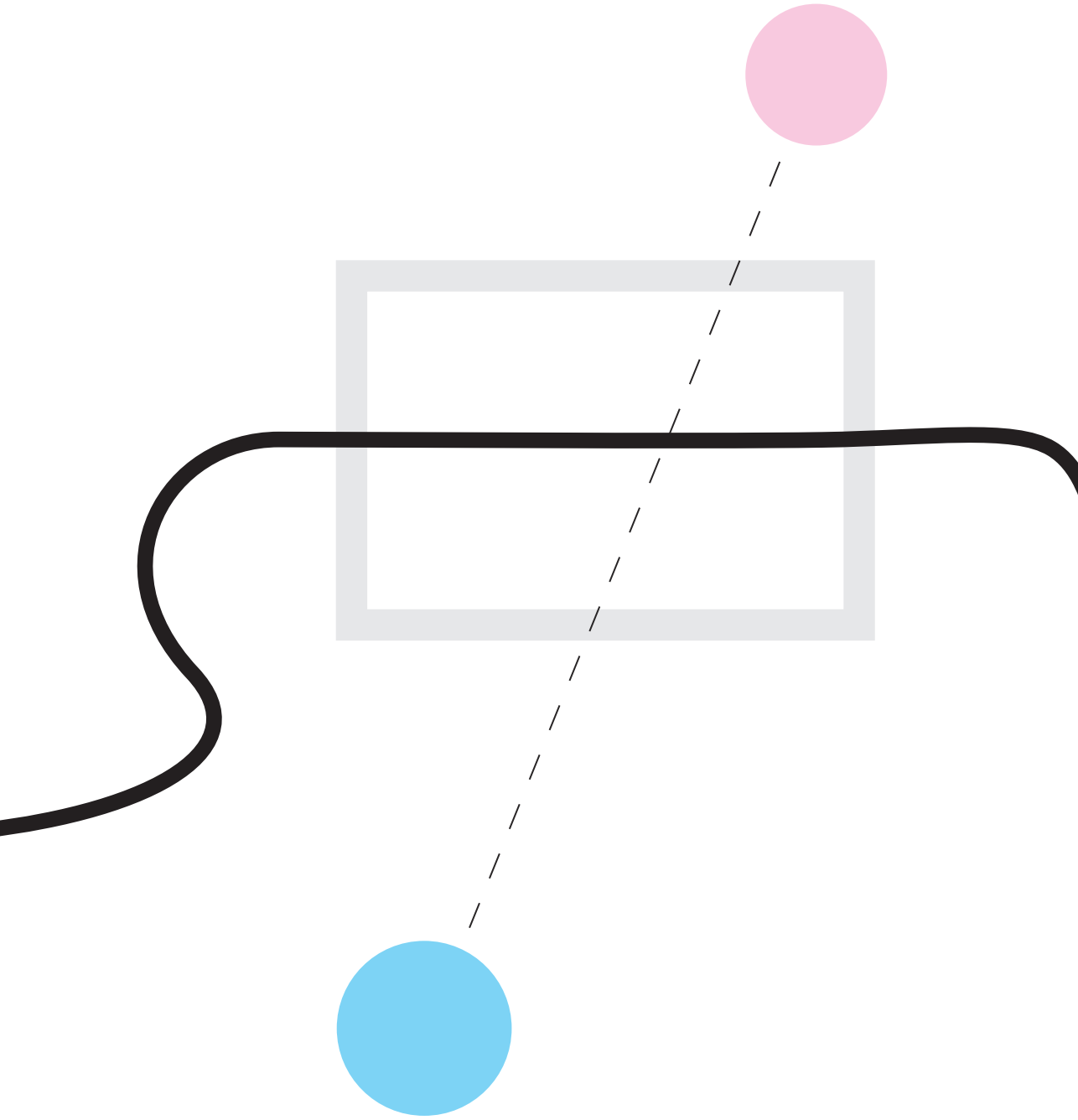
## KNOWLEDGE TRANSLATION

Almost half of oncology nurses providing advice on nutrition and physical activity (PA) to their patients reported insufficient knowledge on nutrition, PA, and cancer.

Oncology nurses perceiving insufficient knowledge were younger, less educated nurses and nurses who counsel patients during treatment only.

An educational training program on nutrition, PA, and cancer for oncology nurses may be used to improve knowledge.



# CHAPTER 6:

## The development of a website providing evidence-based information about nutrition and cancer: fighting fiction and supporting facts

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## ABSTRACT

### BACKGROUND

Although widely available, the general public, cancer patients, and cancer survivors have difficulties accessing evidence-based information on nutrition and cancer. It is challenging to distinguish myths from facts, and sometimes conflicting information can be found in different places. The public and patients would benefit from evidence-based, correct, and clear information from an easily recognizable source.

### OBJECTIVE

The aim of this project is to make scientific information available for the general public, cancer patients, and cancer survivors through a website. The aim of this paper is to describe and evaluate the development of the website as well as related statistics 1st year after its launch.

### METHODS

To develop the initial content for the website, the website was filled with answers to frequently asked questions provided by cancer organizations and the Dutch Dietetic Oncology Group, and by responding to various fiction and facts published in the media. The website was organized into 3 parts, namely, nutrition before (prevention), during, and after cancer therapy; an opportunity for visitors to submit specific questions regarding nutrition and cancer was included. The website was pretested by patients, health care professionals, and communication experts. After launching the website, visitors' questions were answered by nutritional scientists and dieticians with evidence- or eminence-based information on nutrition and cancer. Once the website was live, question categories and website statistics were recorded.

### RESULTS

Before launch, the key areas for improvement, such as navigation, categorization, and missing information, were identified and adjusted. In the 1st year after the launch, 90,111 individuals visited the website, and 404 questions were submitted on nutrition and cancer. Most of the questions were on cancer prevention and nutrition during the treatment of cancer.

### CONCLUSIONS

The website provides access to evidence- and eminence-based information on nutrition and cancer. As can be concluded from the number of visitors and the number of questions submitted to the website, the website fills a gap.



### KEYWORDS

Cancer, information needs, Internet, nutrition, website development

## INTRODUCTION

### Background

With more than 10,000 epidemiological studies, and several animal and in vitro experiments, the major diet- and nutrition-related factors in the aetiology of cancer are now well-known to researchers. Numerous reports and guidelines have been written on cancers, which are widely available both online and in print [1–6]. However, one of the most consistent findings in health services research is that scientific knowledge often does not reach the general public.

Although several studies have shown that adhering to the guidelines concerning a healthy weight, a healthy diet, and sufficient physical activity does reduce cancer risk [7, 8], approximately one half to two thirds of people think these factors do not contribute to their cancer risk [9,10], despite the fact that these guidelines are actively addressed by both national and international organizations in their campaigns for the general public [2, 11].

Not only are the guidelines to reduce the risk of cancer not well-known, but also cancer patients are not well informed about the guidelines regarding nutrition during and after cancer treatment. Because these guidelines are not sufficiently implemented in daily practice [12], this can result in inefficient, inappropriate, or even harmful care [13]. Furthermore, information about nutrition and cancer is often provided on request and is not routinely discussed during consultation [14]. The literature shows that there is a high demand for nutritional information among cancer patients [15], and that 30-66% of cancer patients have unmet nutritional information needs [15–20]. As a result, cancer patients and survivors try to fulfill these needs by finding information. In a survey conducted among 217 young adult cancer patients, almost 90% reported the need for nutritional information, and 95% of the respondents have used websites to search for information [15]. In a study involving around 2000 breast, prostate, and colon cancer patients, approximately 25% of patients reported searching for information online [21]. The monitoring of Internet use in the Netherlands in 2014 showed that 50% of health care users searched the Internet for information on nutrition and exercise [22].

The actual information on nutrition and cancer available online is overwhelming, with numerous websites from individuals, foundations, and industry and health care organizations providing information [2, 11, 23–28]. However, for the visitors of these websites, it may be hard to distinguish evidence-based websites from those that are not and to separate myths from facts. This may lead to misconceptions resulting in unnecessary or worse changes in dietary habits with a negative effect on nutritional status and response to treatment [29]. Furthermore, conflicting information leads to confusion and uncertainty, which may negatively influence the quality of life of cancer

patients. The provision of appropriate information can result in an improved health competence, a better sense of control over cancer, better symptom management, lower levels of distress, and higher levels of health-related quality of life [30].

A recent study shows that active information seeking about cancer from nonclinical sources may lead to improved dietary habits among cancer patients [31]. Furthermore, an evidence-based website may lead to a better sense of control over cancer. A recently launched website for lung cancer patients was used by patients to better understand the information given by their own specialist. An evaluation of the site showed that access to this information helped them to better cope with their disease [32].

## Objective

Thus, cancer patients, both during and after treatment, as well as the general public, would benefit from correct, clear, and evidence-based information from an easily recognizable and evidence-based source. Therefore, the aim of this project is to make scientific information available to all people who have to deal with cancer. Because of the aforementioned positive effects, a website is used to provide people with nutritional advice to prevent cancer, nutritional advice during cancer treatment, and advice about what to do once their treatment is finished. The aim of this paper is to describe and evaluate the development of the website and to describe the experiences of the 1st year after the launch.

# METHODS

## Prelaunch

The first content of the website Voeding en Kanker Info (Nutrition and Cancer Info) [33] was composed by collecting (1) items from oncology dieticians in daily practice (members of the Dutch Dietetic Oncology Group); (2) questions received by the helplines of various cancer organizations (eg, the Dutch Cancer Society and the World Cancer Research Fund); and (3) various fiction and facts published in the media.

### ANSWERING QUESTIONS

Questions were answered by registered dieticians specializing in oncology and nutritional scientists and were reviewed by members of the Dutch Dietetic Oncology Group. Evidence from meta-analyses of observational studies, reviews, and randomized controlled trials (RCTs), in combination with evidence from animal and in vitro studies, was used to formulate those answers. All questions and answers were used as content for the website.

#### DESIGN

The website was designed with a home page where the questions were displayed. The editorial board, including the authors of the website, was fully shown on the home page. The 5 most prevalent tumor types (lung, breast, prostate, colorectal, and skin tumors) were described on separate pages; questions were categorized by tumor type and by the following categories: prevention, during treatment, or after treatment/ tertiary prevention.

#### PRETEST

Before the official launch, a pretest was performed, and the website was evaluated by cancer survivors, health care professionals, and communication experts. Survivors were recruited from the Online Cancer Patient Panel of the Netherlands Comprehensive Cancer Organization and from the oncology day-care center of a peripheral hospital where the questionnaire was filled out while the patients received chemotherapy. The professionals were communication specialists, registered dieticians, nutritional scientists, the staff of the World Cancer Research Fund and the Dutch Cancer Society, and patient advocates. Those who tested the website filled out a questionnaire on site design and layout, content, readability, and comprehensiveness of the texts. The questionnaire contained both open-ended and closed questions. The questions asked in the questionnaire for professionals can be found in Multimedia Appendix 1, and the questions in the questionnaire for patients can be found in Multimedia Appendix 2.

### After the Launch

#### PUBLIC RELATION

Immediately after the official launch, media attention was sought. One of the authors (EK) had interviews on regional and national radio stations, and articles were published in both regional and national newspapers and in magazines from patient organizations, health professionals, and the university. In addition, many websites (eg, Voeding Nu [34], Gezondheid [35], Foodlog [36], Onderzoekers [37]) paid attention to the launch of the website on nutrition and cancer. Each time a question was answered on the website, a notice was sent out via Twitter.

#### SUBMITTED QUESTIONS

After the launch, visitors of the website could submit questions. After submitting the question, the person received a standard email explaining the answering procedure: a literature search is performed, the answer is read by a team of experts, and then it is sent to the submitter of the question. The questions were answered by nutritional scientists and dieticians and reviewed by members of the Dutch Dietetic Oncology Group. When necessary, advice was sought from other experts. Questions about specific

personal and unique situations received a direct and personal answer. If the patient needed more personal feedback or additional guidance, referral to a dietician or to the treating physician was made. Questions or opinions from people with strong beliefs regarding nutrition and cancer were directly answered by the nutritional scientists and registered dieticians and were not placed on the website. In these answers, an explanation was given that only scientific evidence from sufficient observational studies, meta-analyses, reviews, and RCTs was used to formulate answers, in combination with animal, in vitro, and case studies. General questions on cancer were redirected to other sources of information, such as to the website of the Dutch Cancer Society [11]. General questions about nutrition were redirected to the Netherlands Nutrition Centre [38]. Questions and answers on nutrition and cancer were placed on our website.

### Categorization of Questions

Visitors of the website who asked a question did not have to sign in or make a profile. Instead, they had to submit a form in which their name, email address, and some questions had to be filled in. To gain insight into the information needs of the visitors of the website, the questions were analyzed. Each form and question, with its matching answer, were read and imported to a Microsoft Access database (Microsoft, Redmond, WA, USA). Questions were categorized and ordered independently by 3 of the authors (MRV, SB, and AMAA). The categories were 'products promoting health' and 'products harming health/increasing cancer risk'. In addition, 3 periods were defined, namely, 'prevention of cancer', 'nutrition during treatment', and 'nutrition after treatment'. Information on the number of question submitters and the number of questions per submitter was recorded and calculated.

#### USER STATISTICS

Google Analytics was used to collect information about the number of page views, the number of visitors, and the length of stay.

## RESULTS

### Prelaunch

#### OVERVIEW

Feedback was provided on content and site design; in addition, improvements were also suggested. Based on the results of the pretest, improvements in design, content, and navigation were made before the official launch of the website.

