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## Experiences of Cancer Rehabilitation

### A Cross-Sectional Study

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## Experiences of Cancer Rehabilitation: A Cross-Sectional Study

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## **Abstract**

**Aims and objectives:** To investigate the cancer rehabilitation experiences of working-age cancer survivors.

**Background:** Cancer survivors have extremely complex needs, spanning physical, vocational, and sexual domains. Although cancer rehabilitation services have been found to eliminate or reduce these strains, these services are often underutilized.

**Design:** A cross-sectional study design was employed.

**Methods:** A survey of persons over the age of 18 with a cancer diagnosis, enrolled in the Social Insurance Agency in a municipality in southern Sweden (n =168, 68% women) was conducted.

**Results:** Patients who used the cancer rehabilitation service (57%) were generally satisfied with it. Of participants, 26% reported not having received an offer of rehabilitation. Of those who reported that they received information about cancer rehabilitation services, most also reported that they received this information from a healthcare service professional (69%): for example, from the oncology nurse or the oncologist, whereas 20% claimed they received the information from the administrator of the Swedish Social Insurance Agency. A minority of children and family members of patients received support from the healthcare system.

**Conclusions:** More efforts should be taken to reach patients in need of cancer rehabilitation. Additionally, more attention should be directed toward family members and young children.

**Relevance to clinical practice:** More than one in four patients claimed to not have received an offer of cancer rehabilitation, and an even greater number of patients claimed that their spouses and children had never received an offer for this service either. Hence, there is a communication barrier that needs to be overcome. Health providers should be aware that information needs to be repeated several times, and presented both orally and in writing.

**Keywords:** Cancer rehabilitation services, Oncology, Cancer survivors, Cross sectional study, Social Insurance Agency.

## **Introduction**

Cancer rehabilitation should incorporate patient-centered care—which is respectful of patients, their wishes, needs, and values (Epstein & Street, 2011). The phrase "surviving cancer" was created to describe the experiences of living with, through, and beyond a cancer diagnosis (Feuerstein, 2007). Cancer survivorship presents great challenges. Even if most cancer survivors would benefit from cancer rehabilitation during and after treatment, this type of service is, unfortunately, underutilized globally (Silver et al., 2015).

## **Background**

Cancer diagnoses are approximately evenly distributed between men and women. However, women are more often diagnosed at a younger age, when they are still in the workforce, whereas men are more often diagnosed after retirement (Moberg, 2017). Therefore, women utilize more long-term sick leave for cancer treatment than men. Of patients who take sick leave for cancer treatment, the most common cancer diagnoses are breast cancer for women and gastrointestinal cancer for men (Moberg, 2017).

Cancer survivors have extraordinarily complex needs spanning physical, vocational, and sexual domains, among others. Most cancer survivors continue to suffer from a variety of symptoms such as fatigue, cognitive dysfunction, pain, neuropathies, imbalance, mobility difficulties, lymphedema, bladder and bowel problems, speech or other communication problems, and various psychosocial problems (Cheville et al., 2017). A growing portion live with chronic cancer-related disorders or treatment side effects, and many conditions can persist for ten years after treatment. (Silver et al., 2015).

Cancer survivors continue to experience a multitude of symptoms, and the burden of these symptoms may be associated with unmet needs across different realms (Cheng, Darshini Devi, Wong, & Koh, 2014). Thus, cancer-related physical impairment and

disability are currently high, as 53% of adult-onset cancer survivors report limitations in their functioning (Cheville, 2017). However, treatment rates for these disabilities remain as low as 1-2%, even for readily remediable physical impairments (Cheville, 2017). In a recent systematic literature review, men diagnosed with cancer were found to need a range of support; however, those needs were often not fulfilled, with the most common being intimacy, knowledge, physical, and psychological needs (Paterson, Robertson, Smith, & Nabi, 2015).

