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Observational Studies

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Access to psychological treatment for chronic cancer-related pain in Sweden[#]

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Abstract

Objectives – Cancer-related pain (CRP) is among the most frequent collateral effects of cancer, with chronic CRP, lasting at least 3 months, affecting >40% of cancer survivors. Evidence-based treatments, including pain-focused cognitive behavioral therapy (CBT), are available, but it appears that cancer patients/survivors are often poorly informed about CRP or the potential benefits of CBT for such pain. This study examined current experience of Swedish cancer patients/survivors in relation to CRP.

Methods – Participants ($N = 276$; 83% female; mean age = 55.5 years, $SD = 11.9$) were recruited to an online survey via cancer websites in Sweden, and they provided information about their history of chronic CRP and whether they received information about or treatment for CRP from a healthcare professional.

Results – Participants had a history of breast (36%), gynecological (12%), lung (10%), colon (8%), and other forms of cancer (36%). A majority (74%) reported a history of chronic CRP and being prescribed analgesic medications (70%). Less than half (47%) received information from their healthcare provider about the risk of CRP and only 13% with chronic CRP received psychological treatment, and of these, only 33% received CBT. Among those receiving psychological

treatment for chronic CRP, satisfaction rates were moderate, reported as an average of 6 on a 0–10 scale (standard deviation 2.6).

Conclusions – Greater efforts are needed to raise awareness among cancer patients/survivors and healthcare providers about the risk of CRP and evidence-based interventions, including CBT, the first-line intervention for chronic pain. These efforts will need to be matched with increases in treatment capacity, particularly pain-focused CBT.

Keywords: cancer, cancer-related pain, chronic pain, psychological treatment, cognitive behavioral therapy

1 Introduction

The number of long-term cancer survivors is steadily increasing due to advances in early detection and treatment, and with these advances, increasing numbers require screening and treatment for a range of cancer-related complications [1]. Among the many complications experienced by cancer patients, pain is the most common [2]. Chronic pain, defined as pain lasting 3 or more months [3], is reported by 55% of patients undergoing cancer treatment and by 40% of all cancer survivors [4], and it is associated with poorer adherence to cancer care, increased healthcare usage, and higher levels of distress and functional impairment at the individual and family level [5,6].

Guidelines for the management of chronic cancer-related pain (CRP) recommend supplementing pharmacological with behavioral interventions during cancer treatment and prioritizing behavioral interventions for cancer survivors [7,8]. The most researched and first-line non-pharmacological intervention for chronic pain is cognitive behavioral therapy (CBT). Meta-analyses find that pain-focused CBT yields superior outcomes to other non-pharmacological approaches, and that relative to no-treatment controls yields moderate-sized reductions in pain-related severity and impairment, as well as in depression, anxiety, and overall distress [9–11]. Meta-analyses identifying a smaller number of CBT trials specifically for CRP find small-to-moderate reductions in pain severity/impairment and

[#] The study data have previously been presented at the Annual Meeting of the Scandinavian Association of the Study of Pain, “Measurement of Pain,” Rigshospitalet, Copenhagen, Denmark, 13-10-2022.

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associated difficulties (e.g., distress and insomnia) relative to no-treatment controls, but with significant heterogeneity in study quality and findings [12–14]. Still, pain-focused CBT is identified as the first-line, non-pharmacological treatment for chronic pain in cancer patients/survivors.

European surveys of cancer patients/survivors find that acute and chronic CRP remain undertreated, particularly with respect to evidence-based, non-pharmacological interventions like pain-focused CBT. Further efforts are needed to identify barriers to care, including provider and patient awareness of the risk of chronic CRP, and to determine whether patients/survivors are being referred for and benefit from psychological interventions such as pain-focused CBT. More than 60,000 individuals are newly diagnosed with cancer in Sweden each year [15,16]. Based on international studies of the prevalence of chronic CRP, as many as 24,000 of these newly diagnosed individuals may develop chronic CRP. Are they being informed about the risk of chronic CRP and are they referred for psychological treatments for pain? As part of a larger survey study of the relationship between chronic CRP and psychological flexibility [17], we asked cancer patient/survivors about their experiences of having been informed about CRP, their access to pain treatments, and their satisfaction with the same. This article presents these findings.

2 Method

2.1 Participants

Participants were 276 adults (83% female; mean age = 55.5 years, SD = 11.9) with a current or previous cancer diagnosis. Breast cancer was the most common diagnosis (41%), followed by gynecological (13%), lung (12%), and colon (9%). The remainder reported various cancer types, none of which were reported by more than 6% of respondents. Just under half (49.8%), reported being in remission from cancer, 37% had a current diagnosis and 14.1% were unsure. Slightly more than half (57%) had completed university, with 37% employed full-time, 26% retired, and 21% on sick leave.