**Table 1:** Results of pre-test by cancer patients.

| | | yes | % | no | % | other | % | total |
|---|---|---|---|---|---|---|---|---|
| **Q2** | **Did you visit other websites on nutrition and cancer?** | 15 | 27 | 41 | 73 | | | 56 |
| **Q6** | **Is it clear in a glimpse what the website is about?** | 31 | 76 | 10 | 24 | | | 41 |
| **Q7** | **Is it clear in a glimpse who is the owner of the website?** | 17 | 40 | 26 | 60 | | | 43 |
| **Q9** | **Does the website meet your expectations?** | 26 | 65 | 14 | 35 | | | 40 |
| **Q12** | **What do you think of the chosen font? Is it clear?** | 36 | 92 | 3 | 8 | | | 39 |
| **Q13** | **What do you think of the colours used? Are they pleasant?** | 34 | 87 | 5 | 13 | | | 39 |
| **Q14** | **What is your opinion of the selection of the pictures? Are they pleasant?** | 34 | 87 | 5 | 13 | | | 39 |
| **Q16** | **Is the layout clear?** | 34 | 87 | 5 | 13 | | | 39 |
| **Q17** | **Can you easily find what you are looking for?** | 34 | 87 | 5 | 13 | | | 39 |
| **Q20** | **Do you think the texts on the website are comprehensible?** | 37 | 95 | 2 | 5 | | | 39 |
| **Q23** | **Do you think the website is complete?** | 20 | 53 | 1 | 3 | 17 | 45 | 38 |
| **Q24** | **Is it clear where you can ask questions?** | 29 | 76 | 9 | 24 | | | 38 |
| **Q27** | **Does the website look reliable?** | 33 | 87 | 5 | 13 | | | 38 |
| **Q28** | **Would you visit this website?** | 32 | 84 | 6 | 16 | | | 38 |
| **Q29** | **Would you recommend the website to others?** | 28 | 74 | 3 | 8 | 7 | 18 | 38 |

#### FEEDBACK FROM PATIENTS

Fifty-six patients started the questionnaire, and 38 patients (68%) filled in the complete questionnaire. As can be seen in Table 1, 15 respondents (27%) had visited a website on nutrition and cancer before the launch of our website or a general search on Google. Ten (24%, 10/41) patients did not find the information in our website to be completely clear. Their reactions were "I can't find which diet is important for my sort of cancer", and "I do not understand the relationship between apricot kernels and nausea." Twenty-five patients (45%) thought the website was not complete: "There are only 5 types of cancer", "What types of food should I avoid?", "Information is missing", "it is not completely clear how many nutrients I need to keep my body healthy and fit", and "You can see the website is not finished yet". Of all of the patients who completed the questionnaire, 28 (74%) would recommend the website to others. The reasons for not recommending the website were "There is not enough new information on this website", "I do not see the difference between the website of the Dutch Cancer Society and this website", and "I hope there will be referrals from other websites, as I do not think you will find this website without a referral".

For most respondents, the first impression of the website was a positive experience: "clear", "fresh", and "looks reliable". Improvements were suggested as follows: "smaller images", "not only young and healthy individuals on the images", "Such a website suggests that you can alter your disease with nutrition, while it actually is about altering your diet to cope with your cancer", and "Always mention the source, where did you find the answer to the question?". Suggestions on the structure of the website were also given: one suggestion was "More links", while another respondent suggested "More scrolling options instead of links".

#### FEEDBACK FROM HEALTH CARE PROFESSIONALS AND COMMUNICATION EXPERTS

Fifty professionals from 5 groups (communication specialists, dieticians, nutritional scientists, staff of the World Cancer Research Fund and the Dutch Cancer Society, and patient advocates) were contacted; 23 professionals (46%) provided feedback on the website. They provided comments about its layout, which were similar to the feedback of the patients: "the images are too large", "the front page is not clear", and "I do not understand the navigational options of the website". In addition, comments were made on the question form: "I cannot find your question form". Other comments included positive remarks on the total look of the website: "I like the vibrant colors and the positive feel of the website", and "the texts are easily accessible and comprehensible". Their general comments on content were as follows: "Why do you only mention the 5 most common types of cancer?", "Where can I find a full reference list?", and "I was looking for information for professionals, a pity it is not there". Opinions differed on the

difficulty level of the texts. Some respondents said the level of the texts was appropriate, whereas others commented that the texts were too difficult for the general public.

As a result of all the feedback, a clear distinction was made between the different phases: before treatment (primary prevention), during treatment, and after treatment. Nondiet-related information on tumor types was deleted, because this can be found on other websites [11]. Categorization by the 5 major tumor types was no longer used. Alterations were made to the logo, the font size of the website, the pictures used, and the navigation options. Additional information on nutrition and cancer was uploaded to the website before the launch. The comprehensiveness of the texts was tested [39] and adjusted in such way that all texts matched the B1 level of the Common European Framework [40]. A preview of the home page of the website just before the launch is shown in Figure 1.

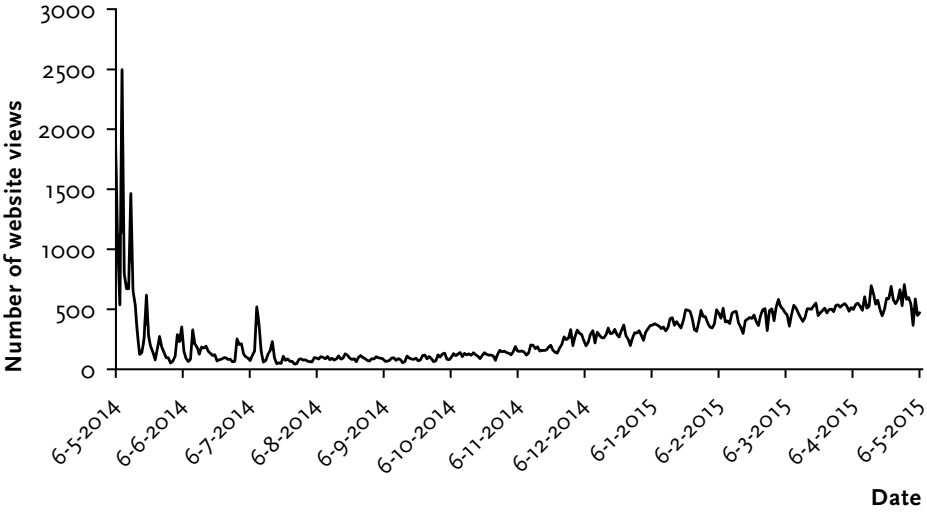
**Figure 1:** Home page of the website (May 2014).

## After the Launch

### PUBLIC RELATION

The results of the public relation activities were reflected in the number of views of the website. Right after the launch in May 2014, the level of media attention was high, and this is reflected in the large number of website views seen in Figure 2. The peaks in May reflect the media attention in the national newspaper Metro and radio interviews, and the peak in July reflects a Facebook post of the National Cancer Institute promoting the website. From December onward, business cards were handed out by dieticians and oncology nurses, and the website was actively promoted at several large conferences, which is reflected by a steady rise in website views and users.

**Figure 2:** Website views per month.



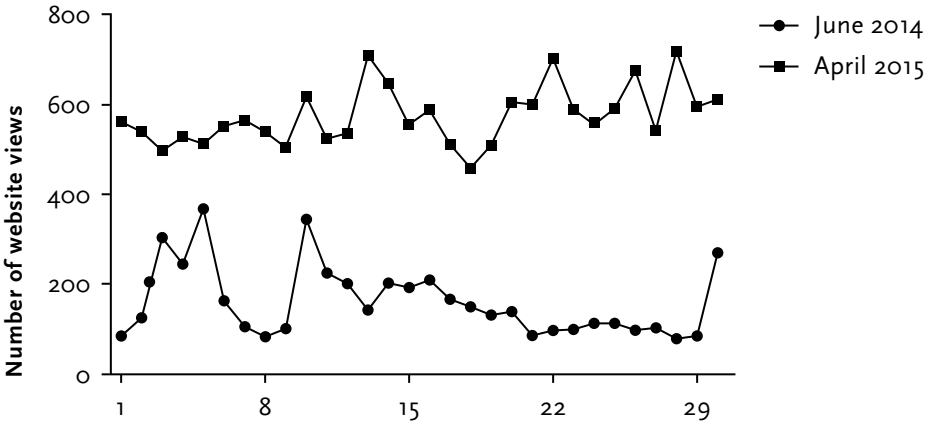

### USER STATISTICS

Between May 6, 2014, and May 5, 2015, 322,627 page views, 2.9 pages per visit, 90,111 visitors, a length of stay of 2.17 minutes per visit, and 109,596 website views were registered; there was an average of 7509 visitors, 26,885 page views, and 9133 website views per month. An increase can be seen in the number of website views, as shown in Figure 3. As much as 88.33% ($n$=96,817) of website views were from the Netherlands, 6.74% ($n$=7391) came from Belgium, and the remaining (4.91%; $n$=5388) came from non-Dutch speaking countries.

#### INFORMATION ON QUESTION SUBMITTERS

In total, 338 people submitted 404 individual questions. A majority of people sent in 1 question ($n$=299, 88.4%). Thirty-nine people (12%) who submitted questions asked more than 1 question: 25 submitters asked 2 questions, 9 submitters asked 3 questions, 3 people asked 4 questions, 1 person asked 7 questions, and 1 person submitted 9 questions. Question submitters were not asked for feedback on the website, because we had not informed the visitors of the website that they could be contacted. Therefore, to make sure the privacy of the question submitters was preserved, no user satisfaction survey was performed.

**Figure 3:** Comparison of website views in June 2014 and April 2015.




#### SUBMITTED QUESTIONS

In the 1st year of the website launch, 404 questions were submitted via the contact form. Detailed information on these questions can be found in Table 2.

**Table 2:** Categorised questions submitted to the website in the first 9 months after the launch.

| | Prevention | During treatment | After treatment | Other questions | Total |
|---|---|---|---|---|---|
| **Products promoting health** | 64 | 135 | 9 | | 208 |
| **Products harming health / increasing cancer risk** | 31 | 53 | 5 | | 89 |
| **Other topics** | | | | 107 | 107 |
| **Total** | 95 | 188 | 14 | 107 | 404 |

As can be seen in Table 2, most of the questions were on factors promoting health, both to prevent cancer and during the treatment of cancer.

Representative examples of questions on nutritional factors to prevent cancer, possibly promoting health were "Is biological fruit better?", "Does the intake of dairy products affect my cancer risk?", "Can a product such as chia seeds prevent cancer?", and "What do you think of the use of curcuma to prevent cancer?". Examples of questions on nutritional factors to prevent cancer, possibly harming health were "Does drinking coffee increase my cancer risk?", "Is it true that people with a low cholesterol level have an increased cancer risk?", "Does omega 6 increase cancer risk?", and "Do artificial sweeteners increase my risk of getting cancer?".

Questions on nutritional factors during cancer treatment, possibly promoting health were "Can you advise me how to season my foods, to improve taste?", "Is it known whether broccoli helps to treat my cancer?", "Can I use probiotics during my cancer treatment?", and "Are red fruits good to use for breast cancer patients?".

Questions on nutritional factors during cancer treatment, possibly harming health were "Is it true that sugar feeds my tumor?", "Is it harmful to eat soy products during my breast cancer treatment?", and "Is it true that green tea interferes with my antitumor treatment?".

The questions on nutritional factors after cancer treatment, possibly promoting health were "What can I eat now that my stoma is removed to prevent the recurrence of my cancer?", "Will eating soy products along with my tamoxifen use help to prevent the recurrence of my breast cancer?", and "What nutrition can you advise to prevent the recurrence of prostate cancer?". Questions on nutritional factors after cancer

treatment, possibly harming health were "Does cheese harm you when you had breast cancer?", "Can you drink wine if you are using tamoxifen after breast cancer?", "Can using curcuma after melanoma treatment harm my health?", "Does consuming sugar increase my risk of cancer recurrence?", and "Can I use fruit and yoghurt together after being cured of colorectal cancer?".

The majority of submitted questions were on specific foods or food components, not on complaints. However, when looking at the questions visited at the website, the top 10 were mostly filled with questions regarding complaints related to their disease, such as nausea, dry mouth, or diarrhea. In addition, 61 questions were requests for business cards.

After 1 year, 121 articles could be found on the website. In these 121 articles, 238 questions could be answered. In total, 372 questions ($n$=404; 92.0%) were answered. Expert advice was sought on the topics of diabetes/sugar and cancer, vitamin D and cancer, the interaction of foods and nutrients, and pharmaceuticals. The response time to questions was 1 day for the standard response, and the median response time was 3 days (range 0–280 days) for a detailed answer.

## DISCUSSION

### Principal Findings

Before the official launch, the website was designed (based on feedback and suggestions), pretested, and adjusted according to the provided feedback: extra questions and answers were added, the subdivision by tumor type was removed, and alterations were made to the logo, the font size, the pictures used, and the navigation options. In the 1st year after the launch, a total of 404 questions were submitted on nutrition and cancer. Most of the questions were on food products promoting health, both in the prevention of cancer and during the treatment of cancer. A total of 90,111 people visited the website during this period.

When investigating the submitted questions, it was noticed that there are a lot of opinions on nutrition and cancer, which are not completely evidence based. These beliefs often arise from the results of in vitro and animal studies, but are not confirmed in human studies. Therefore, most of the answers to commonly asked questions on the website start with "No, there is no scientific evidence." This is due to the fact that only studies in humans were used as evidence, because research only conducted in animals and in in vitro studies cannot be directly translated into humans. Besides the evidence-based answers, some answers are based on best practice-based evidence. Questions on complaints are mostly answered according to best practice-based evidence, whereas questions on specific nutrients are provided with evidence-based answers.

The very limited results from in vitro or animal studies sometimes lead to hypes in the media. Some examples are specific foods that people believe could prevent cancer, support cancer treatment, or promote general health (curcuma, chia seeds, etc). A large number of people follow this hype, which is reflected in the number of questions on these food products that were posted on the website. The question arises regarding why a large number of people use these products to prevent cancer or to support cancer treatment, despite the fact that their use is not evidence based. It might be possible that people do not want to put much effort into following healthy lifestyle advice, and therefore, they look for supplements or specific foods that can support their treatment. Indeed, a high number of questions about dietary supplements that might support cancer treatment or might decrease cancer risk were posted on the website.

There was a discrepancy between the topics of the submitted questions and the top 10 questions visited on the website. Therefore, it is likely that the questions on complaints were already answered by the content of the website, and fewer questions had to be asked on this topic.

## Limitations

In the prelaunch test, the nonresponse might have been due to the fact that patients were asked to fill out the questionnaire while receiving their chemotherapy. Furthermore, open questions lead to the highest number of dropouts: "What is your first impression of this website?" and "Is it clear at first sight what information can be found on this website?"

The visitors were not asked for feedback after the launch of the website. However, in a focus group, the patients were asked for their opinions of the website. These patients were glad the website was launched, and they were able to find the information that they were looking for. In their opinion, the website was clear, informative, and complementary to the online information available at that point.