There is currently no internationally established definition of cancer rehabilitation services. The Swedish National Care Program (Eckerdal, 2017) uses the following definition: *Cancer rehabilitation services aim at preventing and reducing the physical, psychological, social, and existential consequences of a cancer diagnosis and its treatment. The rehabilitation services shall give the patient and next of kin support and help to achieve as good a life as possible* (Eckerdal, 2017, page 11). The need for cancer rehabilitation is growing steadily as cancer incidence and survival increase (Cheville et al., 2017). In cancer rehabilitation, the aim is to improve quality of life (QoL) for those with cancer diagnoses. It should aim to improve the effectiveness of health care, minimize costs by reducing hospital stays and revisits, and lessen disorders related to care and treatment side effects (Silver et al., 2015). Cancer rehabilitation can improve one's function while still being cost effective. It can reduce the costs of lost productivity or early retirement from work (Silver et al., 2015). Additionally, it may also influence QoL by decreasing fatigue and improving a patient's general condition, mood, and coping abilities (Salakari, Surakka, Nurminen, & Pylkkanen, 2015).

Successful cancer rehabilitation programs that involve physical activities have been evaluated by Musanti and Murley (2016). Evidence shows that cancer survivors engaged in active lifestyles experience less fatigue, better QoL, and, in cases of breast or colon cancer, reduced risk of relapse (Musanti & Murley, 2016). Moreover, cancer survivors with various

physical and functional problems would benefit from an interdisciplinary rehabilitation team (McNeely, Dolgoy, Onazi, & Suderman, 2016). Psychoeducation was also found to improve mental health and provide beneficial tools for coping with cancer pain (Ohlsson-Nevo, Karlsson, & Nilsson, 2016). A recent Cochrane review found that education about fatigue reduced its intensity and improved daily life functions (Bennett et al., 2016). Bennett et al. (2016) claim that education about fatigue management should be incorporated as part of routine cancer care.

Underutilization of cancer rehabilitation services are complex and multifold (Cheville et al., 2017). Important factors include low detection, documentation, and referral rates in oncology practices. Due to the low number of qualified cancer rehabilitation specialists, there is a great need to explore strategies that minimize personnel and geographic barriers. These services are disadvantaged by limited patient access to guidelines, printed material, and web-based resources to manage common cancer-related impairments (Cheville, 2017).

In summary, many cancer survivors experience physical, emotional, and social strains at least 10 years after treatment (Cheville et al., 2017). Although cancer rehabilitation services have been found to eliminate or ease these strains, these services are underutilized (Silver et al., 2015). For individuals of working age, it is possible that underutilization may lead to prolonged sick leave, resulting in a higher cost to society. There are few studies investigating cancer survivors of working age, although the well-being of this population has great impact on societal costs. There is little research about the utilization of cancer rehabilitation services for patients and their next of kin, as well as patient experiences of services. As stated, the use of cancer rehabilitation services is often underutilized, so it is of great importance to explore the characteristics associated with these services. The current study aimed to investigate the rehabilitation service experience of working-age cancer survivors.

## **Methods**

This cross-sectional survey was approved by the Regional Ethical Review Board in Lund, Sweden (2016/424) prior to the recruitment of participants.

### *Settings*

The cancer rehabilitation service is located at a regional hospital in southern Sweden and offers psychosocial support, physiotherapy, sexual counseling and treatment, general counseling, cognitive behavioral therapy, and acupuncture. The service employs two oncology nurses, one of whom has special training in sexual health; a physiotherapist; an occupational therapist; and a social worker (Garmy & Jakobsson, 2016).

### *Sample and participants*

All persons over the age of 18 with a cancer diagnosis and enrolled in the Swedish Social Insurance Agency from January 2013 to April 2016 in a municipality in southern Sweden were included in the study (n = 384, 68% women). All those working in Sweden are enrolled in the Swedish Social Insurance Agency (2012), so participants were of working age when they received a cancer diagnosis. The Social Insurance Agency's role is to administer social insurance that provides financial security in the event of illness and disability (2012).

