

PAPER

Cancer patients' motives for psychosocial consultation—Oncology social workers' perceptions of 226 patient cases

Joakim Isaksson^{1,2}  | Sara Lilliehorn^{1,3} | Pär Salander¹

¹Department of Social Work, Umeå University, Umeå, Sweden

²Department of Social Work, Stockholm University, Stockholm, Sweden

³Department of Radiation Sciences—Oncology, Umeå University, Umeå, Sweden

Correspondence

Joakim Isaksson, MSc, PhD, Department of Social Work, Stockholm University, SE 106 91, Stockholm, Sweden.

Email: joakim.isaksson@socarb.su.se

Funding information

The Kamprad Family Foundation for Entrepreneurship, Research and Charity, Grant/Award Number: 20150039

Abstract

Objective: Although oncology social workers (OSWs) have emerged as a core profession in the provision of psychosocial services, there is a lack of empirical studies that describe their daily clinical work with patients. The overall aim of this study was to explore cancer patients' motives for consulting an OSW.

Methods: From a nationwide survey, we used data from 226 patient cases that OSWs met face to face. The OSWs were asked to describe how the case was referred to them, the patient's characteristics, and what they perceived as the patient's motives for contacting them as well as additional motives that came up during the consultations.

Results: Patients have different motives for consulting an OSW, and these motives change over the course of consultations; while feelings associated with being diagnosed with cancer were often the initial motive, questions associated with moving on in life and dealing with relationships and the overall life situation were added over time.

Conclusions: The results show that Swedish OSWs' function is multifaceted and that the initial motives among patients rarely predict the content in consultations over time. Based on the diversity of motives, it seems obvious that OSWs (at least in Sweden) need a broad education in the psychology of counselling. It also seems obvious that even if patients initially were referred by health care staff to the OSW due to psychological reactions to being ill, staff should also be attentive to the fact that relational and socio-economic/juridical issues are of great concern for the patients.

KEYWORDS

cancer, counseling, oncology, oncology social workers, patients' motives

1 | INTRODUCTION

Some patients with cancer are in need of different types of psychosocial interventions and services to be able to resume a new everyday life in family, work, and leisure time. The provision of psychosocial interventions and psychosocial care has been studied extensively, but these studies have usually had experimental designs that do not consider the patients' motives for consulting various health care professionals. Understanding patient motives is important because they provide us with insights into what health care professionals are facing in their clinical work and what types of skills they need to fulfil their professional duties.

Alongside psychologists, oncology social workers (OSWs) have emerged as a specialised discipline and core profession in psycho-oncology that provides a wide range of psychosocial services.¹⁻³

However, in both Sweden and other countries, there is a lack of empirical studies focusing on the OSWs' daily clinical duty.

The overall purpose of this study was to explore cancer patients' motives for consulting an OSW. Research questions included what are the characteristics of cancer patients who are seen by OSWs and how are they referred to OSWs? What does the OSW perceive as the patients' initial motives for consulting the OSW, and what additional motives come up during the consultations?

1.1 | The Swedish health care system and the function of the OSW

Sweden is often described as a typical representative of a Nordic or Scandinavian model of welfare politics with equal access to health care

services as a central feature. With few exceptions, hospital care is part of the tax-financed public sector, and patients pay a small fee for treatment by different professionals.⁴

Hospital social workers are the only health care professionals in Sweden with higher education (bachelor) who are engaged in patient work but lack any legislation regarding their role and function. Thus, their roles and clinical functions are quite vague and are mainly described in general terms, such as supporting and maintaining a psychosocial perspective in the care of patients and bridging between the biomedical and the social perspectives in the medical context.⁵

Approximately 4000 hospital social workers are employed within the Swedish public health sector,⁶ and some of them are employed full or part-time in oncology (OSWs). All Swedish social workers receive the same basic training towards a bachelor degree in social work at university social work departments, and there is no specific orientation towards social work in health care, although a few universities offer optional advanced-level courses focused on psychosocial work in health care.⁵

The OSWs' clinical work is primarily conducted in face-to-face contacts with patients. There are no regulations about the number of sessions patients have the right to, and thus the number of sessions might be rather high,⁷ especially compared to countries with different health insurance systems (eg, the United States) and with less funded social work services at hospitals. Furthermore, Swedish OSWs are usually not involved in discharge planning or screening patients for distress, which seem to constitute important functions of OSWs in other countries.⁸⁻¹³ Instead, the main function of Swedish OSWs consists of providing psychosocial support and counselling.¹⁴ In addition, there are no national guidelines in Sweden regarding distress screening, and patients are ordinarily referred to the OSW based on other staff members' clinically based judgement of the patient's well-being.