As mentioned earlier, to preserve privacy, no information on the sex and age of visitors was recorded. Therefore, no conclusions can be drawn on the characteristics of the visitors. Because the average time spent on the website was 2.17 minutes, and the visitors visited 2.9 pages on average, we assume that the visitors really searched for information on nutrition and cancer and did not visit the website by accident. However, it is unknown whether these visitors are cancer patients, relatives, health care professionals, or members of the general public. When looking at the type of questions submitted to the website, most of the questions were on the prevention of cancer and nutrition during treatment. This might suggest that both the general public and cancer patients visit the website. The lack of questions on nutrition after treatment could be due to the fact that once people are cured from cancer, they do not want to read about cancer anymore, so these people will not visit the website.

Another reason could be that cancer survivors do not think about cancer in relation to tertiary prevention, or that the submitter of the question makes no distinction between primary or tertiary prevention.

The response time in answering questions varied widely for different questions. This was due to the vast number of questions submitted following the launch, and the fact that there were so many questions that needed extensive research. Therefore, the response time was much longer than anticipated. Because it is not appropriate to make people wait for so long, especially in palliative settings, this needed to be resolved. Extra personnel were hired, and the answering methods were optimized: standard answers were formulated that could be adjusted for specific personal situations. The response time has decreased since these measures were taken: most questions are answered within 2 weeks. In addition, questions were submitted that already could be found on the website; these readers were referred to the specific question and answer on the website. This also decreased the response time.

To reach a larger number of potential users of the website, beginning in December 1, 2014, business cards were distributed via oncology nurses, dieticians, and oncologists to inform patients about the existence of the website. This led to an increased number of visitors to the website and eventually to more questions.

### Comparison With Prior Work

Globally, there are more websites on nutrition and cancer; however, our website is the only Dutch website solely on nutrition and cancer where people can ask questions. Internationally, there are other websites, such as that of The Cancer Nutrition Center [41] and the American Society of Clinical Oncology [42]. However, the focus of these websites is exclusively on practical information for the patient, and no scientific evidence is presented. Therefore, our website has a unique concept.

In the Netherlands, there are no other websites on the full scope of cancer and nutrition to prevent cancer, or during treatment and after treatment. Therefore, our website was compared with the nutritional part of The Dutch Cancer Society website [11] and with the Dutch Lung Cancer Information Center website [43].

When comparing the user statistics of our website with the user statistics of the nutritional part of The Dutch Cancer Society [11], we noted some differences. Our website had 7500 visitors per month versus 1250 visitors per month on the nutritional section of the other website. However, the length of stay on our website was substantially shorter: 2.19 minutes on our website, compared with 7.63 minutes on the nutritional part of The Dutch Cancer Society website. The country of origin of the visitors was comparable for both websites. The Dutch Cancer Society website has not seen a change in the number of visitors since the launch of our website [44]. A reason for this might be that our website attracts different people than those

visiting the nutritional part of The Dutch Cancer Society website or that people visit both websites. It might also be that people are looking for information on The Dutch Cancer Society website and accidentally visited the part about nutritional information, instead of specifically searching for information on nutrition and cancer. In the past, people might have used other, less reliable websites in addition to their potential use of The Dutch Cancer Society website. Since the launch of our website, they have access to evidence-based information on nutrition and cancer and the opportunity to ask questions about nutrition and cancer.

Some differences were also noted when comparing the results of our website with the results of the website of the Dutch Lung Cancer Information Center [43]. First, the number of questions was substantially higher for the lung cancer website (57 versus 34 questions/month). The relative difference in the number of questions may be due to the topic of both websites. The Lung Cancer website focused on medical questions, which were answered by medical specialists. In comparison, a smaller number of questions could be expected for our website, because it only focuses on nutrition and cancer, thereby targeting only a smaller group of people. Another difference between the 2 websites is that the Lung Cancer website was able to register the identity and sex of its visitors. This information was not recorded on our website. A similarity between both websites is that most visitors only asked 1 question.

### Recommendations for Future Website Developers

Based on the experience from developing this website, the following recommendations are provided to future website developers:

- Start with an assessment of the information needs within the target group. For instance, a patient panel or patient focus groups can be used to explore wishes and demands regarding the future website.

- Before launching the website, test for its readability, usability, completeness, etc. Ask potential users/target group (ie, patients, health care professionals) and communication experts for feedback.

- Make it possible to register user information of the website visitors using cookies, to be able to further tailor the website to your visitors' demands.

- Do not underestimate the man power needed to maintain a website driven by visitors' questions. Be sure that there is enough man power to respond quickly to patients' questions.

- Make use of printed press and social media channels to promote your website to the target group, so your website is used to its full potential.

## CONCLUSIONS

The Voeding en Kanker website provides access to evidence-based, best practice-based, and eminence-based information on nutrition and cancer. As can be concluded from the number of questions submitted and the number of visitors to the website, in comparison with the number of visitors to the nutritional part page of The Dutch Cancer Society website and the Dutch Lung Cancer Information Center website, our website fills a gap in the provision of information about nutrition and cancer. Future work includes ongoing improvement of the website by answering questions and responding to current events more quickly. The website will be used to respond to actual news events; additionally, a section with recipes for cancer patients suffering from alterations in their taste and a section especially focused on health care professionals will be developed.

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### CONTRIBUTED BY

Authors' Contributions: MRV was responsible for answering questions on the website and for collecting questions, the prelaunch test, the analyses, promoting the website, and writing the manuscript. SB was responsible for answering questions on the website, collecting questions, the prelaunch test, promoting the website, and reviewing the manuscript. AMAA was responsible for answering questions on the website, promoting the website, and reviewing the manuscript. JV-B and EK were responsible for answering questions on the website, collecting questions, promoting the website, and reviewing the manuscript.

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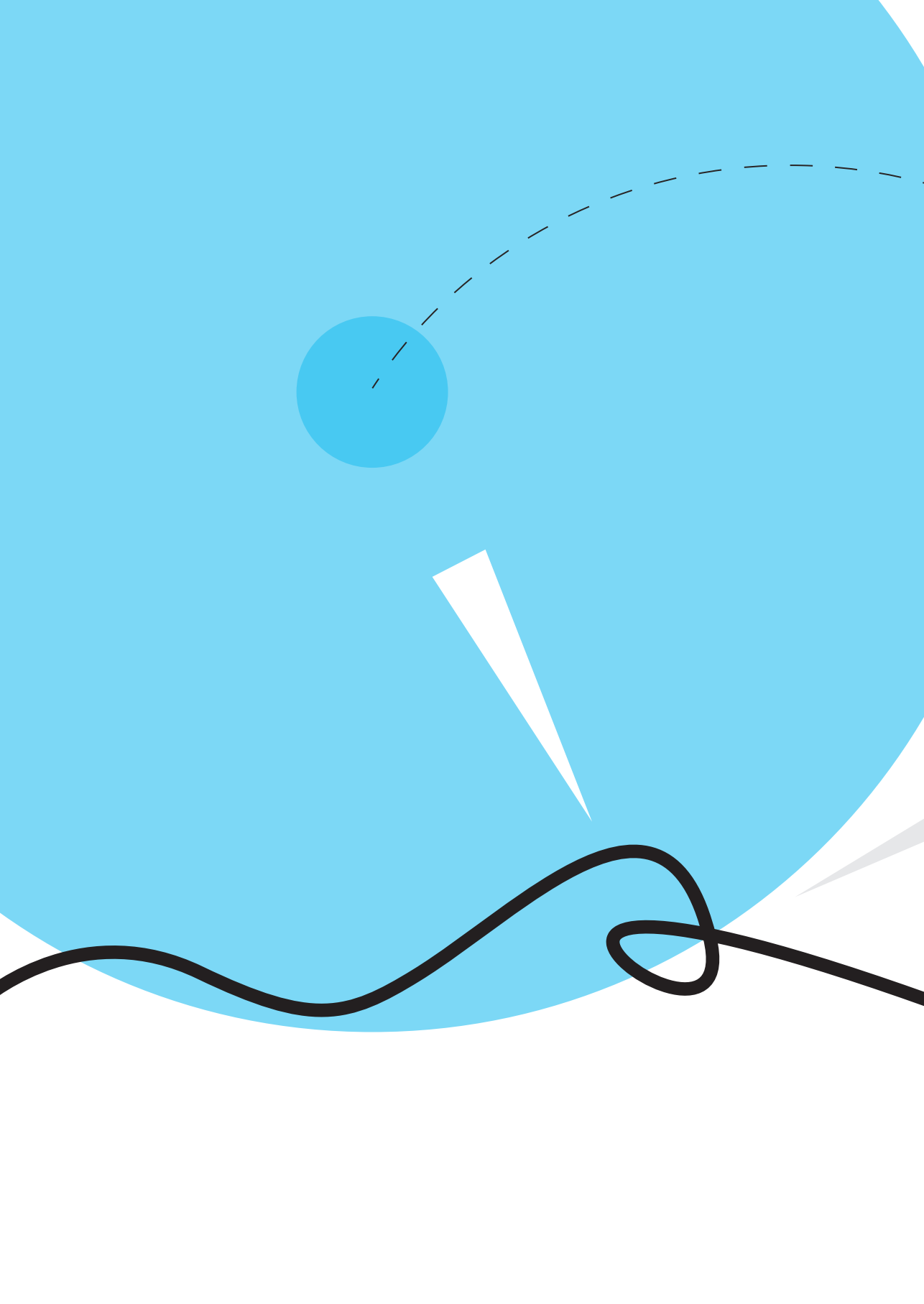
**Multimedia appendix 1**
Questions we asked healthcare professionals and communication experts:

- What is your first impression of the website?
- What is the look of the website?
- How can we improve the appearance of the website?
- What is your opinion about the amount of text, the level of the texts, the font, the use of colours and the selection of images?
- Do you have any suggestions for improvement?
- Is the layout of the website appropriate, is the navigation convenient, and can you find what you are looking for?
- What would you want to change about the website, and what can be improved from the point of view of a communication expert?

**Multimedia appendix 2**

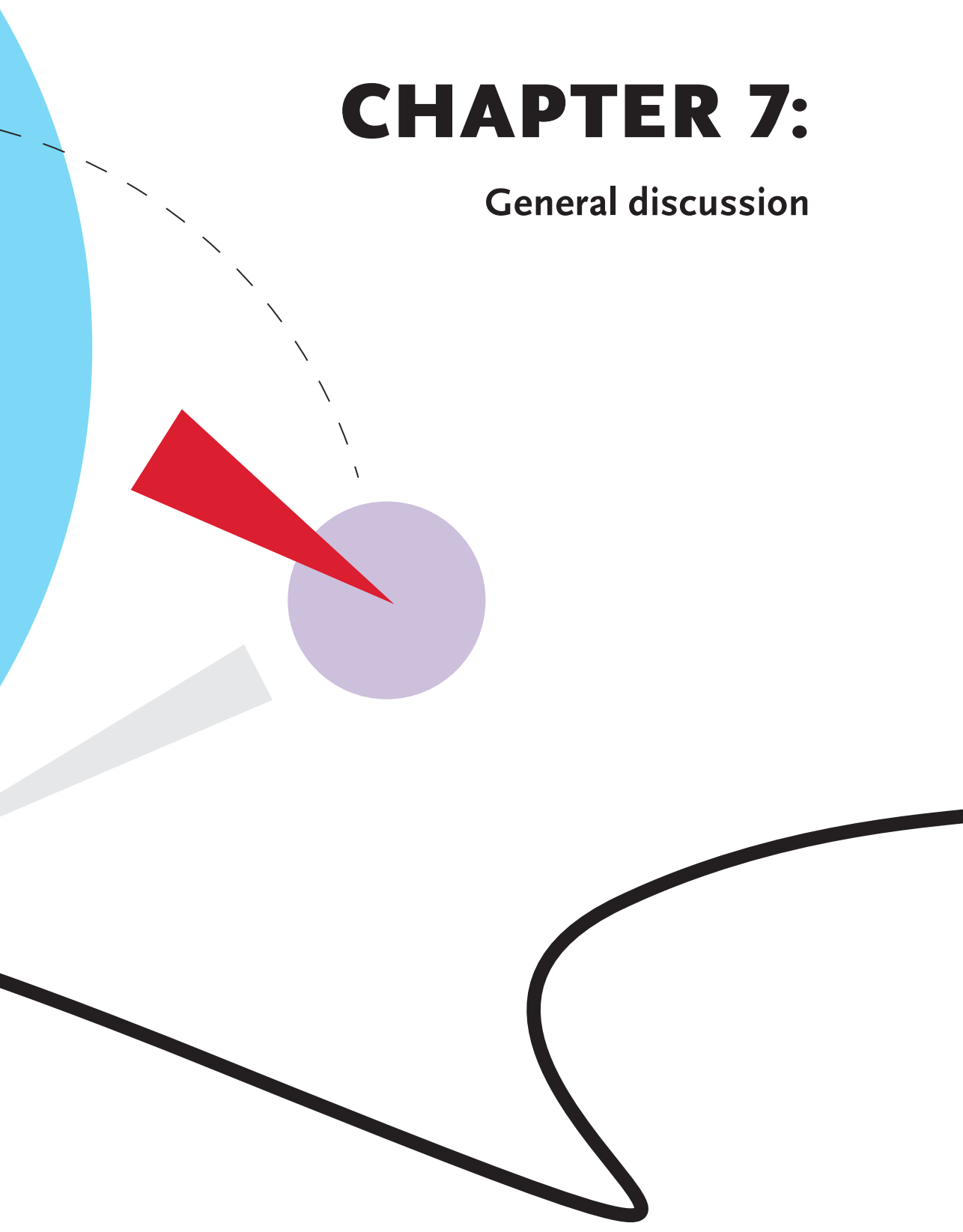
Pre-test questionnaire we sent to the cancer survivors.

