



SHORT COMMUNICATION

Evaluating a centralised cancer support centre in the remote region of Northern Norway

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ABSTRACT:

Introduction: Being diagnosed with cancer and undergoing treatment is a life-changing experience, and many cancer patients find the physical, emotional and social effects of the disease to be stressful. This study explores the experiences of cancer patients and their relatives from all parts of Northern Norway visiting the centralised cancer support centre.

Methods: In a comprehensive prospective survey, 286 visitors

were invited to participate and 181 of these accepted. The characteristics of the participants, their expectations for visiting the centre, whether they wanted to meet peers or volunteers rather than clinicians and how they viewed the centre in the context of cancer care were evaluated.

Results: Most satisfied were visitors aged less than 50 years, women and those reporting a 'strong social network'. The majority

of the visitors wanted to have better access to peers (with a similar cancer diagnosis) (89%), cancer nurses (75%) or oncologists (71%). About a third of the participants (29.8%) lived in communities with fewer than 5000 inhabitants and 59.4% in municipalities with fewer than 15 inhabitants/km². There were no significant differences in the characteristics of the participants, or in their evaluation of the support centre, when stratified by number of inhabitants or population density in their home community.

Keywords:

cancer, counselling, Norway, peers, prospective survey, rehabilitation, support centre

Conclusion: The cancer support centre was highly valued by patients and their relatives for meeting peers. The centre was most frequently visited by and most popular among women and those self-reporting strong social networks. Access to oncology doctors and nurses in this setting could be valuable. Participants living in remote areas had similar characteristics and evaluated the support centre similarly to those living in more urban areas.

FULL ARTICLE:

Introduction

Cancer is a frequently occurring disease and can be frightening for patients and their relatives, leading to important changes in daily life. Treatment regimens often stretch over weeks and months, and many patients in Norway live far from the hospital responsible for their treatment, especially in the many remote areas of Northern Norway. This means being away from home for long periods at a vulnerable time in their lives.

In general, hospital wards are busy, allowing limited time to discuss subjects other than treatment and diagnosis-related issues. Additionally, the past decade has seen a shift toward more outpatient treatment. Hence, many unaddressed questions arise after outpatient treatment, or after the end of initial treatment^{1,2}. As a result, health authorities are increasingly focusing on supportive care and rehabilitation for cancer patients and their relatives. A report on rehabilitation for cancer patients from the Norwegian Directorate of Health points out the gap between what could be offered by the public health system and what individuals have to deal with on their own³. Peers, patient organisations and non-profit organisations play important roles in filling this gap⁴.

In Norway, there are few rehabilitation centres for cancer patients. However, establishing a cancer support centre, known as *Vardesenter* in Norwegian (hereafter abbreviated to VS) in the main hospitals in Norway is one way of addressing the needs of patients and relatives for information and support during and after treatment. These are 'drop-in' centres, where visitors may receive information, support and counselling, take part in activities, meet peers or just find some peace and rest. In addition to peers and volunteers, two full-time workers run the centre at the University Hospital of North Norway (UNN) on a daily basis: one cancer nurse and one assistant without healthcare education.

The concept of VS is somewhat rare internationally and there is limited knowledge of its impact, especially when located in a centralised hospital with many visitors living in remote communities.

This prospective survey explored the following questions:

- What are the characteristics of the visitors using the centre?
- What are their reasons and expectations for visiting the centre?
- If available, would patients and their relatives prefer to meet healthcare professionals rather than peers and volunteers?
- How do patients and their relatives understand the position and role of the centre in the context of cancer care as a whole?
- Are there any major significant differences in the characteristics of the participants, or of the evaluation of the support centre, when stratified by participants living in towns versus remote communities?

Methods

The Northern Norway Regional Health Authority is one of four regional health authorities in Norway under the Ministry of Health providing specialised health care to the population. UNN is the only tertiary level hospital in the region and is responsible for most cancer specialist services⁵. The population density is 4.3 inhabitants/km²^{5,6} – less than the average for Norway (15.4 people/km²) but quite similar to that of Canada (4.0 inhabitants/km²) and of Australia (3.1 people/km²). Most people in Norway live in small community centres (82%), but Northern Norway is the region with the highest proportion (27%) of people whose house is more than 50 m to the nearest neighbour⁷.

