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Exploring the meaning, role and experiences of a patient-led social innovation for people affected by cancer: a new collaborative care model complementing traditional cancer rehabilitation in Sweden

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ABSTRACT

Objective Kraftens Hus is the first support centre in Sweden designed by and for people affected by cancer, including patients, family, friends, staff members and local community representatives (collectively 'stakeholders'). The purpose of this study was to explore the meaning, role and experiences of Kraftens Hus stakeholders using a patient and public involved methodology.

Methods To understand and map the experiences of visitors to Kraftens Hus, we applied concept mapping (CM), a mixed methods approach where data are collected and analysed in four structured steps designed to capture the diverse perspectives of multiple stakeholders. Qualitative interviews with relevant stakeholders supplemented the CM findings.

Results The final concept map contained six clusters of ideas. Within the clusters, there was a recurring theme that cancer-affected people value accessible and long-term psychosocial support (PSS). The intended emotional, social and practical needs identified in a previous design process seem to have been addressed and appreciated by Kraftens Hus visitors.

Conclusion Kraftens Hus is an example of a new patient-led social innovation based on a life-event perspective and integration of resources from different sectors in society. By focusing on life, not the disease, the care continuum expands, and long-term PSS is provided alongside cancer treatment. The evaluation confirms that PSS should focus on health and well-being in the broadest sense.

INTRODUCTION

Shifting the focus from cancer as solely a medical condition to the life of the person affected by cancer can enable new actors to emerge, and services evolve. Such new components can complement and exceed the parameters of healthcare institutions. In this manuscript, we describe and evaluate the patient-led social innovation of Kraftens Hus (ie, a new solution with collaboration between private and public actors in Sweden with the aim of improving the well-being of people affected by cancer (patients, family, friends, staff members and local community representatives) in cancer support. By focusing on the persons affected by cancer and their surrounding ecologies, that is, stakeholders, a new collaborative care model that integrates resources in the society (private and public) has been generated.

Receiving a cancer diagnosis is often a frightening experience that affects patients and their social network, including family, friends and even the surrounding community. Patients with cancer often stress the need for ongoing psychosocial support (PSS) for themselves and their loved ones, not only during the time of treatment. This need includes both rehabilitation and PSS. Rehabilitation provided by healthcare institutions more often than not focuses on medical aspects and thereby more on the object (the patient with cancer) rather than on the subject (the person living with cancer in a social context). There are examples of rehabilitation in connection to treatment[1] and as internet-led interventions,[2] but most are time-restricted and require a referral from the cancer clinic. The European Partnership for Action Against Cancer has emphasised the need for a more patient-centred approach with less focus on disease management.[3] Recently, the term cancer rehabilitation has been introduced in Sweden and incorporated into policy documents and national guidelines. Cancer rehabilitation in the Swedish context takes a more holistic view of the patient within their social context and emphasises long-term supportive care strategies.[4] Healthcare institutions are also more actively including the

patients' perspective by increased use of person-centred approaches,[5] self-reported patient outcomes[6] and mobile technologies to collect patient mission statements to guide care.[7] However, most actions are directed towards specialist care and not for the vulnerable time following cancer treatment. Additionally, even though many countries have incorporated PSS into their national guidelines, there are still many difficulties, barriers and constraints before it is implemented in daily care.[8]

After completed cancer treatment, patients are expected to return to everyday life, but many still report feeling lonely and experiencing existential needs that are hard to express.[9] Patients tend to seek help from their loved ones or close friends.[10] Even if most loved ones want to provide support, it can become burdensome, particularly if the patient suffers a relapse or is in a palliative state of the disease.[11] There is a risk that the loved ones themselves develop a stress-related illness after supporting a family member.[12] However, oncology-specific care might not be able to meet this need for further PSS for the patient and their surrounding network. In fact, there is a need to distinguish, or at least discuss, when the oncology clinic's responsibility to provide rehabilitation should end and instead be transferred to other sources within the society. Such PSS could and should then focus on all people affected by cancer, not just the individual patient.