| | |
|---|---|
| Q1 | Before you visit www.voedingenkankerinfo.nl, can you elaborate on what information you expect to find there? |
| Q2 | Did you visit other websites on nutrition and cancer before visiting this website? |
| Q3 | What is your first impression of the website? |
| Q4 | What do you think of the look and feel of the website? |
| Q5 | How can we improve the look and feel of the website? |
| Q6 | Is it clear in a glimpse what the website is about? |
| Q7 | Is it clear in a glimpse who is the owner of the website? |
| Q8 | The information displayed on the website is... new/partly new/familiar... to me. |
| Q9 | Does the website meet your expectations? |
| Q10 | If the website does not meet your expectations: what expectations did you have? |
| Q11 | Do you have any suggestions for improvements or adjustments to the website? |
| Q12 | What do you think of the chosen font? Is it clear? |
| Q13 | What do you think of the colours used? Are they pleasant? |
| Q14 | What is your opinion of the selection of the pictures? Are they pleasant? |
| Q15 | Do you have any suggestions with regard to the images? |
| Q16 | Is the layout clear? |
| Q17 | Can you easily find what you are looking for? |
| Q18 | Do you have any suggestions to improve the structure of the website? |
| Q19 | What is your opinion of the amount of text on a page? |
| Q20 | Do you think the texts on the website are comprehensible? |
| Q21 | What do you think of the use of language on the website? |
| Q22 | If the use of language is too difficult or too easy, do you have any suggestions for improvement? |
| Q23 | Do you think the website is complete? |
| Q24 | Is it clear where you can ask questions? |
| Q25 | If you take the website as a whole, what attracts your attention in a positive way? |
| Q26 | If you take the website as a whole, what attracts your attention in a negative way? |
| Q27 | Does the website look reliable? |
| Q28 | Would you visit this website? |
| Q29 | Would you recommend the website to others? |
| Q30 | If you have any final remarks, please post them here. |



# CHAPTER 7:

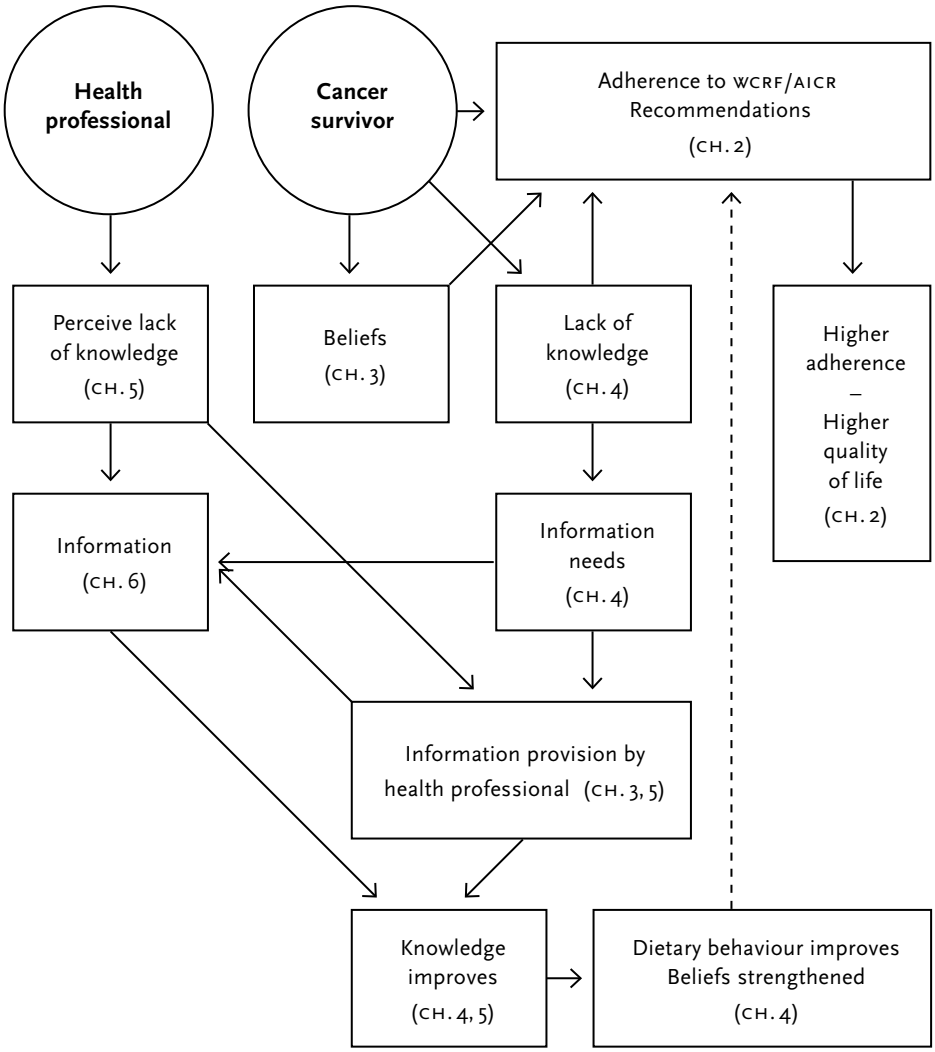
## General discussion



In the previous chapters of this thesis, studies on information provision for cancer survivors and information provision by health professionals were described. **Figure 1** summarizes the main findings of these studies. Higher adherence to dietary recommendations for cancer prevention (the World Cancer Research Fund / American Institute of Cancer Research (WCRF/AICR) dietary recommendations) was associated with better physical, role, cognitive, and social functioning, better global health status and less fatigue among CRC survivors (**chapter 2**). A first step to increase adherence might be enhancing cancer survivors' beliefs that nutrition has an important role in feelings of well-being, and influences recurrence, recovery and complaints. Providing information about nutrition and cancer by different health professionals is important in strengthening these beliefs on nutrition and cancer (**chapter 3**). Actually, cancer survivors and their relatives who obtained nutritional information, more often reported to have positively altered their dietary habits compared to respondents who did not obtain information (**chapter 4**). Oncology nurses have a central role in information provision about nutrition and cancer. However, nearly half of the oncology nurses who reported providing advice to their patients on nutrition and physical activity perceived themselves to have insufficient knowledge to be able to provide such advice. Younger oncology nurses, oncology nurses with an intermediate vocational education, and nurses who counselled their patients only during treatment were less likely to perceive themselves to have sufficient knowledge on nutrition (**chapter 5**). To support health professionals and patients, the Nutrition and Cancer website (from now on referred to as voedingenkankerinfo.nl) provides access to evidence-based, best practice-based, and eminence-based information on nutrition and cancer and is used extensively (**chapter 6**).

In the **chapters 2–6**, methodological considerations specific for the respective chapters have been addressed. The following paragraphs will discuss overarching considerations introduced by four propositions. Different professionals have been consulted in the process of discussing these propositions. Jeanne Vogel, dietician with a focus on oncology, and Wineke Remijnse, policy advisor of the Dutch Dietetic Organisation were consulted for **proposition 2**. Germund Daal, Head of Communications and Health Information of WCRF was consulted for **proposition 3** and Dr. Floor Mols, Associate Professor at Tilburg University, Department of Medical and Clinical Psychology, was consulted for the suggestions for further research concerning quality of life research. At the end of this chapter, suggestions for further research, implications for public health and clinical practice, and an overall conclusion are presented.

**Figure 1:** Major findings of this thesis with corresponding chapters (CH).



## 1.
## HEALTHY LIFESTYLE SCREENING SHOULD BE IMPLEMENTED IN ALL PHASES OF CANCER CARE.

Screening for malnourishment and undernutrition is widely implemented in healthcare [1]. There is a lot of attention for malnourishment and undernutrition. However, there is less attention for a healthy diet and lifestyle and promoting a healthy diet is not as widely spread [2]. The American Society of Clinical Oncology considers the transition from patient with cancer to cancer survivor as a teachable moment when health professionals have an opportunity to encourage healthy behavioural and lifestyle changes that may help prevent or reduce the risk of recurrence, reduce the risk of other diseases, and improve the overall quality and length of life [3]. Screening for adherence to the dietary recommendations for the prevention of cancer would raise awareness on a healthy diet both in health professionals and in patients.

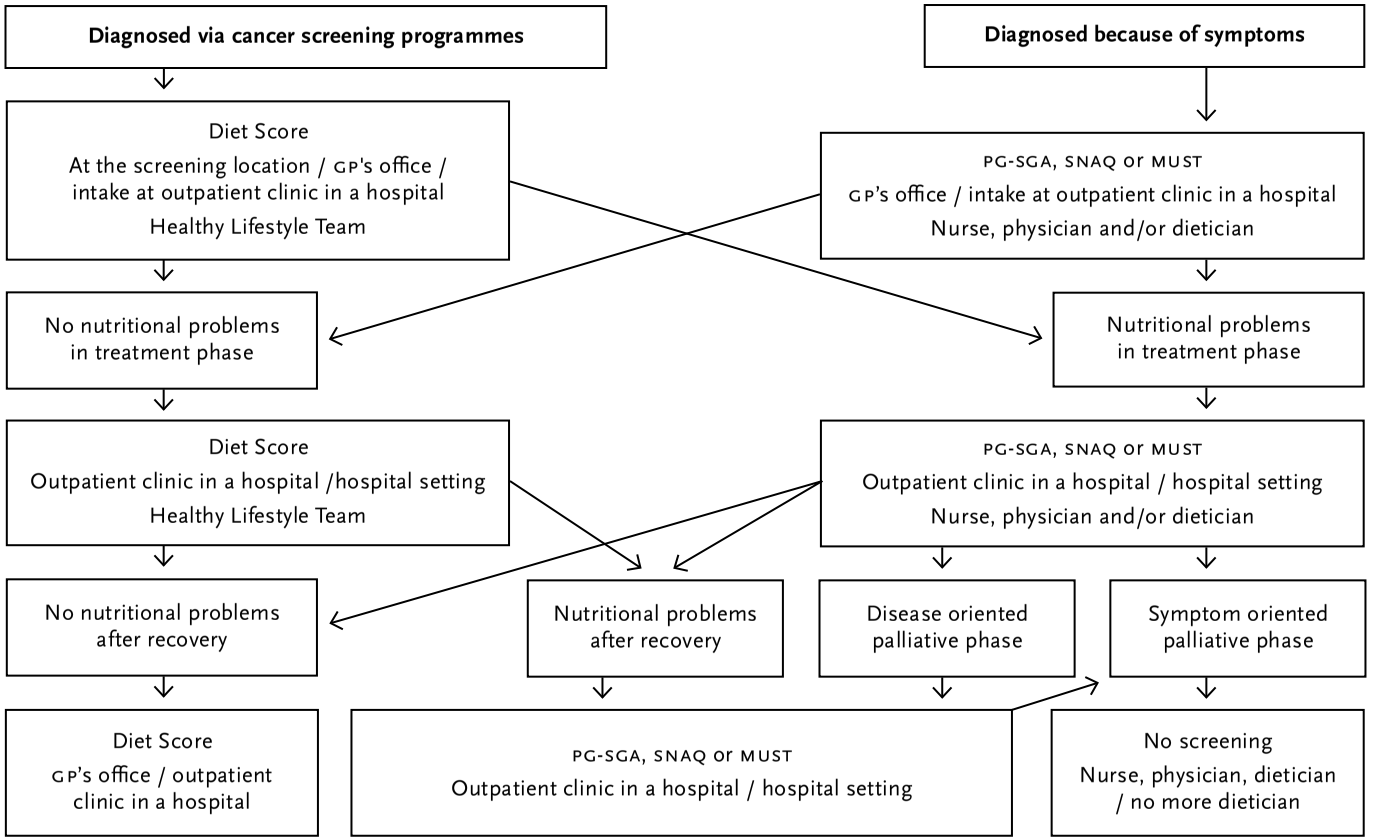
Depending on one or more of the factors: the diagnosis, nutritional complaints, treatment, prognosis and timing in the total process of cancer treatment, either screening for adherence to a healthy diet or screening for malnutrition should take place [4] (**figure 2**). For patients detected via cancer screening programmes (generally early stage cancer) and patients without nutritional problems or other acute situations and a good prognosis, screening for adherence to a healthy diet is the appropriate method. Screening for adherence to the healthy diet recommendations should also be implemented in care for all patients after recovery of cancer, when no serious long term effects remain (**figure 2**), since a healthy lifestyle influences quality of life [5], and survival [6] in cancer survivors. For cancer patients diagnosed because of symptoms, screening for malnutrition [7–9] seems the most appropriate method. In acute situations, such as when nutritional complaints occur, macronutrient intake is most important, with less emphasis on adherence to the recommendations for a healthy diet. When the acute situation has passed, after recovery and in a curative setting, the focus should again be on a healthy diet [10].

Adherence to the recommendations for a healthy diet could be assessed using the Diet Score ("Eetscore" in Dutch) [11], the Healthy Eating Index [12], the Dutch Healthy Diet Index [13] or the WCRF/AICR adherence score [14] (from now on: dietary scores). The Short Nutritional Assessment Questionnaire (SNAQ) [7], Malnutrition Universal Screening Tool (MUST) [8] or Patient-Generated Subjective Global Assessment (PG-SGA) [9] (from now on: malnutrition screening instruments) screen for weight changes in combination with body mass index (BMI), nutritional complaints and/or nutritional intake. Screening for adherence to a healthy diet is not part of these screening instruments [7–9, 15]. The use of malnutrition screening instruments and dietary scores gives health professionals tools to provide the cancer survivor with specific nutritional

information targeted at the individual's phase in the cancer trajectory, varying from e.g. energy and protein enriched nutrition with a liquid consistency to energy restricted advises with more fibre and less red meat.

There is ample room for improvement of dietary behaviour in the general public [16] and in virtually all cancer survivors [14, 17–19]. In **chapter 2**, we concluded that only 14% of CRC survivors adhered to six or more of a total of eight WCRF recommendations, comparable to the observational study of Winkels et al., where only 12% of CRC survivors adhered to six or more of a total of eight WCRF recommendations [14]. In our study, adherence to the dietary recommendations for the prevention of cancer was especially low for the recommendations on 'plant-based foods: eat more grains, vegetables, fruit and beans', 'animal foods: limit red meat and avoid processed meat' and to 'preservation, processing & preparation: eat less salt and avoid mouldy grains & cereals'. The same trend was seen in the results of the Dutch National Food Consumption Survey 2012–2016, which assessed dietary intake of the general population [16, 20]. Screening for a healthy lifestyle and accordingly providing advice increase awareness which is the first step in altering lifestyle.

**Figure 2:** Different screening methods and different health professionals involved in different phases of cancer care.



## 2.
## DIETICIANS ARE RESPONSIBLE FOR NUTRITIONAL SUPPORT AND INFORMATION PROVISION FOR ALL CANCER PATIENTS.

Currently, only a selection of cancer patients is supported by a dietician. It is not necessary that each cancer patient is supported by a dietician in person. However, the dietician needs to secure that nutritional support and information provision is properly arranged in usual care.

In **chapter 4**, we demonstrated that cancer patients reported they would like to receive information on nutrition and cancer from physicians, (oncology) nurses, dieticians and via brochures and leaflets. In **chapter 5**, we showed that nearly half of the oncology nurses do not feel adequately trained to provide cancer patients with nutritional information. We argued that oncology nurses should collaborate with dieticians to discuss what information should be provided to patients and by whom. In **chapter 3** we demonstrated that evidence-based information provision by different health professionals may help in altering nutritional beliefs and behaviour in cancer patients. We argue that the dietician should be responsible for the content of the nutritional information, securing the evidence-based character of the information but that also other professionals, e.g. oncology nurses, could provide this information.