2 | METHOD

2.1 | Study design

The present study is part of a larger project focusing on the function of OSWs in Sweden (running from 2015 to 2018). Within this larger project, a nationwide survey was conducted with questionnaires sent to all OSWs working at least 50% in adult oncology in various settings in Sweden. A total of 134 OSWs (59% of the identified population) completed the survey. On average, the OSWs had been engaged in oncology social work for 8 years, they worked 75% in oncology, and they were typically in contact with 12 patients and 5 next of kin every week.¹⁴ The present study focuses more specifically on their clinical duty, ie, on real patient cases they meet during a typical week and how they perceive the patients' different motives for consulting them. The project was approved by the Ethical Review Board at Umeå University (Dnr 2015/401-31Ö).

2.2 | Patient cases in the survey

To find out more about OSWs' specific clinical function and what they are facing in their clinical work, one part of the survey asked the OSWs to describe the first 3 patient cases that they met face-to-face during

the previous week. For each case, the OSWs were asked to describe how the case was referred to them, what they perceived as the patient's initial motive for contacting them, and any additional motives that came up during the consultations. They were also asked to provide information about the patient's age, gender, diagnosis, and, because most cases were still on the agenda, an estimation of how many sessions the case would probably call for. In total, 226 patient cases were provided. Due to the detailed information (diagnosis, age, referral source, etc) that was provided, it is reasonable to assume that the OSWs mainly based their information about the patients on their casebooks and notes.

2.3 | Qualitative analysis of the survey data

All patient motives were put into new documents—one for initial motives and another for additional motives that later came up during the consultations. The motives were then coded by the first author (JI), ie, they were given a short label telling what the motive was about.¹⁵

We then sought to determine whether the codes fit within the categories that had been developed in a previous study based on the same survey but which focused on the OSWs' descriptions of the 3 most common motives that patients had for contacting them.¹⁴ The rationale for this endeavour was that the respondents were the same and the studied questions were both aspects of the same clinical reality. The previously identified categories covered the new codes properly and thus no additional categories were needed. However, because the motives in the previous study were more general compared to the motives that arose directly from patient cases, the categorisation was jointly scrutinised with the other authors in order to reach dialogical intersubjectivity.¹⁶

3 | RESULTS

3.1 | Patient characteristics and referral source

Most patients were women (62%), and the mean age was 54 years (range 21-92 years). The most common diagnosis was breast cancer (24%), and the frequencies of other cancer diagnoses were quite evenly distributed in the sample. The majority of the patients were estimated to need 1 to 10 sessions (59%), and 8 sessions was the mean number of contacts (Table 1).

Patient contacts were most commonly initiated by referrals from other health care professionals, and mainly by nurses (40%) and physicians (16%). A substantial number of contacts were also initiated by the patients themselves or their spouses (15%). In some cases, referrals were initiated from more than one source.

3.2 | Motives for consulting an OSW

Table 2 displays the motives (n = 393) that the patients had for consulting an OSW. The most frequent initial motive, category 1, was to receive help in dealing with feelings connected to being diagnosed with cancer (33.5%), followed by category 2 (25.2%) involving distressing symptoms such as anxiety, worry, and depression. These

TABLE 1 Patient characteristics, referral source, and estimated number of sessions (N = 226)

| | Number, % |
|------------------------------|-----------|
| Mean age | 54 |
| Gender | |
| Female | 139 (62) |
| Male | 82 (36) |
| N/A | 5 (2) |
| Cancer diagnosis | |
| Breast | 55 (24) |
| Gastrointestinal | 23 (10) |
| Lung | 21 (9) |
| Prostate | 19 (8) |
| Gynaecological | 17 (8) |
| Brain | 17 (8) |
| Head and neck | 15 (7) |
| Other | 59 (26) |
| Referral source | |
| Nurse | 91 (40) |
| Physician | 36 (16) |
| Patient or spouse | 34 (15) |
| Several sources ¹ | 8 (4) |
| Other source ² | 53 (23) |
| Missing | 4 (2) |
| Number of sessions | |
| 1-5 | 72 (32) |
| 6-10 | 60 (27) |
| 11-15 | 23 (10) |
| 16-20 | 16 (7) |
| 21-25 | 8 (4) |
| >25 | 19 (8) |
| Mean | 8 |
| Missing/unspecified | 28 (12) |

¹For example, both physician and nurse.

²For example, physiotherapist, dietician, and occupational therapist.