To view a person in social context also reveals actors outside the traditional healthcare system (public, private, non-profit and personal) that may be relevant for the person's cancer rehabilitation. However, the 'pillarisation' or 'siloisation'[13–15] in the Swedish—and other comparable—welfare systems is a well-recognised difficulty when addressing challenges that require interorganisational and intersectoral collaboration.[16 17] In these situations, person-centred approaches[18] are helpful in recognising the active contribution of the patients in these collaborations,[19] since they are the ones who need to navigate the fragmented welfare system.[20] In order to achieve a more person-centred PSS, there is a need for new collaborative care models stretching over the care continuum to complement and exceed the parameters of healthcare institutions.

Kraftens Hus cancer support centre

A vast majority of Swedish cancer care is tax-financed and delivered by each of 21 counties with independent financial responsibility. In 2009, the Swedish government launched a national cancer strategy. As a result, six regional cancer centres received a governmental assignment to enable more patient-oriented cancer care with focus areas including, but not limited to, PSS, rehabilitation and the patient's role in care. Regional Cancer Centre West (RCC West) was early in finding ways for patient involvement and challenging existing structures between separate entities within the healthcare system.

Kraftens Hus was initiated by representatives on RCC West's board of patients and relatives, who highlighted the need for complementary rehabilitation, focusing on emotional and social support for all people affected by cancer, not just the individuals diagnosed with cancer. The design process of Kraftens Hus was highly influenced by patients who were an active part of the design team. In the design process, a life-event perspective (the life event of getting a cancer diagnosis)[21] was applied to include the perspective of all actors that are involved in the life event, essentially shifting the focus from the disease (medical) to the patient's entire ecology (emotional, social and practical).

Kraftens Hus (translated to mean 'the house of power') is a social innovation between private and public sectors designed to improve emotional, social and practical well-being of all those affected by cancer. Kraftens Hus opened in 2018 in the city of Borås and is run as a non-profit organisation (NPO) with a board of cancer-affected persons and representatives from the local hospital, the municipality, the region and local businesses. It is not part of the hospital and is located close to the city centre to be accessible for all citizens. By offering people affected by cancer emotional, social and practical support, Kraftens Hus takes on a new role in the Swedish welfare system on the boundary between the healthcare system and other social actors. Visitors come to the venue to meet and support each other, participate in physical activities such as yoga and meditation, enjoy a cup of coffee and conversation around the kitchen table, engage in creative arts-based activities like painting and listen to lectures on cancer-related topics. All activities are developed in close cooperation with the visitors. The activities are free of charge and intended to promote health, increase the ability for self-care and to be a complement to the cancer rehabilitation offered by the hospital.

As the first Swedish cancer support centre designed by and for people affected by cancer, it is essential that the evaluation of Kraftens Hus considers the lived experiences of those affected by cancer as well as other relevant stakeholders interacting with Kraftens Hus. Thus, the purpose of this study was to explore the meaning, role and experiences of Kraftens Hus for relevant stakeholders.

METHOD

This study is part of a longitudinal action research project[22] on how patients can lead and contribute to social innovation in cancer support. One important aspect of action research is achieving change and improving social practice,[23] and it is vital to address inequities such as inadequate access to public services.[24] In the present article, we focus on the evaluation of Kraftens Hus using a mixed methods approach (qualitative interviews and concept mapping (CM)) to capture the range of stakeholder perspectives. The transdisciplinary research team consisted of people with experience in action research, research methodology specifically CM, codesign and Patient and Public Involvement (PPI).

Patient and public involvement

The methodology used in this study engaged Kraftens Hus stakeholders in data generation and some parts of the interpretation of findings. In our case, stakeholders were people affected by cancer, including patients, family, friends and members of staff at Kraftens Hus.

Qualitative interviews

As a part of the action research project described previously, we conducted semistructured qualitative interviews with 9 patients with cancer and 12 representatives from the local community (ie, hospital, government, business, social insurance and job centre). Prior to the individual interviews, the interviewer facilitated a focus group discussion with patients with cancer who had visited Kraftens Hus. The focus group discussion plus meetings with Kraftens Hus staff informed the development of the interview guide. In the current paper, quotes from these interviews are used to supplement the CM findings and are not intended for independent interpretation.

Concept mapping

We applied CM, a mixed methods research approach in which data were collected and analysed in four structured steps.[25 26] The methodology has been used to help define and evaluate experience not easily captured by standard evaluation techniques.[27] CM enables coproduction of data and analysis since the stakeholders are involved in multiple steps of the process.