Currently, nutritional counselling for cancer patients is arranged in the following manner. The Dutch Dietetics Organisation, together with the Dutch Dietetic Oncology Group [21], composed a guideline [22, 23] concerning when a cancer patient should be counselled and by whom; the four care profiles. In profile 1, the cancer patient has no nutritional problems, and no weight loss or gain. Self-management, directed by a health professional, is the preferred route. The cancer patient is advised to visit several websites, such as voedingenkankerinfo.nl (**chapter 6**), voedingscentrum.nl [24] or kanker.nl [25]. In profile 2, the cancer patient has no weight loss or gain, but has a simple nutrition-related complaint caused by the cancer or treatment, such as nausea, diarrhoea, obstipation or a sore mouth. The desired route is via health professionals who can provide a general advice, such as a general practitioner, medical specialist or a nurse. However, the content of the advice is secured by the dietician. In profile 3, the cancer patient is malnourished or at risk of malnourishment ( >5% weight loss in the last month or >10% weight loss in the last six months), has unintended weight gain (>3 kg since diagnosis) or overweight or there are two or more nutrition-related complaints. The person in charge is the dietician. Treatment is focused on prevention and limiting problems related to nutrition, following the available guidelines: to prevent deterioration of nutritional status, including counselling patients who gain weight. In profile 4, the cancer patient has tumour or treatment related complaints that will lead to complex nutrition-related complaints and malnourishment. The person in

charge is the dietician with specific knowledge on oncology. This is necessary because of the complexity of the disease and complaints/side effects and/or of the cancer patients' condition [22, 23].

The result of the screening with the dietary scores or the screening with the malnutrition screening instruments, as described in **proposition 1**, should be used to determine which profile the cancer patient fits. When there is no acute situation, no weight loss and no nutritional complaints, determined with one of the malnutrition screening instruments, and adherence to the recommendations is good (score 6 out of 8 or higher), profile 1 can be followed. When there is a simple nutrition-related complaint or adherence to the recommendations is low (score <6 out of 8), it fits profile 2. In profile 2, the information should be provided by a physician or nurse, in addition to the self-management approach in profile 1. The physician or nurse should emphasize the importance of adherence to the dietary recommendations, provide basic nutritional advice, should be signalling nutritional problems and should refer to a dietician for more care if necessary. In these two profiles the dietician must have an advisory role, educating physicians and nurses on what information sources should be used in profile 1 and what basic advice should be provided in profile 2. For profile 3 and 4, a dietician should be the person providing the nutritional counselling, as is described by the Dutch Dietetics Organisation [22, 23]; the physician and nurse must know when to refer to the dietician. This way, the dietician is in charge of the nutritional support and information provision of all cancer patients.

## 3.
## CANCER DIAGNOSIS IS NOT THE WINDOW OF OPPORTUNITY FOR SUSTAINED LIFESTYLE CHANGES.

Several studies suggest there is a teachable moment, 'a window of opportunity', during the period following active treatment: the time frame following a health event in which a patient is most amenable to lifestyle changes [3, 26]. Multiple studies found that patients and family members of cancer survivors express strong intentions to engage in health-promoting behaviours related to physical activity and nutrition during the post treatment transition [27–29]. However, teachable moments do not automatically lead to sustained behaviour change, as can be seen in **chapter 2**, where cancer survivors only showed intermediate adherence to the dietary recommendations for cancer prevention, comparable to behaviours of the general population [16]. This finding is supported by literature, which shows that many cancer survivors are inactive, have a poor diet and/or are obese at the time of diagnosis which may become even more evident after treatment [28, 30, 31]. A review showed that approximately 70%

of breast and prostate cancer survivors are overweight or obese and less than half of the survivors consume adequate amounts of fruits and vegetables [32]. Other studies showed that many cancer survivors do not adhere to behavioural guidelines that could reduce their health risks and that rates of adherence to guidelines for cancer survivors do not differ significantly from those of adults without cancer [29, 33]. Cancer survivors often report to make healthy behavioural changes, however, these changes are not always about nutrition and physical activity, but more about positive thinking, starting meditation or mindfulness training [34]. In focus groups in CRC survivors [35], stress was often mentioned as a major contributor to the onset of bowel cancer, with only some respondents linking bowel cancer to red meat and processed meat. As long as cancer survivors do not identify the correct risk factors, changing the behaviours related to these risk factors will be very hard. An intervention study in 329 CRC survivors demonstrated that educating CRC survivors about nutrition and physical activity led to better awareness of lifestyle factors, higher rates of weight loss, a healthier diet and physical activity habits than the control group [36].

Being able to make behavioural changes depends on many factors, such as motivation, time, abstaining from old behaviours and temptations and perseverance, all influencing the ability to succeed [37], as well as social economic status [38] and age. Fear of failure may increase with the individuals' age, preventing older individuals from seeking and participating in educational and training opportunities [39]. As cancer survivors are mostly elderly individuals, this might be a problem [40]. As seen in **chapter 3**, in our study the oldest participants least believed in the influence of nutrition on feelings of wellbeing, and might therefore be the least inclined to participate in educational and training opportunities.

To help the population make behavioural changes, The National Prevention Programme 2018 (in Dutch: Nationaal Preventieakkoord) has been set up by the Ministry of Health, Welfare and Sport [41]. However, this is a prevention programme for the general public, addressing smoking, being overweight and alcohol abuse. No evidence based programmes are available for cancer survivors yet. These programmes must be developed. I suggest to specifically focus on overweight cancer survivors, since they have an increased risk of cancer recurrence or a second primary cancer [6]. In the future, available combined lifestyle interventions that are proven to be effective in cancer survivors can be used. My advice is to focus these interventions on a healthy lifestyle: a healthy bodyweight, sufficient physical activity, no smoking, no alcohol and a healthy diet [42]. To be able to support patients in a good manner, I suggest forming 'Healthy Lifestyle Teams' including dieticians, physical therapists and oncology nurses. Such a team should focus on a healthy lifestyle, and as part of this can screen for nutritional problems and educate fellow health professionals and

cancer patients. This team should be working on the cutting edge of the outpatient clinic and primary care facilities, since that is where cancer patients who need advice on a healthy lifestyle will be found (**figure 2**).

## 4.
## PHYSICIANS ARE THE ONES TO STRESS THE IMPORTANCE OF A HEALTHY DIET TO CANCER SURVIVORS, BUT SHOULD REFER TO EXPERTS FOR THE ACTUAL ADVICE.

Physicians should start by stressing the importance of a healthy diet and lifestyle to all cancer survivors, because people put a lot of trust in their physicians' opinion [30]. Physicians should also be able to mention trustworthy information sources and to know when to refer cancer survivors to an expert. Oncology nurses should be able to provide basic dietary advice, and to refer cancer survivors to a dietician in case of more complex dietary advice (**figure 3**).

**Figure 3:** Tasks of different health professionals in providing dietary counselling.

| Physician | Oncology nurse | Dietician |
|---|---|---|
| • Mention importance of nutrition<br>• Referral to correct information sources<br>• Referral to oncology nurse for basic dietary advice<br>• Referral to dietician for complex dietary advice | • Basic dietary advice<br>• Referral to correct information sources<br>• Referral to dietician for more complex dietary advice<br>• Discuss importance of diet | • Complex dietary advice<br>• Referral to correct information sources<br>• Discuss importance of diet |

In the Netherlands, physicians receive a few hours of nutritional schooling during their educational program. During the six years of training to become a physician, on average only 29 hours are spend on diet and 30 hours on lifestyle education. About twenty percent of interns and a quarter of general practitioners (GPs) report they have been taught when to refer a patient for diet or lifestyle counselling, and one third of interns report they have been taught to whom to refer a patient for dietary or lifestyle counselling [43]. Most interns and two thirds of GPs rarely use websites such as the Physicians' Reference Guide on Dietetics (Artsenwijzer Diëtetiek) [22], which is the main source of information for physicians on dietary protocols in the Netherlands. 80% of interns and GPs report they want to receive more training on diet and disease [43]. In line with this need, a study among Dutch GPs showed that about twenty percent of physician-patient contacts included questions about nutrition [44], indicating knowledge about nutrition is necessary. In 2018, members of parliament sent a letter to the Minister of Health, asking for more nutritional schooling in the educational programme for physicians [45]. The Minister responded that it is indeed important that physicians are trained in nutrition and lifestyle [46], however that this is secured in the Outline Agreement Medical-specialist Care (in Dutch: hoofdlijnenakkoord medisch specialistische zorg) and no further action was taken [47]. Besides, in the National Prevention Programme 2018 it is also incorporated that there must be a focus on healthy lifestyle in the education of physicians and GPs [41]. In my opinion, physicians training on nutrition should (depending on the phase in the cancer trajectory) focus on signalling nutritional problems, (risk of) malnutrition and unhealthy lifestyle, including unhealthy dietary habits, when to refer to a dietician and emphasizing to the patient that nutrition has an important role in cancer treatment and cancer after care [48].

Next to physicians, nurses have an important role in nutritional information provision for cancer survivors. However, diet is only a very small part of nurses education. Nutrition and physical activity should become part of the educational training for oncology nurses so that all future oncology nurses will be properly educated [49, 50]. Since 2018, one of the nursing training facilities of the Netherlands has started a lectureship 'Care for Diet and Health' [51]. This is a first step in improving the nutritional knowledge of nurses. In combination with the implementation of the proposed 'Healthy Lifestyle Team', nurses will be able to provide basic dietary advice to cancer survivors, to refer survivors to a dietician for more complex nutritional advice, to refer survivors to correct information sources and to discuss the importance of a healthy diet. A next step is to decide how this training in nutrition and lifestyle should take place after their vocational training. Research has demonstrated that nurses are already familiar with online education tools, providing a viable method to reach oncology nurses [52]. An option is to use e-learning modules or massive open online courses (MOOCs) [53] for oncology healthcare professionals to improve knowledge on

nutrition, physical activity, and cancer [54]. We organised focus groups with oncology nurses, asking them about preferences for nutritional education. Nurses explicitly mentioned that e-learning is not the way to go, since it is a one-time exposure to information: once the e-learning is concluded, they do not refer back to the learning materials. They preferred a more structural access to information. We tried to fulfil their wish by adding a section for professionals to the website voedingenkankerinfo.nl, which can be used as an instant source of dietary information (**chapter 6**). This section for professionals can also be used for the instructions of the 'Healthy Lifestyle Team' to help oncology nurses provide basic advice for nutritional complaints.

## IMPLICATIONS FOR FUTURE RESEARCH

Considering the previous propositions and discussions with different professionals has led to ideas for future research, which will be discussed in the following paragraphs.

The most important topic leading from the propositions and discussions is the need for cancer survivors to better adhere to the recommendations for a healthy lifestyle. As proposed in **proposition 3**, Healthy Lifestyle Teams should be established. These teams must consist of dieticians trained in oncology, physical therapists and oncology nurses. The functioning of the teams can be tested in an intervention study. These teams will:

1. Educate health professionals in the hospital to be able to signal an unhealthy lifestyle.
   Signalling a problem is the first step in making a change. This signalling can be done by implementation of screening for a healthy lifestyle, by making use of the Diet Score and questionnaires on physical activity and smoking.

2. Make use of the website voedingenkankerinfo.nl to have easy access to evidence-based information and practical advice.
   After the development of the website voedingenkankerinfo.nl for the general public, cancer survivors and people otherwise interested, a section especially for health professionals was developed. In focus groups with oncology nurses, we learned they want a quick and simple guide with information about nutritional advices for specific nutritional complaints related to cancer and its treatment, being accessible in an easy manner. This section for professionals also includes a checklist including questions about weight loss or gain, enteral nutrition use, nutritional complaints related to the cancer and its treatment. When this checklist is used during contact with the cancer survivor, practical advice and background information becomes available for the health professional, as well as information on when to refer to a

dietician. The practical advice is also accessible without completing the checklist. After the development of the website section for professionals, we evaluated the usability of this section. Preliminary results show that after using the website: 1. nurses more often felt they had enough knowledge to provide nutritional advice to cancer survivors, 2. more often advice was given when the lifestyle of the cancer survivor was considered unhealthy, and 3. more cancer survivors were referred to the website voedingenkankerinfo.nl.

3. Teach health professionals to successfully coach cancer survivors into a healthy lifestyle.
   Since not all the coaching can be done by the Healthy Lifestyle Teams, it is important that other health professionals are also aware of the program, and will coach the cancer survivors in the intervention group into a healthy lifestyle.

4. Support cancer survivors directly to better adhere to the recommendations for a healthy lifestyle.
   Next to the support of other health professionals, members of the Healthy Lifestyle Teams must also support and coach cancer survivors.

Changes in lifestyle behaviour after implementation of the Healthy Lifestyle Teams can be evaluated in an intervention study in cancer survivors, in which half of the group receives regular care (control group), and the other half of the group is supported by the Healthy Lifestyle Teams (intervention group). The coaching by the Healthy Lifestyle Team can consist of several subjects:

- Showing confidence in the ability of cancer survivors to alter their lifestyle;
- Determine whether there are limiting factors that will influence the cancer survivors' ability to alter his or her lifestyle;
- Discuss potential actions and how to take them to be able to improve the cancer survivors' lifestyle.

This can all be done as part of education: a combination of group education, by offering multiple interactive sessions, and individual sessions with a member of the Healthy Lifestyle Team. This member of the Team can support the cancer survivor in implementing lifestyle changes by referring to other health professionals and by providing practical support.

Health related quality of life (HRQL) and lifestyle behaviour should be measured at baseline, prospectively during and up to two years after the intervention.