TABLE 2 Initial and additional motives for consulting an oncology social worker

| Patients Ask for | Initial Motives (N = 254), N (%) | Additional Motives (N = 139), N (%) |
|---|----------------------------------|-------------------------------------|
| 1. Help in dealing with feelings connected to being diagnosed with cancer | 85 (33.5) | 8 (5.8) |
| 2. Help with distressing symptoms | 64 (25.2) | 18 (12.9) |
| 3. Guidance in how to deal with relationships with next of kin and others | 24 (9.4) | 52 (37.4) |
| 4. Assistance regarding socio-economic and juridical questions | 35 (13.8) | 37 (26.6) |
| 5. Guidance in how to carry on despite being burdened by cancer | 38 (15.0) | 19 (13.7) |
| 6. Reflections about dying and death | 8 (3.1) | 5 (3.6) |

latter motives concerned symptoms—rather than more specified psychosocial needs—without any reference to what they were about, for instance, if the symptoms were related or not to having cancer. Hence,

rather than making simplified assumptions and placing them in category 1, we chose to put these motives in a separate category even though it is reasonable to believe that a considerable portion of these motives were connected to the other categories, especially to category 1.

In contrast to categories 1 and 2, category 5 (how to carry on despite being burdened by cancer) was more associated with the return to everyday life after treatment (return to work and family, dealing with side effects, etc) and was generally not related to a critical situation, such as receiving the diagnosis. Similarly, categories 3 and 4 were also related to everyday life issues, eg, how to deal with relationships to next of kin and others and a need for socio-economic and juridical help to handle the new situation (eg, specific rights to economic support, applications for rehabilitation, sick leave, etc). Finally, category 6 concerned more existential issues about dying and death that the patients wanted to talk about (eg, fear of death, leaving next of kin and children behind, practical arrangements, etc).

In contrast to the initial motives, the most prominent additional motives that later came up during consultations were a need for guidance in how to deal with relationships with next of kin and others (37.4%) and assistance regarding socio-economic and juridical questions (26.6%). Adding the additional motives to the initial motives did not change the rank order of the first 2 motives, but the frequency of the four most prominent motives became more evenly distributed.

4 | DISCUSSION

Collecting patient cases that Swedish OSWs met during a typical week presented some interesting findings about their clinical work and function. Women were overrepresented in the cases, and breast cancer was by far the most common diagnosis (24%). Men and prostate cancer (8%) were underrepresented in the patient cases because prostate cancer (like breast cancer) represents about 30% of cancer incidences in Sweden.¹⁷ These results confirm previous studies suggesting that a woman with breast cancer is the “typical patient” in psychosocial care.¹⁸ It has also been suggested that men with prostate cancer are more likely to find their support within the family.¹⁹ We also found that brain cancer was overrepresented in the sample (8% in the sample vs 1% in the general population). This might tell us something about the substantial burden and vulnerability that is connected to this particular form of cancer.

In total, more than half of the patients initially consulted the OSW for help and guidance in dealing with feelings connected to being diagnosed with cancer, distressing symptoms, and how to carry on despite being burdened by cancer (categories 1, 2, and 5). However, when taking the additional motives into account, the needs for guidance in how to deal with relationships and for assistance with socio-economic and juridical questions became more evident (categories 3 and 4). The fact that so few motives concerned reflections about dying and death (category 6) might come as a surprise, but this is in fact in line with previous studies showing that patients with severe cancer primarily focus on living in the present and are less interested in talking about dying and death.^{20,21} These results show that the OSW's function is

multifaceted and that the initial motives among patients rarely predict the content in consultations over time.

From the initial despair associated with being diagnosed with cancer, questions associated with managing the new everyday life situation such as moving on in life and dealing with relationships and one's overall life situation were added over time. These results parallel the process of progression when the patient psychologically comes to terms with their new situation. After the initial period of personal despair, which is when the contact with the OSW is most often established, focus is broadened to include more social challenges, ie, the patient begins to focus on returning to work and to reflect on changed relationships, their financial situation, etc. These results might also be seen as a good example of how OSWs are providing services through a "continuum of care,"^{3,22} ie, from diagnosis, through phases of treatment, and then to different transitions to everyday life or "a new type of normal,"²³ and occasionally to terminal care. Overall, the OSWs are providing assistance in helping the patient "to carry on as before."²¹

However, even if this transition is well known, we should be aware of that it reflects something common, but not mandatory, for all patients. In a similar study of motives that cancer patients had for consulting a psychologist, more than a third of the patients wanted to talk about problematic relationships that were not connected or were only remotely connected to the cancer disease.²⁴ It is also known that, overall, distress is not a common denominator for cancer patients' desire for psychosocial support and that quite a few patients without diagnosed distress express a need for support.²⁵ In current psychosocial oncology, there is a focus on identifying distressed patients, preferably at an early stage of the disease process, but it thus seems obvious that this is not enough. To be able to provide appropriate support, we have to be more idiosyncratic, ie, we need to understand *what* kinds of problems are burdening patients with cancer. The present study is a contribution to this.