### *Data collection*

Information about the study and a questionnaire were mailed to each participant between September and October 2016, and a reminder was sent four weeks later to those who did not respond. Written informed consent was requested. Both the questionnaire and consent form were completed by hand and returned in a provided stamped reply envelope.

### *Survey questionnaire*

Content validity of the questionnaire was evaluated by an expert group of cancer rehabilitation professionals (n = 5) and researchers (n = 4), who reviewed the content and provided feedback. The questionnaire was modified after this feedback. Face validity was

established through feedback from two patients of working age in the cancer rehabilitation service who responded to the questionnaire. Minor modifications of the questionnaire were required following this feedback. The questionnaire was considered easy to fill out and consisted of questions about patient history (sex, age, marital status, education level, profession, retirement status, parental status, country of birth, type of cancer, type of treatment, sick leave, presence of other physical or mental disease, and incidence of substance abuse). It also included questions regarding patients' experience with cancer: the following question on cancer experience was included: "To what extent do you consider cancer affected you: (1) socially, (2) emotionally, (3) physically/bodily?" Possible responses were "not at all," "to some extent," "to more than some extent," or "to a great extent." Questions also regarded from whom and when they received information about the cancer rehabilitation service, and how often the service was used, as well as if their children and family received an offer for it. The following questions were posed about perceived treatment at the cancer rehabilitation service: "The person with whom I had contact at the cancer rehabilitation service treated me with respect (1), gave me the information I needed (2), explained so that I could understand (3), was knowledgeable about my case (4), treated me well (5), and was sensitive to my situation" (6) The four possible responses were "not at all," "to some extent," "to more than some extent," or "to a great extent."

### *Analyses*

Descriptive statistics with frequencies, percentages, means and standard deviations (SDs) were used. Bivariate analyses using the chi-square test were conducted to investigate the differences between those who utilized the cancer rehabilitation services along with the following variables: sex; country of birth; years since diagnosis, level of education; type of cancer; type of cancer treatment; completed treatment, still having contact with health care services, received any kind of long-term treatment, profession; comorbidity; being on sick-



leave; and being affected socially, emotionally, and physically by the cancer. The t-test was conducted to investigate if there were age differences between those who utilized the cancer rehabilitation services and those who did not. Factors identified from the bivariate analyses associated with use of the cancer rehabilitation services ( $p < 0.05$ ) were analyzed in a multiple logistic regression (Norman & Streiner, 2014). The Hosmer and Lemeshow goodness-of-fit test, as well as the Nagelkerke  $R^2$  test, evaluated the quality of the regression model (Norman & Streiner, 2008). In addition,  $p$ -values  $< 0.05$  were considered significant. All analyses were performed using the IBM SPSS version 23.0.

## **Results**

### *Description of the participants*

Table 1 outlines the demographics of study respondents. The response rate was 44% ( $n = 168$ ), 68% of whom were women. The mean age of participants was 57 years, ranging from 26 to 71 years (SD 8.8 years). The users of the cancer rehabilitation services were slightly younger than the non-users, 54.8 years compared with 59.2 years. The drop-out analysis showed that the non-respondents did not differ significantly regarding age and gender compared to respondents. All respondents were of working age at the time of diagnosis; however, since the survey was distributed to those who had received their cancer diagnoses one half-year to 4 years earlier, almost one of five had retired at the time of answering the survey. Slightly more than one-third of participants (35%) reported having education at the college/university level. A minority of participants reported being born outside of Sweden. The majority of participants had children (89%); however, only 20% had children under the age of 18 living in their homes. About 39% of the children of cancer patients and 19% of next of kin were offered healthcare support. The users of the cancer rehabilitation services reported that their next of kin received support from health care services to a higher extent, than the non-users ( $p < 0.001$ ).

---Insert Table 1 about here ---

Table 2 presents the type of cancers and treatments reported by questionnaire respondents.