In collaboration with the Norwegian Cancer Society, a VS was established at UNN. Following a pilot study, cancer patients and relatives visiting the centre at the hospital were recruited to participate in a comprehensive prospective survey.

Statistics

All statistical analyses were performed with the Statistical Package for the Social Sciences v24 (SPSS; <http://www.spss.com>). Associations between different variables were examined using Spearman's rank correlation and the χ^2 or Fisher's exact test. $p \leq 0.05$ was considered as statistically significant for all analyses.

Ethics approval

The local data protection officer at UNN approved the collection of information. The study was defined as a registration study (2014/5222-0430), so the ethical committee waived the need for written consent.

Results

From February 2015 to August 2017, 286 visitors to the centre were invited to participate in the survey. A total of 181 accepted, giving an inclusion rate of 63.3%. Median age was 57 (range 24–98) years. Most visitors attended the centre more than once. The median number of visits was 5 (1–111) times.

Visitor characteristics are shown in Table 1 and visitors' reasons and expectations for attending the centre are presented in Table 2. As shown in Table 3, visitors most frequently wanted better access to peers with a cancer diagnosis (89%), a nurse specialised in cancer care (75%), an oncologist (71%) and volunteers (not peers or healthcare professionals) (71%). Understandings of patients and relatives of the role of the centre in cancer care as a whole are shown in Table 4.

Table 1: Demographics of participating visitors at the Vardesenter, University Hospital of North Norway (n=181)

Characteristic	n (valid %)
Gender	
Female	133 (74)
Male	47 (26)
(Missing)	1
Occupational status	
Working	47 (26)
Student	3 (2)
Unemployed	1 (1)
Sick leave	58 (32)
Retired	44 (24)
Disability pension	46 (25)
Other	14 (8)
Education	
Primary school	22 (12)
Secondary school	70 (39)
College/university 1–4 years	47 (26)
College/university >4 years	41 (23)
Status as visitor	
Patient	165 (91)
Relative	16 (9)
Cancer diagnosis	
Breast cancer	84 (46)
Prostate cancer	18 (10)
Gastrointestinal cancer	10 (6)
Lung cancer	7 (4)
Other malignancy	49 (27)
No cancer diagnosis	16 (9)
Status cancer treatment	
Outpatient	81 (45)
Inpatient	28 (16)
Treatment ended <5 years ago	41 (23)
Treatment ended >5 years ago	6 (3)
Other	3 (2)
No cancer treatment	16 (9)
Present treatment modality	
Chemotherapy	45 (25)
Radiotherapy	94 (52)
Surgery	12 (7)
Other	13 (7)
No present cancer treatment	60 (33)

Table 2: Participating visitors' reasons and expectations for attending the *Vardesenter* (n=181)

Question about and reason for VS visit	n (valid %)
Why did you visit the VS? (You may choose more than one option)	
To meet others in the same situation	104 (58)
To get information	56 (31)
To participate in a course/group	29 (16)
For a change of environment	60 (33)
No specific reason	44 (24)
For an appointment	2 (1)
Other	47 (26)
How did you get in contact with the VS?	
Other patients	58 (32)
General practitioner in local community	2 (1)
Physician at UNN	17 (9)
Nurse in local community	20 (11)
Nurse at UNN	64 (35)
Leaflets	63 (35)
Internet	16 (9)
Other	26 (14)
Which statement(s) best describe(s) today's visit? (You may choose more than one option)	
A setting and meeting place to meet cancer patients, their relatives and healthcare professionals	107 (60)
A place with quality of life promoting activities	69 (39)
A place to get information, support and guidance	103 (58)
A place to take part in activities	54 (30)
A place to meet peers	119 (67)
A place for rest and peace	57 (32)
Who did you meet at the VS today? (You may choose more than one option)	
Healthcare professionals	84 (46)
Peer	65 (36)
Peer with the same cancer diagnosis	27 (15)
Peer with another cancer diagnosis	32 (18)
Peer – do not know cancer diagnosis	15 (8)
Volunteer	124 (69)
Other patients	79 (44)
Other patients' relatives	14 (8)
Other	17 (9)
Do not know	3 (2)
How satisfied are you with your visit to the VS today?	
Not at all	0 (0)
A little	3 (2)
Quite a bit	29 (16)
Very much	144 (80)
(Missing)	5 (3)

UNN, University Hospital of North Norway, VS, *Vardesenter*.