Considering that more than half of the patients in the present study were referred to the OSWs due to feelings connected to being diagnosed with cancer and distressing symptoms, while issues on relationships were a far more common additional motive during the consultations, our results indicate that health care professionals in general should be attentive to the fact that issues on relationships might be of great concern for patients, even if at first glimpse this does not seem to be the case. The fact that the majority of patients (83%) in this study were referred to an OSW by other health care professionals stresses the importance that these professionals are informed of the OSWs' specific function for cancer patients and what they deal with in consultations with these patients. At present, this kind of knowledge seem scarce.³

The diversity of motives identified here—from questions on socio-economic and juridical grounds, to issues of relationships, to questions about dealing with and living in a new and more vulnerable life situation—tells us something about what kind of broad competence the OSW needs in patient consultations. Because only about 20% of the motives concerned socio-economic and juridical questions and the rest concerned more psychological issues, it seems obvious that OSWs (at least in Sweden) need a broad education in counselling psychology. This is also supported by a previous study¹⁴ where Swedish OSWs

primarily asked for more training in counselling and psychotherapy, while very few asked for additional training regarding juridical and socio-economic issues. The fact that a substantial proportion of the consultations had a focus on symptomatology in terms of anxiety and depression also highlights the importance of providing the OSWs with knowledge of the differentiation between normal sorrow/sadness and depressive disorders, ie, when a more psychiatric intervention is needed. This might be especially challenging in the context of somatic care when medical treatment can interfere with the patient's psychological well-being, ie, that side effects from treatment might be mistaken for mood disorders.

4.1 | Study limitations

A potential limitation of the study is that it is restricted to OSWs working at least 50% in adult oncology. In smaller hospitals, OSWs usually work less than 50% with cancer patients and share their time in different departments, which might restrict the transferability of the findings to these OSWs. Furthermore, the results are obviously tied to a specific sociomedical context, ie, the Swedish health care system and OSWs' function within this system. However, our findings are compatible with previous research^{26,27} and may thus tell us something about cancer patients' needs in consultations with psychosocial expertise even outside the Swedish context.

We should also be aware of that the process of dialogical intersubjectivity, when it comes to categorisation in a research team, is not a simple and straightforward process, as it might be contaminated by preconceptions or even "group think."²⁸ However, to reduce this potential problem, the initial coding procedure in the previous study,¹⁴ where the categories were developed, was independently performed by the first and the second author. It did thus not solely rely on one researcher's interpretations. The few disagreements between these authors were then handled by joint discussions in the research team. Furthermore, the codes were of a concrete and substantial nature, which probably first of all made it less likely that preconceptions were the main causes behind the intersubjective agreement.

Finally, the fact that the motives were based on the OSWs' perceptions and did not emanate directly from the patients themselves might be seen as a shortcoming of the study. However, the OSWs' long experience (on average 8 years) and the fact that they provided concrete information from ongoing, documented contacts suggests that they were well acquainted with the presented cases and with the patients' motives.

There are some obvious methodological strengths of this study. First and foremost, the results are *grounded* in quite a few real patient cases, rather than just OSWs' thoughts about what they were doing. This supports the validity of the findings. The results thus provide insights into the clinical reality of OSWs and what kinds of topics they actually face in patient consultations. Second, it is a nationwide study with a quite acceptable response rate.

4.2 | Clinical implications

Our results show that Swedish OSWs' function is multifaceted and that the initial motives among patients rarely predict the content in

consultations over time. Based on the diversity of motives, it seems obvious that OSWs need a broad education in counselling psychology (eg, CBT and systemic and humanistic/existential psychology) as well as in how to identify a psychiatric disorder. In psychosocial oncology, there is usually a focus on identifying clinical levels of distress at an early stage of the disease process rather than focusing on *what kind* of support patients need.²⁹ The present study tells us that patients by and large are initially referred to the OSW due to psychological reactions to their illness, but relational issues and socio-economic/juridical questions later on become of major concern for the patient. Health care professionals should thus also be attentive to these concerns, even if it hardly is self-evident that they are connected to clinical levels of distress.

ACKNOWLEDGEMENTS

The study was supported by grants from The Kamprad Family Foundation for Entrepreneurship, Research and Charity.

CONFLICT OF INTEREST

The authors have declared that there is no conflict of interest.

ORCID

Joakim Isaksson  <http://orcid.org/0000-0002-2048-9814>

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How to cite this article: Isaksson J, Lilliehorn S, Salander P. Cancer patients' motives for psychosocial consultation—Oncology social workers' perceptions of 226 patient cases. *Psycho-Oncology*. 2018;27:1180-1184. <https://doi.org/10.1002/pon.4633>