The most common type was breast cancer, while the most common treatment was a combination of surgery, chemotherapy, and radiation therapy. A majority of participants (65%) completed treatment, but 81% were still in contact with healthcare services. Less than half of participants (44%) had long-term treatment. Forty percent of participants reported other physical diseases, such as diabetes, stroke, arthrosis, or disc herniation. Psychiatric disorders, such as depression or fatigue syndrome, were reported by 6% of participants.

Substance abuse, such as alcohol or analgesic drugs, was reported among 2% of participants.

Of the participants, 38% were currently on sick leave, with half on total sick leave and the rest on 25-75% sick leave. The causes for sick leave were primarily cancer- and/or cancer treatment-related, but other causes were reported, such as depression and stroke. More than half of participants (58-59%) reported being affected socially, emotionally, and physically by cancer.

---Insert Table 2 about here---

#### *Experience of support from the cancer rehabilitation service*

Of participants, 57% reported having visited the cancer rehabilitation service at least once, and 26% reported not having received an offer of rehabilitation. Of those who reported receiving information about it, most reported they received this information from a healthcare service professional (69%); for example, from the oncology nurse or the oncologist, whereas 20% claimed they received the information from the administrator at the Swedish Social Insurance Agency, and 11% could not remember where they received the information. The majority of participants reported receiving the information early in their treatment. Of those

who visited the cancer rehabilitation service, 32% reported visiting the service once, 39% reported visiting the service 2-9 times, and 29% reported visiting the service 10-40 times.

Almost all participants (94%) felt they were treated respectfully in the important ways at the cancer rehabilitation service (see Table 3).

---Insert Table 3 about here---

Bivariate analysis was used to explore the association between utilization of the rehabilitation service and age; sex; level of education; profession; being of working age; comorbidity; being on sick-leave; type of cancer; and experience of being affected socially, emotionally, and physically by it. Factors identified from the bivariate analyses associated with use of the cancer rehabilitation services ( $p < 0.05$ ) were analyzed in a multiple logistic regression (Table 4). The significant association in the regression analysis was found for younger persons, as well as individuals currently on sick leave, who were more likely to use the cancer rehabilitation services.

---Insert table 4 about here---

## **Discussion**

In the current study, 57% of cancer survivors utilized cancer rehabilitation services; those who did were generally very satisfied with the service. More than one of four participants claimed they had not received any information or offer about the cancer rehabilitation service. It is important to find strategies for disseminating information about these services and overcoming barriers in offering this service. Collaboration among an interdisciplinary team coordinating cancer rehabilitation and palliative care is a suggested strategy for meeting the needs of patients experiencing problems with cancer or its treatment (Silver et al., 2015).

More than half of participants in our study reported being socially, emotionally, or physically affected by their cancer. Cheville et al. (2017) described how cancer rehabilitation services are not offered to all patients because of a limited clinical workforce trained in cancer rehabilitation, yet they were seldom located at tertiary centers, causing a critical barrier to patient access. Thus, broadened efforts to spread information and provide easy access to cancer rehabilitation are necessary to reach a larger number of cancer patients.

It is stated in the Swedish National Care Program for Cancer Rehabilitation (Eckerdal, 2017) that all patients with cancer and their next of kin should receive access to rehabilitation services, and that all children up to the age of 18 having a parent with cancer should receive special attention to address their need for information, advice, and support. However, in our study, only 39% of children of cancer patients and 19% of next of kin reported being offered healthcare service support. Both stress and the burden of a cancer diagnosis are often difficult to handle for the relatives of cancer survivors, including next of kin (Dieperink, Coyne, Creedy, & Ostergaard, 2017; Ferrell & Wittenberg, 2017), who often act as informal caregivers. While providing support for informal caregivers such as spouses, psychoeducation has been used to attend to physical symptoms, and also to strengthen coping and communication skills (Wittenberg, Borneman, Koczywas, Del Ferraro, & Ferrell, 2017).