During this study must be evaluated whether, due to the intervention:

a. Cancer survivors improve their lifestyle, compared to the control group.
The evaluation can be done by filling out the Diet Score before, at baseline, directly after the sessions and six months later, to test for short and long term effects of this coaching on adherence to the dietary recommendations. Difficulties in this research will be the enormous variability among cancer survivors: all the different types of cancer, the different stages at diagnosis, different therapies and possible side-effects and complaints during and after treatment. To tackle this issue, this study should focuse on specific groups of cancer survivors, such as CRC survivors who were treated curatively. If it is possible to perform this study on a large group of cancer survivors, these data could be used to link dietary intake via the Diet Score to patient reported outcomes, for example via PROFILES [55].

b. The change in lifestyle is reflected in an improvement in their HRQL, compared to the control group.
In one of our studies (**chapter 2**), we performed a cross-sectional study to asses HRQL and its association with adherence to the dietary recommendations for the prevention of cancer. This study showed a positive association between adherence to the recommendations and HRQL. However, besides the fact that this design does not allow for causal inferences, we have no evidence about the effect of increasing adherence to those dietary recommendations on changes in quality of life. Also, we did not evaluate how repeated, evidence-based information provision may change adherence in the long run.

A differentiation can be made between the different health professionals who provide the advice, to test whether it matters if one person provides the same advice multiple times, or that multiple health professionals provide the same advice once. The outcome of this study will help to decide in what way nutritional information should be offered to cancer survivors, combined with counselling by a member of the Healthy Lifestyle Team and group consults, to reach the maximum effect on adherence to the dietary recommendations and on quality of life.

c. The information on lifestyle the participants received.
The received nutritional information before and after implementation of the screening and the education and support of the Healthy Lifestyle Team must be evaluated, at the start of treatment and six months after the start of treatment. Follow-up of the participants will be for a minimum of two years, to monitor long-term effects on HRQL and knowledge.

d. Screening was successful, meaning the cancer survivors that need support are identified.
To be able to investigate this, a thorough comparison between the intervention and the control group needs to be made. It must be monitored how many of the survivors of the intervention group are referred to a dietician for counselling, next to this intervention study. If screening is successful, no participating survivors need to be referred outside of this intervention study.

e. Oncology nurses provide the correct information.
As mentioned earlier in this chapter, oncology nurses should receive nutritional education on recommendations, to correct false beliefs, to fulfil information needs of cancer survivors and to provide general nutritional information to all cancer survivors. Our study showed that oncology nurses perceived themselves to have insufficient knowledge. However, we do not know which information is lacking and whether these nurses under- or overestimate their knowledge, since we did not test their actual knowledge. This could be tested by having oncology nurses fill out a questionnaire specifically focused on their knowledge of the evidence-based recommendations, and what advice they provide in specific situations.

## IMPLICATIONS FOR PUBLIC HEALTH AND CLINICAL PRACTICE

A recent study confirmed that cancer survivors are not able to differentiate between reliable and unreliable websites and that this is the main problem with eHealth literacy in cancer survivors [56]. Also, many physicians and other health professionals do not know where to find trustworthy information about nutrition and lifestyle. Therefore it is important to promote the website voedingenkankerinfo.nl and other information sources such as the materials from the Netherlands Nutrition Centre [24], the World Cancer Research Fund [57], the Dutch Cancer Society [58] and kanker.nl [25]. This should be promoted both to health professionals and cancer survivors, so reliable nutritional information becomes more widely known. This can be improved by implementing the website and materials. Implementation can be done in the education of medical students, nurses and other health professionals; in GP practices, in oncology care; via conferences and symposia for physicians, nurses, dieticians and other health professionals. Furthermore, implementation can take place via journals, magazines and via the websites of the Dutch College of General Practitioners [59] and other groups of professionals such as oncology nurses and general practice-based nurse specialists. Getting cancer survivors acquainted with these materials can be achieved via health professionals, but also by making use of media, both in print and in image, by promoting the website to the general public (popular print such as magazines).

The screening materials for adherence to the dietary recommendations to prevent cancer should be implemented in general oncology care. This can be done by including it into the care chain, so that it becomes the norm to use the screening materials. Implementation of this screening will change both clinical and public health practice, since more cancer survivors will be educated about a healthy lifestyle.

A combination of influencing people's knowledge, attitudes and beliefs, and influencing public health policies that prioritize cancer prevention are critical in facilitating behavioural changes [6]. Currently, this is started early in life, since education about healthy nutrition, physical activity and other factors of lifestyle is a small part of primary and secondary education in schools and even in day-care facilities for young children [60]. I consider this a good start, however this education must play a larger role in schools and day-care facilities.

## CONCLUSIONS

Based on the results of this thesis as well as existing literature, it can be concluded that evidence based nutritional information should be provided to cancer survivors. To be able to do so, health professionals should receive more nutritional training to emphasize the important role of nutrition in cancer and to properly refer and advise cancer survivors about nutrition and cancer. The dietician must have the lead in this process. This is important, since correct nutritional information might positively influence cancer survivors' beliefs about the role of nutrition in cancer and stimulate cancer survivors to positively alter their dietary behaviour. The newly developed website voedingenkankerinfo.nl on diet and cancer fills a gap in the provision of information about nutrition and cancer for both patients, the general public and health professionals.

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# SUMMARY

Numerous guidelines are available for the prevention of cancer. Optimal nutrition after a cancer diagnosis may increase survival, reduce the risk of recurrence, limit side-effects and improve recovery and quality of life. However, cancer survivors often do not receive nutritional information and health professionals are often not trained to provide such advice (**chapter 1**). This thesis aims to improve nutritional information provision for cancer survivors, the general public and health professionals by investigating whether adherence to dietary recommendations is associated with improved quality of life; investigating the importance of information provision on nutrition and cancer by assessing nutritional beliefs, assessing information needs of cancer survivors and whether survivors change their dietary behaviour when they receive information on nutrition and cancer, by assessing the ideas of oncology nurses and by developing a website.

In **chapter 2**, the association between adherence to the World Cancer Research Fund/American Institute of Cancer Research (WCRF/AICR) recommendations and health related quality of life (HRQL) among colorectal cancer (CRC) survivors was investigated. All CRC survivors stage I-IV, diagnosed between January 2000 and June 2009 in the southern area of the Netherlands were sampled via the Netherlands Cancer Registry (NCR). Questionnaires about dietary intake, body height/weight, physical activity and HRQL were sent out. WCRF/AICR adherence scores (range 0-8, with a higher score for better adherence) were calculated using the questionnaires on dietary intake, physical activity, and body mass index (BMI). 1,096 CRC survivors with a mean WCRF/AICR adherence score of 4.81 ± 1.04 were included (response rate 67%). Higher WCRF/AICR scores were associated with a better global health status, physical, role, cognitive and social functioning, and with less fatigue. Physical activity seemed to be the main contributor.

In **chapter 3**, the association between nutritional information provision and beliefs on nutrition and cancer was investigated. Questionnaires were filled out by 326 CRC survivors one month after surgery on general characteristics, nutritional information provision by health care professionals, nutritional information needs, satisfaction with nutritional information and patients' beliefs on nutrition and cancer. Most respondents who received information strongly believe nutrition influences feelings of well-being (59%) and recovery after cancer (62%). 62% of respondents received information from one or more health professionals. Respondents who received information from three health professionals had stronger beliefs on the influence of nutrition on cancer outcomes than those who did not receive information about nutritional complaints after treatment (PR 3.2; 95% CI 1.5-6.9), recovery after cancer (PR 1.8; 95% CI 1.2-2.9) and about recurrence of cancer (PR 2.9; 95% CI 1.3-6.4).

**Chapter 4** investigated whether obtaining nutritional information influences changes in dietary behaviour in 239 cancer survivors and their relatives. It was then investigated whether nutritional information needs influenced this association. This panel of cancer survivors and their relatives completed a survey about their experiences with nutritional information provision by healthcare professionals in the period after diagnosis, their information needs regarding nutrition and cancer, and whether they changed their dietary behaviour since diagnosis. The survey showed that 56% of respondents obtained nutritional information, mostly during treatment. Respondents who obtained nutritional information, more often reported to also have positively altered their dietary behaviour after diagnosis (less products that cause weight gain, increased intake of plant foods, decreased meat and alcohol use). In these cases it did not matter whether the respondents had specific nutritional information needs or not.

**Chapter 5** investigated if oncology nurses perceived themselves as having insufficient knowledge to provide advice on nutrition and/or physical activity, and which characteristics were associated with this perception. 355 oncology nurses provided advice on nutrition and of these, 327 provided advice on physical activity. Of these oncology nurses, 43% perceived themselves as having insufficient knowledge to provide advice on nutrition, and 46% perceived having insufficient knowledge to provide advice on physical activity. In particular, younger oncology nurses and oncology nurses with an intermediate vocational education more often perceived themselves as having insufficient knowledge to give these advices.

In **chapter 6**, the development of a website to make scientific information available for cancer survivors was described. Initially, the website was filled with answers to frequently asked questions provided by cancer organizations and the Dutch Dietetic Oncology Group and by responding to various fables and facts published in the media. Furthermore, an opportunity for visitors to submit specific questions regarding nutrition and cancer was included. The answers to these visitors' questions were consequently published on the website.

**Chapter 7** discusses that healthy lifestyle screening should be implemented in all phases of cancer care; that dieticians are responsible for nutritional support and information provision for all cancer patients; that a cancer diagnosis is not the window of opportunity for sustained lifestyle changes and that physicians are the ones to stress the importance of a healthy diet to cancer survivors, but should refer to experts for the actual advice. Future research should focus on the need for cancer survivors to better adhere to the recommendations for a healthy lifestyle, with better information provision by health professionals. For public health and clinical practice, available information sources should be promoted and implemented in health care.

Based on the results of this thesis as well as existing literature, it can be concluded that evidence based nutritional information should be provided to cancer survivors.

To be able to do so, health professionals should receive more nutritional training to emphasize the important role of nutrition in cancer and to properly refer and advice cancer survivors about nutrition and cancer. The dietician must have the lead in this process. This is important, since correct nutritional information might positively influence cancer survivors' beliefs about the role of nutrition in cancer and stimulate cancer survivors to positively alter their dietary behaviour. The newly developed website voedingenkankerinfo.nl on diet and cancer fills a gap in the provision of information about nutrition and cancer for both patients, the general public and health professionals.

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# SAMENVATTING

Er zijn talrijke richtlijnen beschikbaar voor de preventie van kanker. Optimale voeding na een kanker diagnose kan de overleving doen toenemen, het risico op terugkeer verminderen, bijwerking beperken en herstel en de kwaliteit van leven verbeteren. Kankerpatiënten ontvangen echter vaak geen voedingsinformatie en gezondheidsprofessionals zijn doorgaans niet getraind om zulk advies te geven (**hoofdstuk één**). Dit proefschrift heeft als doel de informatievoorziening over voeding en kanker, voor zowel mensen met kanker als het algemeen publiek en gezondheidsprofessionals, te verbeteren door te onderzoeken of het volgen van de voedingsrichtlijnen geassocieerd is met een verbeterde kwaliteit van leven. Het belang van informatievoorziening over voeding en kanker is onderzocht door te kijken naar de ideeën over voeding en naar de informatiebehoefte van mensen met kanker. Er is geanalyseerd of mensen met kanker hun voedingsgedrag veranderen als zij informatie krijgen over voeding en kanker. Tevens is gekeken naar wat de ideeën zijn van oncologieverpleegkundigen over voeding en kanker en er is een website ontwikkeld over voeding en kanker.

In **hoofdstuk twee** is de associatie onderzocht tussen het zich houden aan de richtlijnen van het WCRF/AICR en de gezondheid gerelateerde kwaliteit van leven bij mensen met colorectaal carcinoom. Alle CRC patiënten stadium 1–4, gediagnosticeerd tussen januari 2000 en juni 2009 in het zuidelijke gedeelte van Nederland, zijn geselecteerd via de Nederlandse kankerregistratie. Vragenlijsten over voedingsinname, lichaamslengte, gewicht, fysieke activiteit en gezondheid gerelateerde kwaliteit van leven zijn verstuurd naar deze mensen. Scores voor naleving van de WCRF/AICR aanbevelingen (range 0–8 met een hoge score bij betere naleving) zijn berekend gebruikmakend van de vragenlijsten over voedingsinname, fysieke activiteit en BMI. 1096 CRC patiënten met een gemiddelde nalevingscore van 4.81 + 1.04 zijn geïncludeerd (respons 67%). Hogere WCRF/AICR nalevingscores waren geassocieerd met een betere algemene gezondheidsstatus, een beter fysiek-, rol-, cognitief- en sociaal functioneren en met minder vermoeidheid. Fysieke activiteit leek de grootste rol te spelen bij dit effect.

**Hoofdstuk drie** beschrijft de associatie tussen informatievoorziening over voeding en ideeën over voeding en kanker. 326 CRC patiënten hebben één maand na hun operatie vragenlijsten ingevuld. Deze vragenlijsten vroegen naar algemene karakteristieken, informatievoorziening over voeding door gezondheidsprofessionals, informatiebehoefte over voeding, het tevreden zijn over de voedingsinformatie en de ideeën die de patiënten hadden over voeding en kanker. De meeste respondenten die informatie ontvingen, hadden sterke ideeën dat voeding gevoelens van welbevinden beïnvloedt (59%) en herstel na kanker beïnvloedt (62%). 62% van de respondenten kreeg informatie van één of meer gezondheidsprofessionals. Respondenten die informatie kregen van drie gezondheidsprofessionals hadden sterkere overtuigingen over de invloed van voeding op kanker uitkomsten dan diegenen die geen informatie

kregen. Dit was het geval voor ideeën over klachten na de behandeling (PR 3.2; 95% CI 1.5-6.9), herstel na kanker (PR 1.8; 95% CI 1.2-2.9) en de terugkeer van kanker (PR 2.9; 95% CI 1.3-6.4).

In **hoofdstuk 4** is onderzocht of veranderingen in voedingsgedrag beïnvloed worden door het verkrijgen van informatie over voeding. Dit is onderzocht bij 239 mensen met kanker en hun familieleden. Ook is gekeken of informatiebehoeften over voeding deze associatie beïnvloedden. Dit panel van mensen met kanker en hun familieleden heeft een vragenlijst ingevuld over hun ervaringen ten aanzien van de informatievoorziening over voeding door gezondheidsprofessionals in de periode na diagnose, de informatiebehoeften die zij hadden over voeding en kanker, en of zij hun voedingsgewoontes hebben veranderd sinds de diagnose. De vragenlijst liet zien dat 56% van de panelleden informatie over voeding hebben ontvangen, meestal tijdens de behandeling. Respondenten die informatie over voeding kregen, gaven vaker aan ook hun voedingspatroon te hebben gewijzigd. Dit waren doorgaans positieve veranderingen (minder voedingsmiddelen die zorgen voor gewichtstoename, een verhoogde inname van plantaardige producten, minder vlees en minder alcohol). Hierbij maakte het niet uit of de respondenten een specifieke behoefte hadden aan informatie over voeding of niet.