3 Procedure

A convenience sample was recruited by posting a link to an anonymous online survey, in Swedish, on the websites of various Swedish cancer patient associations, the Swedish Cancer Foundation, and social media. Individuals who

were 18 years of age or older, could read/comprehend Swedish, and had a current or former diagnosis of cancer were invited to participate. The presence of chronic CRP was not a criterion for inclusion. Individuals who clicked on the study link received information about the study and gave consent before completing items about their sociodemographic and clinical history followed by standardized self-report measures of pain, distress, and psychological flexibility. Data on the relationship between distress and psychological flexibility are presented in a previous publication [17]. Only descriptive findings relating to their experience of information provision about and treatment for CRP are presented here. The study was conducted using Qualtrics software, Version 2021–2022 of Qualtrics, and approved by the Swedish Ethical Review Authority (dnr 2021-00499).

4 Items/measures

The survey items of relevance to this study addressed sociodemographic characteristics, cancer type and history, including treatment history, the presence of chronic CRP (self-assessed and defined as pain lasting >3 months as a result of cancer or its treatment), and whether the participant was provided information about CRP by a healthcare professional, received either pharmacological or psychological treatments for such pain, satisfaction rates for the treatments, and preferences regarding CRP treatments.

5 Results

The results regarding experience of chronic CRP and receiving information about CRP from a healthcare professional are presented in Table 1. The results regarding access to pharmacological treatment for CRP, satisfaction with the treatment, and wish for pharmacological treatment, for the participants with history of chronic CRP, are presented in Table 2. The results regarding access to psychological treatment for CRP, satisfaction with the treatment, and wish for psychological treatment, for the participants with history of chronic CRP, are presented in Table 3.

6 Summary and discussion

Consistent with previous findings [2,4], we observed a high prevalence of chronic CRP (74.3%) in this sample of Swedish cancer patients and survivors, of whom 74.2% reported

Table 1: Sample characteristics regarding experience of chronic CRP and receiving information about CRP from a healthcare professional

Item	N	%
Ever experienced chronic CRP ^a	205	74.3
Currently experiencing chronic CRP? ^a	155	74.2 ^b
Received information about CRP from a healthcare professional ^a	130	47.1
Where and from what healthcare professional the information was received ^c		
– Oncology clinic (doctor and/or other)	145	64.7
– Surgery clinic (doctor and/or other)	59	26.3
– Primary care (doctor and/or other)	11	4.9
– Don't know	9	4.0
For those who did not receive information about CRP, number and proportion who wanted such information.	112	76.6

N = 276.

^aReflects the number of participants answering “yes.”

^bReflects the percentage of cases of those who had ever experienced chronic CRP.

^cIndicates that it was possible to give multiple answers.

Table 2: Sample characteristics regarding access to pharmacological treatment for CRP, satisfaction with the treatment, and wish for pharmacological treatment, for the participants with history of chronic CRP

Item	<i>n</i>	%	<i>m</i>	<i>SD</i>
Prescribed pharmacological treatment ^a	144	70.2		
Where the prescription was received ^b				
– Oncology clinic	104	72.2		
– Surgery clinic	36	25.0		
– Primary care	18	12.5		
– Others	18	12.5		
– Don't know	3	2.1		
Current pharmacological treatment in those with current chronic CRP ^a	94	60.6		
Satisfaction with pharmacological treatment in those with current pharmacological treatment ^c			5.72	2.42
Wish to have been prescribed pharmacological treatment ^d				
– Yes	21	34.4		
– No	18	29.5		
– Don't know	22	36.1		

^aReflects the number of participants answering “yes.”

^bIndicates that it was possible to give multiple answers.

^cSatisfaction ratings were reported on a scale from 0 (= not at all satisfied) to 10 (= very satisfied).

^dNumber and proportion of those who were not prescribed.

current chronic CRP. However, less than half (47.1%) of the participants had been informed by a healthcare provider about the risk of CRP and treatments for the same, and 76.6% said they wish they had received such information.

Table 3: Sample characteristics regarding access to psychological treatment for CRP, satisfaction with the treatment, and wish for psychological treatment, for the participants with history of chronic CRP

Item	<i>n</i>	%	<i>m</i>	<i>SD</i>
Received psychological treatment ^a	27	13.2		
Where the treatment was delivered				
– Primary care	6	22.2		
– Adult psychiatric clinic	6	22.2		
– Self-paid at private clinic	2	7.4		
– Others	13	48.1		
Type of psychological treatment received ^b				
– CBT	9	33.3		
– Psychodynamic therapy	8	29.6		
– Mindfulness	7	25.9		
– Other	6	22.2		
Satisfaction with psychological treatment ^c			6.0	2.6
Wish to have been offered psychological treatment				
– Yes	52	29.2		
– No	59	32.0		
– I don't know	67	37.6		
Preferred setting for psychological treatment				
Number and proportion of all participants (<i>N</i> = 276)				
– Face-to-face	164	59.4		
– Online	15	5.4		
– Combination of the two	97	35.1		

^aReflects the number of participants answering “yes.”

^bIndicates that it was possible to give multiple answers.

^cSatisfaction ratings were reported on a scale from 0 (=not at all satisfied) to 10 (=very satisfied).

^dNumber and proportion of those who were not offered.