Nurses must work closely with families of cancer patients to understand their strengths and available resources, while support and information should be tailored for patients and families to promote optimal patient outcomes, and some perceptible relief for the family (Coyne, Dieperink, Ostergaard, & Creedy, 2017).

### **Limitations**

Complexity of cancer rehabilitation makes its evaluation difficult. In the current study, we used a questionnaire about evaluation measures required by the staff of the Swedish Social Insurance Agency and cancer rehabilitation services at the Regional Hospital. This specific

assessment would not have been possible using a general instrument. This, however, combined with a low response rate (44%), makes generalization outside the sample problematic. The low response rate may be a consequence of elapsed time between the study and patients' cancer diagnoses and treatment, and may reflect some hesitation to deal with it.

Most respondents were women with breast cancer. This is partly due to the sample being limited to respondents who were actively working on being diagnosed, and the fact that most men with cancer are retired. The overrepresentation of women occurs in other studies as well: for example, in a Danish study by Holm et al. (2012).

It is important for future research to identify the critical and effective components of cancer rehabilitation so that these matters can be provided to cancer survivors across a number of different care settings (Cheville et al., 2017).

## **Conclusion**

Even though most cancer survivors would benefit from cancer rehabilitation services both during and after cancer treatment, this kind of service is underutilized globally. The current study aimed to investigate rehabilitation service experiences of working-age cancer survivors as a step towards addressing underutilization. The study found that cancer survivors of working age are generally satisfied with their cancer rehabilitation services. However, more efforts must be taken to reach all patients in need of help and to make these services highly visible in hospitals, including ease of access. More attention must be directed toward family members, and children in particular.

## **Relevance for clinical practice**

Many patients received the information about the cancer rehabilitation service from the oncology nurse. However, more than one in four patients claimed to not have received this information, and an even greater number of patients claimed that their spouses and children

had never received an offer for this service. Hence, there is a communication barrier that must be overcome. Oncology nurses have a crucial role in providing patient counseling and support services (Komatsu & Yagasaki, 2014) while guiding patients through the uncertain course of cancer in three phases: 1. Identifying patient needs, 2. Offering patient-centered-care and empowering them to take control of their lives, and 3. Developing more potential for the patient to have positive experiences in life. A structured and carefully organized patient education program could lead to a better understanding of expectations and how post-treatment symptoms should be handled (Nicolaisen, Muller, Patel, & Hanssen, 2014).

### **What does this paper contribute to the wider global clinical community?**

- Cancer survivors of working age are generally satisfied with their cancer rehabilitation services;
- More efforts must be taken to reach all patients in need of cancer rehabilitation;
- Rehabilitation services must be highly visible in hospitals as well as easy to access;
- More attention must be directed towards family members and children in particular.

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Table 1. Description of the sample (n =168).

Sample description	User of the cancer rehabilitation services (n=95, 56.5%)	Non-users of the cancer rehabilitation services (n=73, 43.5%)	p-value
Age in years (mean, SD)	54.8 (9.5)	59.2 (7.2)	<b>0.001<sup>1</sup></b>
Sex			
Women, n (%)	66 (70.2)	47 (64.4)	0.434 <sup>2</sup>
Men, n (%)	28 (29.8)	26 (35.6)	
Highest completed education			
Compulsory school, n (%)	17 (18.1)	21 (28.8)	0.253 <sup>2</sup>
Secondary school, n (%)	41 (43.6)	29 (39.7)	
College/ university, n (%)	36 (38.3)	23 (31.5)	
Country of birth			0.377 <sup>2</sup>
Sweden, n (%)	87 (92.6)	69 (94.5)	
Nordic countries, n (%)	2 (2.1)	0 (0)	
Europe, n (%)	4 (4.3)	2 (2.7)	
Outside Europe, n (%)	1 (1.1)	2 (2.7)	
Married, n (%)	60 (64.5)	44 (60.3)	0.341 <sup>2</sup>
Cohabiting with a partner, n (%)	76 (83.5)	55 (76.4)	0.321 <sup>2</sup>
Parent of children, n (%)	86 (91.5)	63 (90.0)	0.652 <sup>2</sup>
Parent of children under the age of 18, n (%)	27 (28.4)	8 (12.1)	<b>0.007<sup>2</sup></b>
Children under the age of 18 received support from healthcare services, n (%)	12 (44.4)	2 (25.0)	0.432 <sup>2</sup>
Next of kin received support from health care services, n (%)	27 (28.7)	5 (7.4)	<b>&lt; 0.001<sup>2</sup></b>