Table 3: Type of access visitors pursue through the *Vardesenter* (n=181)

Do you want better access to one or more of the following at the VS?	Yes – total (valid % after missing excluded)	Yes – 'very much' (valid % after missing excluded)
Peer (with a cancer diagnosis)	146 (89)	39 (28)
Nurse specialised in cancer care	123 (75)	33 (28)
Oncologist (physician specialised in cancer care)	117 (71)	33 (29)
Volunteer (not a healthcare professional or a peer)	117 (71)	20 (17)
Other patients	116 (70)	28 (25)
Physical therapist	109 (66)	23 (21)
Other patients' relatives	101 (61)	9 (9)
Psychologist	98 (60)	21 (21)
Social worker	96 (58)	14 (16)
Chaplain	92 (56)	6 (7)
Physician (not oncologist)	91 (55)	5 (5)
Nurse not specialised in cancer care	91 (55)	3 (3)
Other	20 (12)	1 (5)

VS, *Vardesenter*.

Table 4: Patients' and relatives' understanding of the position and role of the *Vardesenter* in the total cancer care service (n=181)

Role and position of the VS	n (valid %)
Do you consider the VS as an <i>integrated</i> part of the healthcare system?	
Not at all	7 (4)
A little	34 (19)
Quite a bit	62 (34)
Very much	73 (40)
(Missing)	5 (3)
Do you consider the VS as a <i>supplement</i> to the healthcare system?	
Not at all	3 (2)
A little	17 (9)
Quite a bit	57 (32)
Very much	97 (54)
(Missing)	7 (4)
Regarding why you attended the VS today, could your own network (family and friends) have adequately replaced this visit?	
Not at all	108 (60)
A little	37 (20)
Quite a bit	22 (12)
Very much	6 (3)
(Missing)	8 (4)
How strong would you consider your <i>present</i> network (family and friends)?	
Not at all	0 (0)
A little	24 (13)
Quite a bit	61 (34)
Very much	92 (51)
(Missing)	4 (2)
How strong would you say your network (family and friends) was <i>before</i> your cancer diagnosis?	
Not at all	3 (2)
A little	19 (22)
Quite a bit	66 (37)
Very much	87 (48)
(Missing)	6 (3)
To what extent do you contact the healthcare system when you feel the need for it?	
Not at all	2 (1)
A little	65 (36)
Quite a bit	85 (47)
Very much	24 (13)
(Missing)	5 (3)
To what extent should coordination between services at the VS and services in the rest of the healthcare system be improved?	
Not at all	20 (11)
A little	41 (23)
Quite a bit	71 (39)
Very much	31 (17)
(Missing)	18 (10)
Would you like a VS to be established in your local community?	
Yes	154 (85)
No	10 (6)
(Missing)	17 (9)

VS, *Vardesenter*.

Correlation analyses

As shown in Table 2, 96% of the visitors were 'quite a bit' (16%) or 'very much' (80%) satisfied with their stay at the centre. People in the following categories were most satisfied with their visit: women ($r=0.25, p=0.001$), those aged <50 years ($r=0.19, p=0.13$), those who met peers (other cancer patients) ($r=0.20, p=0.008$), those who regarded the centre as an integrated ($r=0.30, p<0.001$) or complementary part ($r=0.31, p=0.002$) of the healthcare system and those with a self-reported strong social network ($r=0.17, p=0.03$).

Participants' communities classified by number of inhabitants and population density

Some participants came from towns with social structures similar to other European densely populated areas, but many lived in rural and remote municipalities (range 900–71 600 inhabitants). Fifty-six participants (31.1%) lived in urban areas with 25 000–100 000 inhabitants, 40 (22.2%) in communities with 10 000–25 000 inhabitants, 30 (16.7%) in communities with 5000–10 000 inhabitants and 54 (29.8%) in communities with <5000 inhabitants. The communities were also categorised by population density (range 0.3–55.7 inhabitants/km²): 73 (40.6%) lived in areas with more than 15 inhabitants/km², 48 (26.7%) in areas with 5–15 inhabitants/km² and 59 (32.7 %) in areas with

<5 inhabitants/km². There were no significant differences ($r<0.2$ and/or $p>0.05$) in the characteristics of the participants, or in the evaluation of the support centre, when stratified by number of inhabitants or population density.