Idea generation and sampling strategy

As a first step, three stakeholders who regularly visited Kraftens Hus were provided with three suggested evaluative focus prompts. After feedback from these stakeholders, an evaluative focus prompt, 'For me, visiting Kraftens Hus has meant…', was used for idea generation. The aim was to reach the population of visitors at Kraftens Hus between July and September 2019. A convenience sampling strategy was applied to recruit participants.

During the study period, a member of the research team, stationed on site, invited all visitors to respond to the prompt and provided assistance if needed. Those who consented were provided an online link to fill in at home or using a computer available at the facility. In addition to data gathering on site, the link was also distributed via a mailing list and posted on social media.

The study form included the evaluative focus prompt, along with background and demographic questions. Participants were asked to reply to the prompt, forming a complete statement, at least three and no more than five times. These responses are referred to as 'ideas'.

To prepare for the additional CM steps, research team members cleaned the set of ideas. This involved eliminating identical or very similar ideas while ensuring no unique idea was excluded. Furthermore, complex answers consisting of more than one idea were split to contain only one idea each, whereas ideas which were out of scope (not consistent with prompt) were eliminated. Spelling and grammar were corrected. These actions resulted in a final set of unique ideas to be used in the next CM step—sorting.

Statistical methods

Sorting the ideas

A subset of participants from the idea generation step and additional stakeholders with professional knowledge of Kraftens Hus were recruited to sort the ideas. Using the online card sorting platform Optimal Sort,[28] the sorters individually generated categories/themes in which they placed ideas according to perceived conceptual similarity. The sorters were required to assign all ideas to a category and to provide a descriptive label for each category. Sorters were free to create as many categories as they found appropriate.

Mapping the ideas

The sorting data consisted of a matrix where rows and columns corresponded to the set of unique ideas, and each cell contained the number of times a particular pair of ideas had been sorted together, which could be translated to a distance in high-dimensional space (with as many dimensions as there were ideas). To enable graphical presentation of the sorting data, we applied multidimensional scaling (MDS),[25] which for each idea generated x-coordinates and y-coordinates in two-dimensional space. As a measure of how this represented the sorting data, a so-called stress value was calculated. Stress is a measure of how well the multidimensional sorting data can be represented by coordinates in two dimensions.[25]

Sturrock and Rocha[29] have suggested cut-off values which, depending on the number of ideas, signify a less than 1% chance of ideas being randomly sorted. Values below the cut-off indicate a structured and non-random sorting result.

Identifying concepts

Hierarchical cluster analysis (HCA)[25] applied on the coordinate output of MDS yielded clusters of ideas. Each iteration identifies which two clusters are closest together creating a new cluster from the union of the two, gradually decreasing the number of clusters. Any iteration in HCA corresponds to a cluster solution, and consequently, there are as many possible cluster solutions as there are ideas. The cluster solution is meant to balance details of the ideas without being too cumbersome. The final cluster solution is determined by the research team through a qualitative review of cluster solutions. The level of detail in the solutions studied should depend on the project in question.[25] Typically, a good balance is achieved with 5–15 clusters.

Cluster label analysis[25] is the final step of identifying the concepts. For each cluster, a mathematical algorithm is used to identify the closest fitting cluster labels suggested by the sorters. Finally, the research team carries out a final review and adjustment of the suggested labels. The resulting concept map is a point-plot of the coordinates