<sup>1</sup>t-test.

<sup>2</sup>Chi Square test.

SD = Standard Deviation.

Missing cases: < 5%.

p < 0.05 were considered significant, and marked boldface.

Table 2. Type of cancer and treatment (n = 168).

Diagnosis and treatment	User of the cancer rehabilitation services (n=95)	Non-users of the cancer rehabilitation services (n=73)	p-value <sup>1</sup>
<b>Type of cancer</b>			
Breast	44 (46.3)	30 (41.7)	0.377
Colorectal	10 (10.5)	6 (8.3)	
Uterine/ Ovarian	11 (11.6)	4 (5.6)	
Prostate	5 (5.3)	7 (9.7)	
Head/neck	6 (6.3)	3 (4.2)	
Lung	3 (3.2)	6 (8.3)	
Myeloma	3 (3.2)	4 (5.6)	
Other	18 (13.6)	13 (16.6)	
<b>Type of treatment</b>			
Surgery, chemotherapy, and radiation	27 (28.7)	14 (19.2)	0.443
Chemotherapy and radiation	14 (14.9)	10 (13.7)	
Surgery	11 (11.7)	7 (9.6)	
Surgery and chemotherapy	10 (10.6)	9 (12.3)	
Chemotherapy	7 (7.4)	9 (12.3)	
Hormone treatment	3 (3.2)	1 (1.4)	
Other treatment combinations	28 (23.5)	23 (31.5)	
<b>Being currently on sick-leave</b>	44 (47.3)	19 (26.0)	<b>0.006</b>
<b>Completed treatment</b>	59 (64.1)	48 (66.7)	0.745
<b>Still have contact with healthcare services</b>	76 (81.7)	58 (80.6)	0.522
<b>Received any kind of long-term treatment</b>	43 (45.7)	29 (40.8)	0.635
<b>Have other physical diseases</b>	35 (38.0)	31 (43.1)	0.526
<b>Have mental illness</b>	6 (6.3)	4 (5.5)	1.0
<b>Have substance abuse disorder</b>	2 (2.1)	2 (2.7)	1.0
<b>Were affected by the cancer to more than some extent</b>			
Socially	61 (64.9)	38 (52.7)	0.151
Emotionally	62 (65.3)	35 (48.6)	<b>0.025</b>
Physically/bodily	62 (65.3)	35 (48.6)	<b>0.025</b>

<sup>1</sup>Chi Square.

Missing cases: < 3%.

$p < 0.05$  were considered significant and marked in boldface.

Table 3. Perceived support from the cancer rehabilitation services (n = 94).

<b>Perceived support from cancer rehabilitation services</b>	<b>n (%)</b>
<b>Treated me with respect</b>	
Not at all	1 (1.1)
To some extent	3 (3.2)
To more than some extent	16 (17.0)
To a great extent	72 (76.6)
<b>Gave me the information that I needed</b>	
Not at all	2 (2.1)
To some extent	15 (16.0)
To more than some extent	22 (23.4)
To a great extent	55 (58.5)
<b>Explained so that I understood</b>	
Not at all	2 (2.1)
To some extent	7 (7.4)
To more than some extent	24 (25.5)
To a great extent	61 (64.9)
<b>Was knowledgeable about my case</b>	
Not at all	2 (2.1)
To some extent	12 (12.8)
To more than some extent	31 (33.0)
To a great extent	49 (52.1)
<b>Treated me well</b>	
Not at all	1 (1.1)
To some extent	3 (3.2)
To more than some extent	12 (12.8)
To a great extent	78 (83.0)
<b>Was sensitive to my situation</b>	
Not at all	3 (3.2)
To some extent	6 (6.4)
To more than some extent	20 (21.3)
To a great extent	65 (69.1)

Table 4. Logistic regression analyses of factors associated with using cancer rehabilitation services (n = 140).