When informed, the majority said that the information about CRP came from a member of the oncology (64.7%) or surgical teams (26.3%). Only 4.9% received information about CRP in primary care. Informing patients about their conditions is fundamental to increasing their health and well-being and promoting their active participation in decisions regarding their healthcare. Our findings suggest that there may be limited understanding among healthcare professionals about the high prevalence of CRP in cancer patients/survivors and the importance of informing patients about it.

In relation to treatment for CRP, a majority (70.2%) of the individuals with chronic CRP in this study reported having been prescribed analgesic medicines to relieve their pain, with satisfaction rates for this medication falling in the moderate range, with an average score of 5.72 on a 0–10 scale. Thus, and despite advances in the treatment of acute CRP, nearly one-third (29.8%) had never received pharmacological treatment, and of these, 34.4% wished they had. These findings suggest that a significant

proportion of Swedish cancer patients may be under-prescribed analgesics for CRP, which would be in line with previous findings which find that almost 50% of the cancer patients report their pain as inadequately controlled [18,19]. Again, it is important to point out that the long-term use of analgesics for chronic pain brings with it a significant risk for negative collateral effects, and a range of non-pharmacological approaches for CRP are available. Pain-focused CBT is the first-line recommended treatment for chronic pain in Sweden and around the world [9–11].

Our findings suggest that psychological interventions for chronic CRP, especially CBT, may be underutilized by cancer patients and survivors with chronic CRP in Sweden, either because they are not appropriately referred, there is very limited access to the treatment, or the patient/survivor is unaware of the potential benefits of the treatment. Despite the presence of specialist chronic pain services in Sweden, and pain treatments in primary care, only 13% of the participants experiencing chronic CRP received psychological treatment, and of these, only a third (33.3%) received CBT. Among the participants who did receive psychological treatment for chronic CRP, satisfaction rates were moderately high, slightly higher than the satisfaction rates for pharmacological treatments, with an average score of 6 on a 0–10 scale. It is worth noting that 29.2% of the participants who had not been offered psychological treatment for CRP wished they had been; 32.0% did not wish for it, and 37.6% were unsure. Participants were asked to indicate their preferred setting for psychological treatments for chronic CRP. Most participants (59.4%) preferred face-to-face contact, while 5.4% preferred an online treatment and 35.1% preferred a combination of the two.

Taken together, these findings strongly suggest the need for awareness raising among both healthcare professionals and cancer patients/survivors about the risk for acute and chronic CRP and the range of available treatments. In addition, and given the large number of newly diagnosed cancer patients each year and their risk for acute and chronic CRP, these findings point to the need for increasing treatment capacity, particularly for pain-focused CBT. The present findings suggest that offers of internet-only treatment for CRP may be poorly accessed because of patient preferences for face-to-face. However, mixed models of delivery where individuals have a more limited set of face-to-face session among internet-delivered sessions may help to fill the current capacity gap for individuals with chronic pain.

The present findings must be viewed in the context of several limitations. First, the study used a convenience sample, recruited through online sources from national cancer patient organizations and charities, which may

have introduced a selection bias. Second, the sample was predominantly female (83%), and a high proportion of the participants reported a history of breast cancer over other cancer types, which may limit the generalizability of the findings to the population of cancer patients/survivors. Third, the study relied on self-reported data, which may be subject to recall bias and social desirability bias. Future research should aim to address these limitations by using more diverse and representative samples and using more refined measures of CRP and treatment outcomes. Survey studies targeting healthcare providers about information and treatment routines could provide further information.

7 Conclusion

The findings of the present study are consistent with previous research and suggest that chronic CRP is common in cancer patients and survivors in Sweden and that these individuals are under-informed and under-treated for CRP. A minority of cancer patients/survivors in this survey were provided information about the risk of CRP. Participants were under-prescribed pharmacological treatments for CRP, and those who received such treatment rated it as only moderately helpful. Despite the availability of evidence-based, pain-focused CBT interventions in Sweden, a minority of patients with chronic CRP were referred for such treatment or, indeed, any psychological treatment. Greater efforts are needed at raising awareness among individuals with cancer and their healthcare providers about the risk of CRP and the available treatments. With 60,000 individuals being newly diagnosed with cancer each year in Sweden, these awareness-raising efforts about CRP will need to be matched with increases in treatment capacity, particularly for pain-focused CBT, the first-line evidence-based treatment for chronic pain.

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Research ethics: Research involving human subjects complied with all the relevant regulations and institutional policies and is in accordance with the Helsinki Declaration (as amended in 2013) and has been approved by the Swedish Ethical Review Authority (reference number: dnr 2021-00499).

Informed consent: Informed consent has been obtained from all participants in this study.

Author contributions: Frida Köhler Björkstrand, Joana Duarte, Lance M McCracken, and Sean Perrin all contributed to the design of the study and data collection/analysis; discussed the results; and prepared and commented on the manuscript. All authors have accepted responsibility for the entire content of this manuscript and approved submission.

Competing interests: Lance M McCracken is a Section Editor of Scandinavian Journal of Pain. The authors state no conflict of interest.

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Data availability: The raw data can be obtained on request from the corresponding author.

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