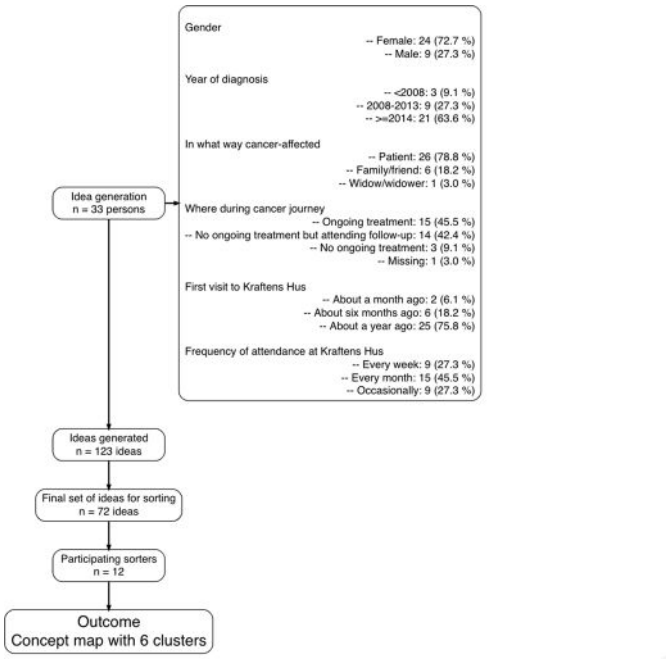

Figure 1 Consolidated Standards of Reporting Trials style flow diagram illustrating the participants and background data as well as the different data collection steps and output.

of the unique ideas also highlighting which points are contained in each specific cluster.

Data analysis was performed using R software.[30]

RESULTS

During the time of data collection, 303 visits were registered to Kraftens Hus (not equivalent to unique visitors). Thirty-three individuals responded to the study form and focus prompt. A flow diagram of participants and study procedures is shown in figure 1. Twenty-four (73.7%) of the participants were women. A majority of the respondents (78.8%) were patients with cancer, while the remaining ~20% were family/friends of patients diagnosed with cancer. For 21 individuals (63.6%), the connection to Kraftens Hus was in relation to cancers diagnosed in 2014 or later, and most were either actively undergoing treatment (45.5%) or attending regular follow-up (42.4%) at the time of participation in this study.

The participants generated a total of 123 ideas in response to the focus prompt. The research team then cleaned the data and obtained a set of 72 unique statements that most clearly represented the overall responses.

Twelve individuals took part in the sorting task of the study. Performing MDS on the sorted data yielded a two-dimensional point graph with a stress value of 0.208, which indicated non-randomly arranged ideas.[29] After reviewing the HCA output of possible cluster solutions, the research team agreed on a final cluster solution with six clusters. These clusters are described further together with illustrative quotes from the qualitative interviews as applicable. The final concept map is shown in figure 2 and examples of ideas in table 1. (All ideas are available in online supplemental file 1.)

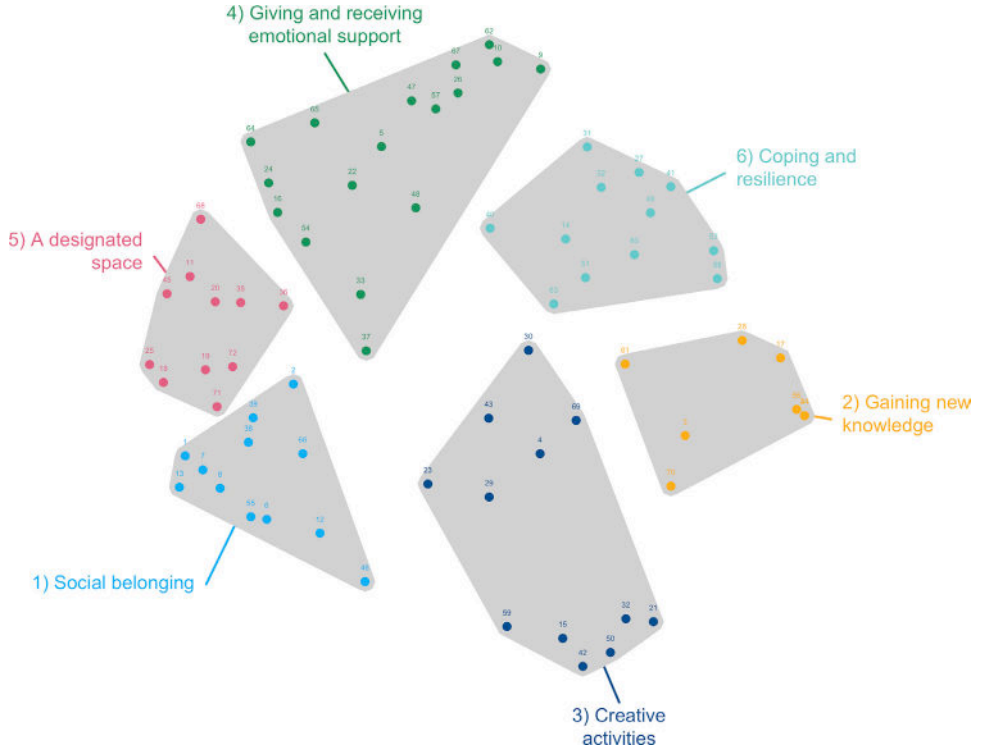

Figure 2 Final concept map. Each of the 72 ideas is shown as a numbered point in the map, with coordinates determined through multidimensional scaling of the sorting data. The shaded areas illustrate the six concepts identified through hierarchical cluster analysis.