Discussion

The majority of visitors to the VS were women, and breast cancer was the most frequent diagnosis. Almost half of the visitors were outpatients. 'To meet others in the same situation' was the most frequent reason for visiting the centre. Visitors wanted better access to peers with a cancer diagnosis, a nurse specialised in cancer care, an oncologist or volunteers. Visitors regarded the centre both as an integrated and a complementary part of the healthcare system and wanted a cancer care centre to be established in their local community. Four out of five people were very satisfied with their visit to the centre, and most satisfied were visitors aged less than 50 years, women, those reporting a 'strong social network', or those categorising the VS as an integrated or complementary part of the healthcare system.

One of the most striking findings was that participants living in more remote areas had similar characteristics and evaluated the support centre in a similar way to those living in more urban areas. There is evidence from an Australian study that increasing remoteness is not associated with higher distress among cancer

patients; hence, emotional concerns appear to be prevalent irrespective of urban or remote location⁸. This also concurs with a Scottish study, where rural female breast cancer patients reported similar unmet needs to their urban counterparts⁹. However, in the same study the authors emphasised specific concerns among rural women related to distance from services. This is mirrored by the fact that a large majority of the visitors in the present study wanted a similar support centre in their home community.

In agreement with previous findings that men participate less in cancer rehabilitation programs than women¹⁰⁻¹², the majority of visitors to this centre were women. Further supporting these findings, two comprehensive reviews showed that most rehabilitation programs for cancer patients addressed women with breast cancer^{13,14}. This study does not explain why women were in the majority; however, the finding is in accordance with the results from a study by Ohlsson-Nevo et al¹⁵, showing that women were most interested in participating in rehabilitation programs. Further, Holm et al¹⁰ state that women are 'more likely to express a need for rehabilitation; they took part more often in activities relevant for psychological and physical problems and had, to a higher extent, fulfilled their emotional needs'.

Many of the women visiting the centre were outpatients, as a result of their breast cancer diagnosis and adjuvant radiotherapy treatment. Additionally, as emphasised, this university hospital recruits patients from a vast area with remote locations. Hence, their stay in the city of Tromsø (eg at the patient hotel) may last several weeks, even though they are outpatients. Finally, the location of the centre, close to the treatment facilities, encourages drop-in visits.

In this study, patients who met peers (other cancer patients), or health personnel with special knowledge of cancer (cancer nurses or oncologists), were most satisfied with their visit to the centre. Meeting peer supporters can provide a framework for positive social comparisons and they are often empathic listeners, functioning as 'containers' for the fears and emotional chaos of patients and relatives¹⁶. Skirbekk et al⁴ observed how peer supporters communicate well with both patients and relatives. Peer supporters could also provide patients and relatives with hope simply by demonstrating that survival is possible, but also through their friendly acceptance of the stories of patients and relatives⁴.

Another important finding is that visitors wanted to talk to specialised cancer care providers rather than general physicians,

nurses and other allied healthcare providers. A comprehensive qualitative study by Ervik et al¹ reported that men with prostate cancer preferred to talk to someone with in-depth knowledge of their specific cancer type. As treatment strategies for patients with the same diagnosis may vary considerably, placing one's own treatment/situation in the right context by talking to a specialist may be pivotal to avoid misunderstandings. This is also supported by Kinnane¹⁷ and Garmy and Jakobsson¹¹, who emphasise the importance of employing a specialised trained nurse in addition to trained volunteers in drop-in centres.

Strengths and limitations

The major strength of this study is the prospective design and the fact that both urban and most types of remote and rural communities are represented. Even though a pilot was conducted, a major limitation is that the survey has not been validated in other cohorts. Ideally, the researchers would have preferred to include a larger group of relatives, as the low number excludes the possibility to perform a solid analysis of this subgroup separately.

Conclusion

The VS at UNN seemed to be a much-appreciated meeting place where the visitors valued information from both healthcare providers and peers. This service is probably not well known among GPs, and efforts to improve this could encourage even more patients to visit the centre. Increased recruitment of peers representing a wide variety of tumour types with an even gender distribution may be a reasonable aim for a future study. Participants living in remote areas had similar characteristics and evaluated the VS similarly to those living in more urban areas. Peers with a cancer diagnosis and healthcare providers specialised in cancer care are probably less accessible in remote areas. However, emotional concerns appear to be prevalent irrespective of urban or remote location, which is an issue deserving of attention after visitors return to their home community.

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