Variables	OR	95% CIs for OR	p-values
Age	0.95	0.91-0.99	<b>0.028</b>
Profession	0.90	0.80-1.02	0.102
Being currently on sick-leave	0.44	0.20-0.98	<b>0.044</b>
Emotionally affected by the cancer	1.88	0.79-4.42	0.156
Physically affected by the cancer	0.81	0.33-1.96	0.636

Hosmer and Lemeshow goodness-of-fit test

$p = 0.649$ ; Nagelkerke  $R^2 = 0.194$ .

Missing cases: 16.7%.

$p < 0.05$  were considered significant and marked in boldface.

OR: odds ratio

CI: confidence intervals.

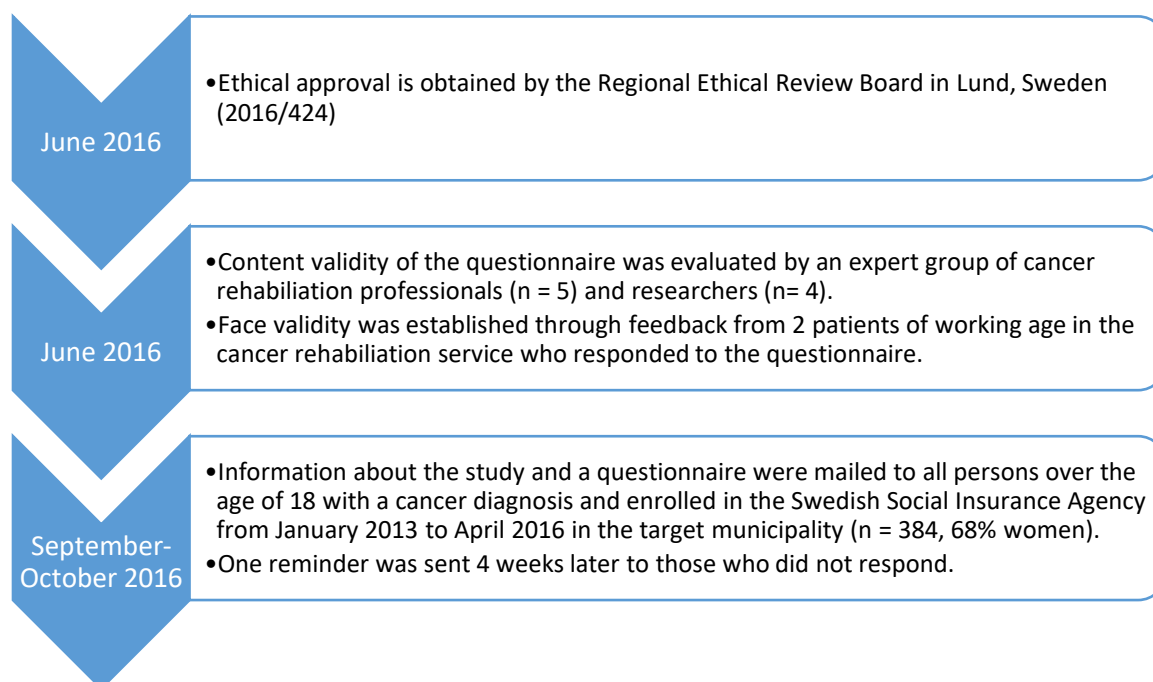


Figure 1. Flow diagram explaining the study process.