Table 1 Examples of ideas from each of the six clusters

Idea number	For me, visiting Kraftens Hus has meant …
1. Social belonging (12 ideas in total).	
7	A comfortable place to meet in a difficult situation
13	That I can meet friends
39	A place where I am viewed as a person and not a patient
2. Gaining new knowledge (8 ideas in total).	
3	Inspiration to get to grips with my rehabilitation
17	New knowledge
44	That I have gained new knowledge about diet and the importance thereof
3. Creative activities (12 ideas in total).	
15	Support and enjoyment through arts and crafts.
32	Being able to be in a creative flow
59	That I have somewhere to go on the spur of the moment where I can just breathe out, chat and maybe do a jigsaw puzzle for a while
4. Giving and receiving emotional support (17 ideas in total).	
5	Working through the difficulties we have experienced in life together with my friends
22	That we were able to talk and get things out of our system
65	That I don't have to speak, only listen to others' experiences
5. A designated space (11 ideas in total)	
35	Being able to be yourself without having to explain
36	Enjoyable conversations
71	Feeling secure
6. Coping and resilience (12 ideas in total)	
41	That my husband and I have gained tools to cope with parenting two children of primary school age
53	That I have been able to find the energy to keep on fighting
60	The opportunity to see a psychologist/social worker

According to the respondents, meeting with other people who have similar experiences is an essential function of Kraftens Hus. Clusters 1, 4 and 5 highlight the importance of having a meeting place for people in the midst of a difficult life situation like cancer diagnosis, treatment and rehabilitation. This applies to the patients with cancer as well as their surrounding network of friends and family. Meeting others with similar experiences is seen as valuable as the visitor is seen as a person, not just as a patient, and that you do not have to explain yourself because the others often have similar experiences. This community also provides value by being given the opportunity to listen to the experiences of others.

Kraftens Hus as a meeting place also provides value through its activities, which is highlighted in clusters 2, 3 and 6. This can include gathering for creative or artistic exercises, which also provides social and emotional support in a difficult situation. Further, Kraftens Hus is valued as a source of knowledge on questions about living with cancer and inspiration for how to stimulate well-being and inspire rehabilitation.

Social belonging

Ideas identified in this cluster relate to the desire to be viewed as a person rather than a patient and being able to meet friends in a comfortable place, despite being in a difficult situation. Respondents noted the need for a space for patients themselves as well as their family members. The interviews confirmed the importance of social belonging. Interviewees discussed that when meeting others with similar experiences, they were able to talk, not only about healthcare specific topics but also about everyday life situations. Meeting others with a similar background was mentioned because of the loneliness and distress that many patients experienced:

> 'You know that the others understand. People who never had cancer can never understand. They can have an idea, but they cannot understand' (patient).

Moreover, it was strongly suggested that the loved ones also need support to deal with the life situation:

> 'The family, too, is affected. Physically, psychologically, socially, existentially and financially' (organisation representative).

Gaining new knowledge

At Kraftens Hus, lectures are given about various subjects related generally to cancer diagnoses and cancer rehabilitation specifically. The stakeholders' view on such input was mirrored in this cluster, including ideas such as finding inspiration to come to grips with rehabilitation and gaining knowledge about diet and physical activity.

> We participate by giving lectures and I believe we should strengthen this kind of collaboration […] rehabilitation coordinators have provided information about their process. (A healthcare professional from the local hospital).

Creative activities

Cluster 3 highlights the importance of creative activities such as physical and meditative exercises, painting and cooking—activities that feel meaningful and put you in a creative state together with others. Respondents emphasised that the focus is on well-being and not on the disease itself.