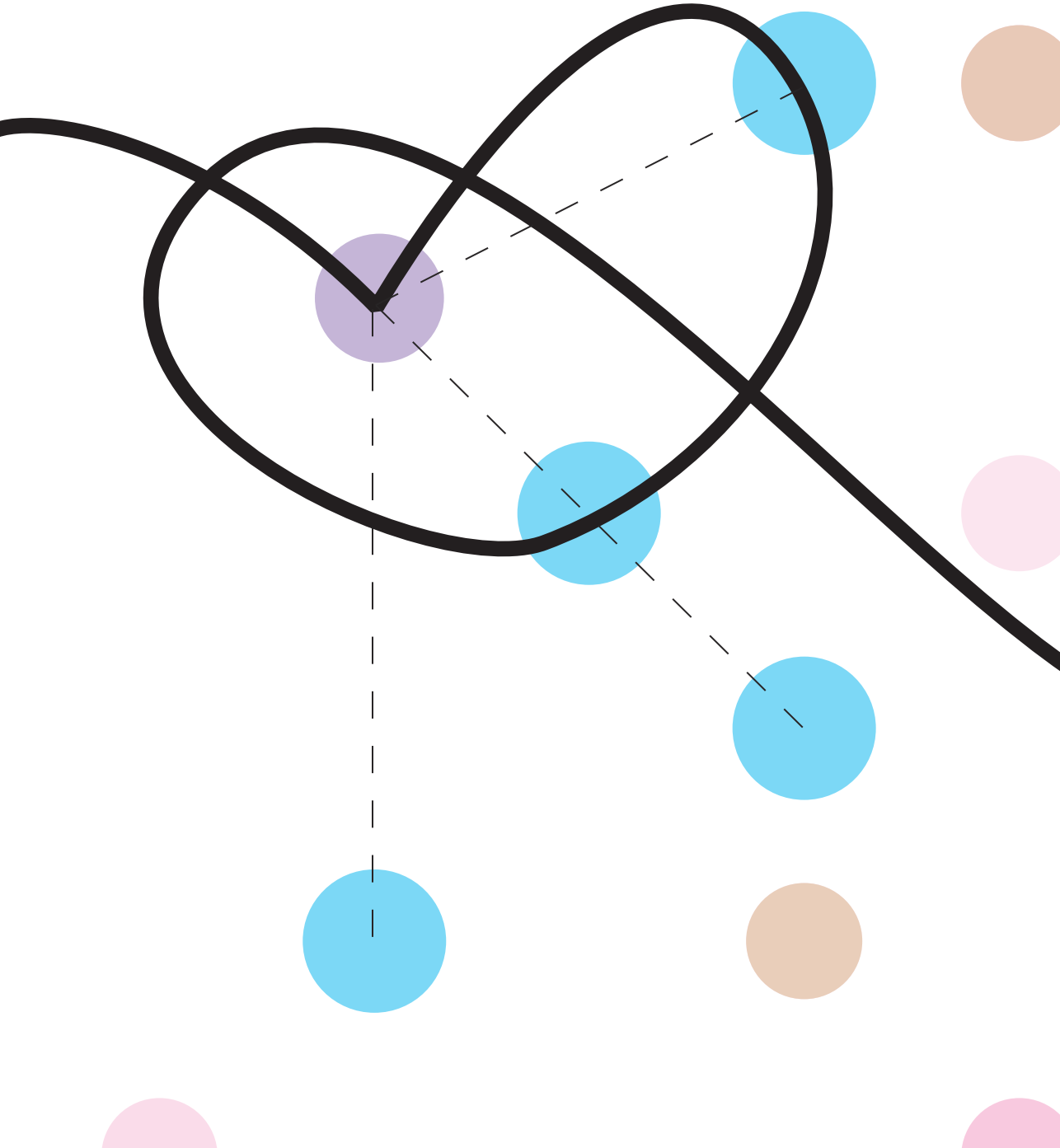
In **hoofdstuk 5** is gekeken of oncologieverpleegkundigen het idee hebben dat ze onvoldoende kennis hebben om advies te geven over voeding en/of fysieke activiteit en welke kenmerken geassocieerd zijn met dit idee. 355 oncologieverpleegkundigen gaven advies over voeding en van deze verpleegkundigen gaven 327 ook advies over fysieke activiteit. Van de verpleegkundigen die advies gaven, vond 43% van zichzelf dat ze te weinig kennis hadden om advies te geven over voeding. 46% vond dat ze te weinig kennis hadden om advies te geven over fysieke activiteit. Jongere oncologieverpleegkundigen en oncologieverpleegkundigen met een MBO-opleiding vonden vaker van zichzelf dat ze onvoldoende kennis hadden om dergelijk advies te geven.

**Hoofdstuk 6** beschrijft de ontwikkeling van een website om wetenschappelijke informatie beschikbaar te maken voor mensen met kanker. In het begin is de website gevuld met antwoorden op vaak gestelde vragen, die aangeleverd zijn door verschillende kankerorganisaties en de Landelijke Werkgroep Diëtisten Oncologie. Daarnaast werd op de site gereageerd op verschillende fabels en feiten die in de media zijn gepubliceerd. Bezoekers hadden de mogelijkheid om specifieke vragen over voeding en kanker in te dienen. De antwoorden op deze vragen zijn gepubliceerd op de website.

**Hoofdstuk 7** bediscussieert dat screening op een gezonde leefstijl geïmplementeerd moet worden in alle fasen van zorg bij kanker; dat diëtisten verantwoordelijk zijn voor voedingszorg en informatievoorziening voor alle mensen met kanker; dat een kankerdiagnose niet hét moment is om duurzame leefstijlveranderingen door te voeren

en dat artsen de personen zijn om het belang van een gezonde voeding te benadrukken bij mensen met kanker, maar dat zij voor het inhoudelijke advies moeten verwijzen naar de experts op dat gebied. Toekomstig onderzoek moet gericht worden op de noodzaak voor mensen met kanker om zich beter aan de aanbevelingen voor een gezonde leefstijl te houden, met betere informatievoorziening door gezondheidsprofessionals. Voor de volksgezondheid en de klinische praktijk zouden beschikbare informatiebronnen over voeding en kanker gepromoot en geïmplementeerd moeten worden in de zorg.

Op basis van de resultaten van dit proefschrift en de beschikbare literatuur kan geconcludeerd worden dat evidence-based voedingsinformatie verstrekt moet worden aan mensen met kanker. Om dit te kunnen doen zouden gezondheidsprofessionals meer scholing moeten krijgen over voeding en kanker om het belang van de rol van voeding bij kanker te onderstrepen, om mensen met kanker goed te kunnen doorverwijzen en om hen goed te adviseren over voeding en kanker. De diëtist moet de leidende rol hebben in dit proces. Dit is belangrijk, omdat correcte voedingsinformatie mogelijk de ideeën van mensen met kanker positief beïnvloedt en het mensen mogelijk aanzet hun voedingsgewoonten positief te veranderen. De nieuw ontwikkelde website over voeding en kanker voorziet in een behoefte wat betreft de informatievoorziening over voeding en kanker voor mensen met kanker, het algemeen publiek en gezondheidsprofessionals.



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compatibel krijgen van mijn IKNL laptop met de faciliteiten van de WUR, dat was nogal een uitdaging. Gelukkig vonden we een onconventionele oplossing die wel werkte.

Ook in Eindhoven (en Utrecht) heb ik vijf fijne jaren gehad. Ook al was ik een van de weinigen die slechts zeer beperkt kennis had van de NKR en alle daarbij behorende analyses, toch hoorde ik erbij. Dank Kim, Marjolein, Yvette, Nienke, Lieke, Felice, Corina, Erna, Nicole E., Nicole H., Sandra, Maarten, Amanda, Erna, Britt, Gitty, Erica, Pauline, Simone, Margreet, Lonneke, Rob V., Lindy, Mieke, Mies, Valery, Jan Maarten, Victor, Annemiek, Heidi, Natasja, Nora, Carla, Debbie, Janneke, Louis, Jan en Rob van L.

Hetty, dank voor je luisterend oor en je praktische hulp toen ik met mijn arm zat. Dank ook aan het team bij Revalidatiecentrum Klimmendaal, die ervoor zorgden dat ik zo snel mogelijk weer aan het werk kon zonder pijn. Sander, dank je wel dat je me op de been houdt – letterlijk! Ik weet niet of ik zonder jou dit traject fysiek had volgehouden.

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Sven, fijn dat je er op zoveel belangrijke momenten in ons leven bent om dat vast te leggen. Ik kijk uit naar je foto's! Paul, als ik dit schrijf hebben we alleen een voorbespreking gehad over de vormgeving. Maar ik heb er alle vertrouwen in dat je er iets moois van gaat maken. Dank je wel! Petra, Steven en Charlotte, dank voor jullie scherpe blik!

Lieve vrienden, ik heb de afgelopen jaren niet altijd even veel tijd gehad. Naast het werken en ons gezin had ik niet altijd genoeg energie om af te spreken. Dank voor jullie begrip, en jullie luisterend oor. 'Ons groepje', 'nog een feestje', 'stitch 'n bitch', de 'diëtisten', alle Spelgroepers en alle mensen die niet in een app-groep of toneelvereniging passen: dank jullie wel. Renske, dank je wel. Marloes en de andere Jonge Dames, dank voor alle ontspannen ochtenden! Ik ben blij met zoveel mensen om ons heen.

En dan mijn paranimfen, Agnes en Myrthe. Agnes, we kennen elkaar sinds de Master, een jaar of elf nu dus. Ik werkte als projectdiëtist voor jouw Nu Age studie, waar ik huisbezoeken aflegde en flessen olijfolie en pakken volkoren pasta bezorgde bij jouw bejaarde deelnemers. Wat was dat een leuke tijd! Toen ik ook AIO werd, hadden we iets minder raakvlakken; ik deed immers niet specifiek iets met het Mediterraan dieet of

ouderen. Toen onze jongens geboren werden, werden nog meer gedeelde interesses duidelijk: de draagdoeken, de wasbare luiers en de lekkere wollen kleertjes. Heerlijk om zoveel raakvlakken te hebben. Dank je wel dat je er als paranimf voor me bent. Lieve Myrthe, je vroeg je af of je wel paranimf kon zijn, want inhoudelijk wist je te weinig over mijn onderwerp. Ik kon je geruststellen en daarom zei je ja. Wat fijn dat jij, mijn zus en mijn getuige, deze rol wilt vervullen. Dank je wel!

Lieve Gijs en Monique, ik schrijf dit dankwoord terwijl ik in jullie studeerkamer zit in Meliskerke. Op de achtergrond hoor ik jullie rommelen met de jongens. Wat hebben we het altijd fijn bij jullie. Dank jullie wel voor alle medeleven, het luisteren naar mijn frustraties, dilemma's, triomfen en onzekerheden. Dank voor alle praktische hulp, de ontspanning in jullie fijne (t)huis en het ontzettend warme nest. Coen, Ivo en Laura, dank jullie wel voor de interessante discussies die we altijd hebben, soms tot wanhoop van de anderen. Dank ook voor het onder jullie hoede nemen van Jip, als ik weer eens moest schrijven tijdens een weekend in Zeeland.

Lieve pap en mam, wat ben ik blij dat ik dat nog kan zeggen. We hebben een intensief jaar achter de rug met z'n allen. Dank jullie wel voor al jullie steun, interesse, al die keren dat Jip bij jullie mocht spelen omdat ik nog iets af moest maken, of het opvangen van Daan toen ik toch alvast bij een promotie wilde kijken, ook al was Daan pas een paar weken oud. Dank jullie wel dat jullie er altijd zijn, ook al ligt er al genoeg op jullie eigen bordje. Steven, Charlotte en Myrthe, dank voor het meedenken over mijn onderzoeksprotocol destijds. Dank voor de interesse in wat ik doe, het meeleven en de gezelligheid als we samen zijn. Jullie zijn de beste.

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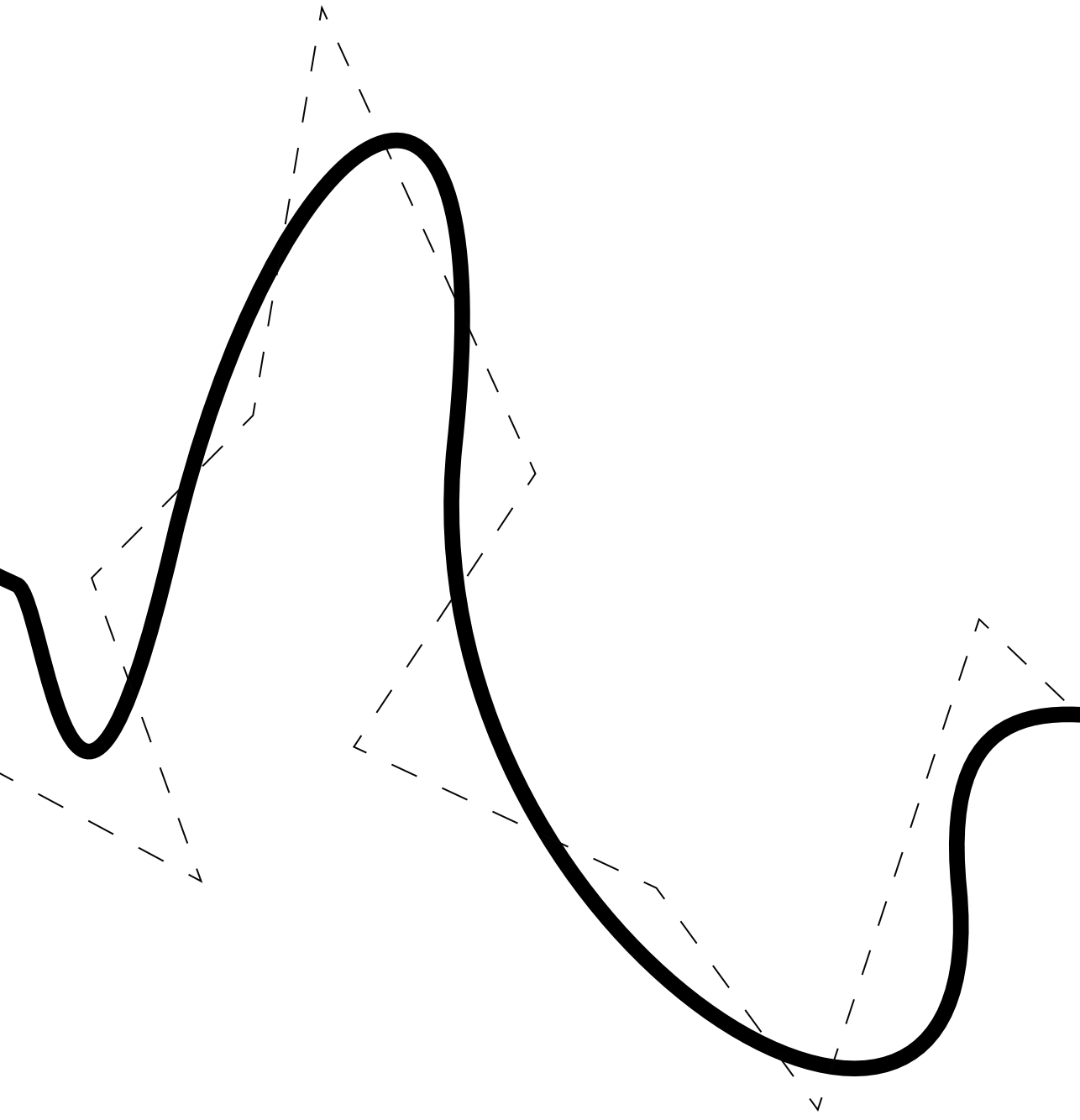
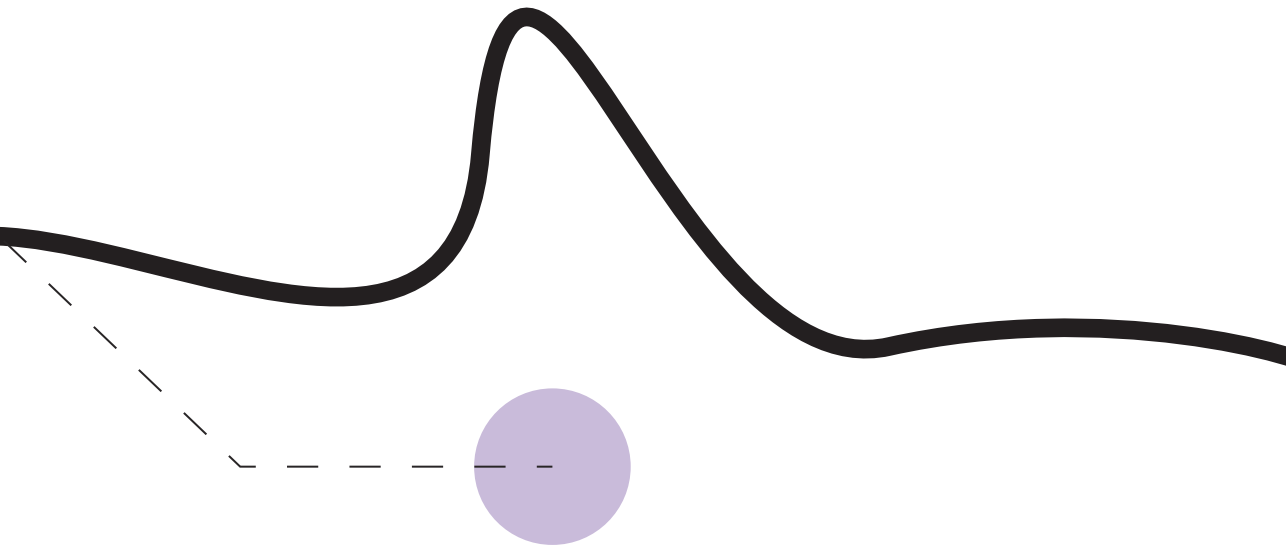


About

# THE AUTHOR



Merel Rebecca van Veen was born in Wageningen on December 11, 1983. After completing secondary school at the 'Marnix College' in Ede in 2002, she started studying Biomedical Sciences at Radboud University, Nijmegen. In 2004, she started her higher vocational education 'Nutrition and Dietetics' at the HAN, Nijmegen. During her clinical internship she worked at hospital 'Gelderse Vallei' in Ede. Merel finished her research thesis at the Dietetics department of Human Nutrition of Wageningen University in Wageningen. After obtaining her BSc degree in 2008, she started the Master Nutrition in Health and Disease at Human Nutrition, Wageningen University. For her first MSc thesis, she worked at the department of Metabolic Disease of the Children's Hospital in Utrecht to find reference values for fasting tests in children suspected of metabolic problems. Merel did an internship at the Julius Centre in Utrecht where she studied the association between PCOS and dietary intake, in women of the EPIC study. Her second thesis was written at the department of Human Nutrition in Wageningen in the VAVO study of Coraline Barends, which investigated taste preferences of babies. In 2010, she completed her Masters with the specialization Nutrition in Health and Disease.

Merel worked as a dietician in Gelre Ziekenhuizen in Zutphen, at the department of Metabolic Disease in the Children's Hospital in Utrecht, and at the Dietetics department of Wageningen University. She was the editor of a book on Dietetics in Metabolic Disease "Dieet bij Metabole Ziekten", and worked as a nutritional scientist in a project on VLCADD: "Newborn screening on long chain fatty acid oxidation defects: development and implementation of treatment guidelines". She contributed to a book on foods from Gelderland, "Gelders Glorie".

Merel started her PhD project in 2013 under supervision of dr. Sandra Beijer of the Netherlands Comprehensive Cancer Organisation and prof. dr. ir. Ellen Kampman from the department of Human Nutrition&Health of Wageningen University&Research. Third partner in the project was the Dutch Dietetic Oncology Group, represented by Jeanne Vogel, oncology dietician. Title of the project was "A Task Force on Nutrition and Cancer to improve Nutritional Care in Cancer Survivors", funded by Alpe d'Huzes/KWF. The results of her PhD project are described in this thesis entitled "Improving information provision on nutrition and cancer – For cancer survivors and health professionals". She was a member of Dutch Dietetic Oncology Group.

Currently, Merel is working at the World Cancer Research Fund in Amsterdam, where she works on the Diet and Cancer programme.

## LIST OF PUBLICATIONS

— van Veen, M.R., et al., *Development of a website providing evidence-based information about nutrition and cancer: fighting fiction and supporting facts online*. JMIR research protocols, 2015. 4(3): p. e110.
— van Veen, M., et al. *Improving Oncology Nurses' Knowledge About Nutrition and Physical Activity for Cancer Survivors*. Oncology nursing forum. 2017.
— Kok, A., et al. *Comparison of the 'ESPEN guidelines on nutrition in cancer patients 2016' with the recommendations of the Dutch Dietitians in Oncology Group*. ESPEN. 2017.
— van Veen, M.R., et al., *Nutritional Information Provision to Cancer Patients and Their Relatives Can Promote Dietary Behavior Changes Independent of Nutritional Information Needs*. Nutrition and cancer, 2018. 70(3): p. 483-489.
— van Veen, M.R., et al., *Adherence to the World Cancer Research Fund/American Institute for Cancer Research recommendations for cancer prevention is associated with better health-related quality of life among long-term colorectal cancer survivors: results of the PROFILES registry*. Supportive Care in Cancer, 2019. p. 1-10.
— van Veen, M.R., et al., *Colorectal cancer survivors' beliefs on nutrition and cancer; correlates with nutritional information provision*. Supportive Care in Cancer, 2019. p. 1-9

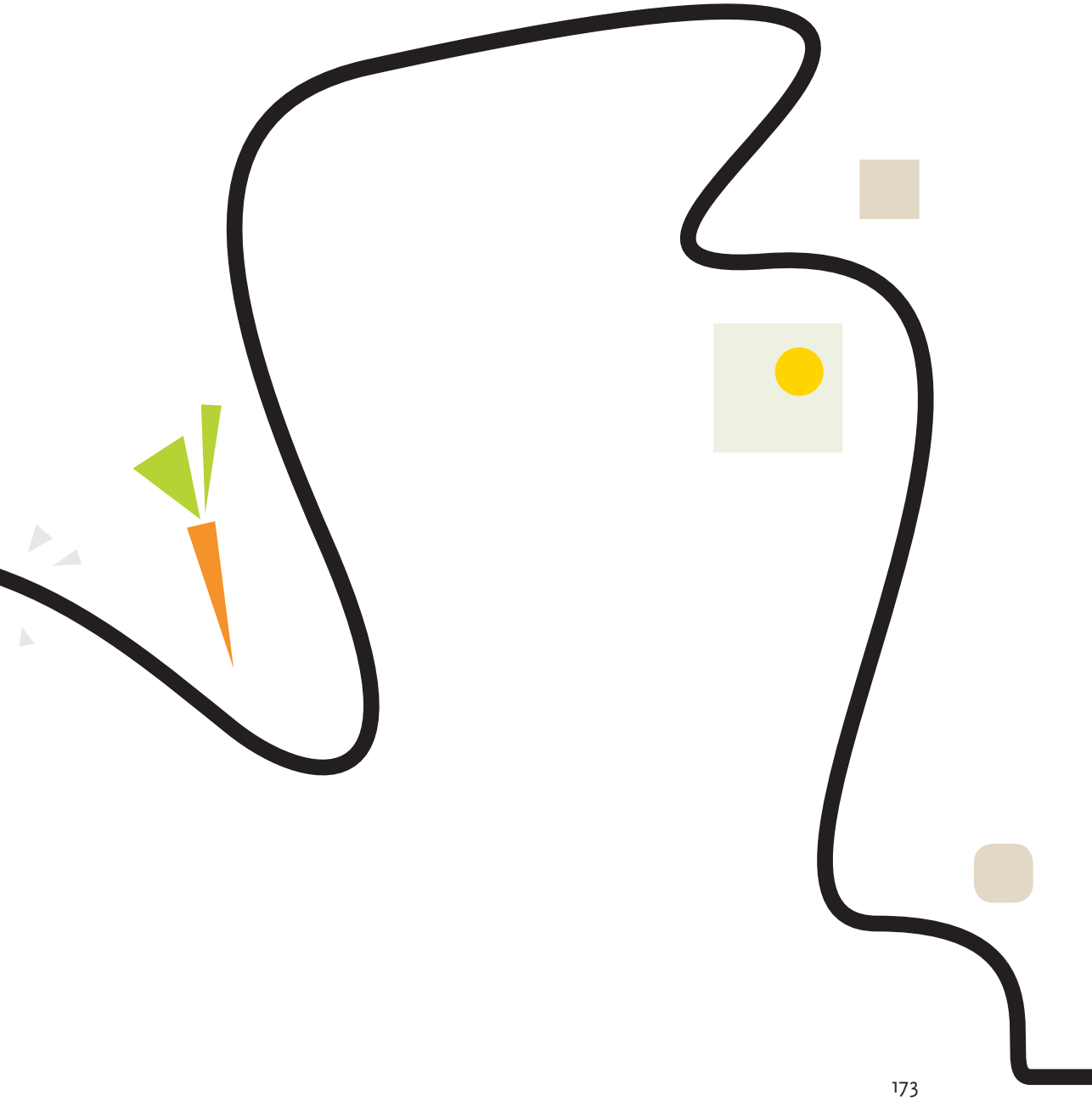
## PUBLISHED ABSTRACTS

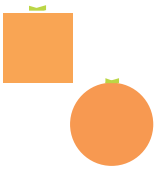
— Kampman, E., S. Beijer, and M. van Veen, *Voeding en kanker info: Wetenschappelijk antwoord van experts op vragen van patiënten*. 2014.
— van Veen, M., et al., *SUN-PP137: A Website on Nutrition and Cancer-Patients Perspective*. Clinical Nutrition, 2015. 34: p. S74.
— Kok, A., et al., *SUN-P082: Comparison of the "ESPEN Guidelines on Nutrition in Cancer Patients 2016" with the Recommendations of the Dutch Dietitians in Oncology Group*. Clinical Nutrition, 2017. 36: p. S84.

## OVERVIEW OF COMPLETED TRAINING ACTIVITIES

| Discipline specific activities | Organiser & location | Year |
|---|---|---|
| **Courses** | | |
| Symposium Kankerpreventie | KWF, Amsterdam | 2013 |
| Kwalitatief onderzoek in de praktijk van de gezondheidszorg | EPIDM, Amsterdam | 2014 |
| Basiscursus oncologie | NVVO, Ellecom | 2014 |
| Masterclass Diet and Cancer | VLAG, Wageningen | 2014 |
| Conferences and meetings | | |
| NVVO Milestonedag | NVVO, Amsterdam | 2014 |
| LWDO bijeenkomsten (2*6 uur per jaar) | Utrecht, Netherlands | 2013–2018 |
| **Presentations** | | |
| V&VN Oncologiedagen Mondelinge presentatie abstract | V&VN, Ede | 2014 |
| Post-HBO Voeding bij Kanker | LWDO, Amersfoort | 2015 |
| Verdiepingsdag Post-HBO Voeding bij Kanker | LWDO, Utrecht | 2015 |
| BBMRI-NL | BBMRI, Amersfoort | 2015 |
| Studiedag Voeding, Beweging en Kanker | MarkTwo Academy, Ede/ Utrecht/Bussum | 2014–2017 |
| ESPEN Lissabon 2015 | ESPEN, Lisbon, Portugal | 2015 |
| ICD Granada 2016 | ICD, Granada, Spain | 2016 |
| Diëtistendagen 2016 | NVD, Noordwijkerhout | 2016 |
| MASCC Vienna 2018 | MASCC, Vienna, Austria | 2018 |

| | | |
|---|---|---|
| **General courses** | | |
| Wageningen PhD Symposium | WPC, Wageningen | 2013 |
| Kort en bondig schrijven | HVDS, Weesp | 2013 |
| VLAG PhD week | VLAG, Wageningen | 2014 |
| VLAG PhD carousel | VLAG, Wageningen | 2014 |
| Atlas.ti | WASS, Wageningen | 2014 |
| Presenting with impact | WGSC, Wageningen | 2016 |
| Scientific writing | WGSC, Wageningen | 2015 |
| Brain Training | WGSC, Wageningen | 2015 |
| **Optional courses** | | |
| Preparing PhD research proposal | WUR, Wageningen | 2013 |
| PhD tour committee | WUR, Wageningen | 2014 |
| Staff seminars | IKNL, Eindhoven | 2013–2018 |
| Journal club | WUR, Wageningen | 2013–2018 |
| Epi research meetings / MenuD | WUR, Wageningen | 2013–2018 |





**COLOPHON**

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