> I have experienced, when I have been feeling really down, that one forgets ailment, time and space, pain,

everything, worries, while being creative. Because it is not possible to focus on those things at the same time [as painting]. (Patient)

Giving and receiving social support

The duality of both giving and receiving social support was at the core of cluster 4. To be able to give of one's time to something meaningful by providing support, and to share experiences with those who needed them were for many as important as receiving support from people that could really understand what the person went through. This was confirmed by the interviews, where most patients mentioned the value of being able to discuss their experiences with others who had suffered from cancer, not least by sharing tips and tricks with one another about how to cope with pain, fatigue and so forth. One patient mentioned a positive experience of such peer discussions:

What motivates me is to help others. (Patient)

Designated space

Respondents attributed high importance to a physical meeting place where people can meet face-to-face. Being able to gather and engage in activities with people in similar situations filled a gap left after being dismissed from the safe setting of the oncology department. A hospital representative confirmed this, mentioning that cancer care has been improved considerably over the last 10 years by the introduction of special contact nurses, standardised pathways and so forth:

… but when we are done, there's a huge void. (Organisation representative)

Coping and resilience

Visitors to Kraftens Hus discussed finding ways to cope and be resilient in order to live and find hope in a vulnerable situation. Respondents said they wanted to mitigate the fear of cancer but also to get support and tools to cope in everyday life as cancer-affected individuals:

It was nothing that interfered with my everyday life, but rather I came home and felt that I had gained energy. (Patient)

DISCUSSION

To evaluate the meaning, role and experiences of Kraftens Hus stakeholders, we used CM methodology, which allowed the respondents to provide information that might have been missed using traditional evaluation surveys. Instead of responding to predetermined questions, a wider range of ideas were captured, diversifying the data from the respondents' perspective.[31] Further, CM methodology aligns with the cocreated design of Kraftens Hus, in which the intended users' perspectives have, from the beginning, guided and reinforced the development. Therefore, the current study responds to the GRIPP2 (Guidance for Reporting Involvement of Patients and the Public) guidelines for PPI in research.[32] Letting the stakeholders themselves define what visiting Kraftens Hus has meant can be seen as a form of member checking (ie, determining if the original ideas from the design process were also seen as valuable by Kraftens Hus stakeholders). Our findings indicate support for a life-perspective approach within PSS and cancer rehabilitation.

Our findings indicate that the intended emotional, social and practical needs seem to have been addressed and appreciated by Kraftens Hus visitors. All six clusters cover different aspects of such needs, with the left-hand side clusters (1, 4 and 5) more directed towards Kraftens Hus itself and the interaction it enables. Clusters on the right-hand side (2, 3 and 6) are more directed towards an inner development from visiting Kraftens Hus. Interestingly, no cluster specifically concerned medical aspects of the cancer, apart from cluster 2 (gaining new knowledge), but even here ideas were more related to moving on and feeling better.

Our results suggest that Kraftens Hus may meet the needs for PSS after cancer treatment and similar initiatives can be a part of long-term cancer rehabilitation. That some respondents were diagnosed even before 2008 indicates that receiving a cancer diagnosis may be, for some patients, a life-long event. In addition, the fact that over 20% of our respondents were not patients but were family/friend or widow/widower corresponds to the reported PSS needs for family members of patients with cancer.[11 12] To meet PSS needs is difficult for the healthcare system to accomplish and needs to be addressed by other means. In fact, cluster 5 and the quote illustrating it lead us to believe that this is well recognised by patients, their loved ones and oncology care professionals. However, when discussing long-term survivorship after cancer, there is still a concentrated focus on the healthcare institutions and no other actors in society.[33] In fact, the patient-led design of Kraftens Hus shows that when patients are leading social innovations, new aspects of how and where such PSS can be delivered are discovered. All activities at Kraftens Hus have been developed in close collaboration with people affected by cancer. Intended to complement the cancer rehabilitation offered by the healthcare system, Kraftens Hus is aimed at promoting the broadest sense of health and well-being within the entire ecological system of those affected by cancer. Thus, clusters 3 (creative activities) and 5 (a designated space) suggest that the intended goals are recognised and appreciated by the visitors.

The role and meaning of Kraftens Hus described in clusters 1 (social belonging), 4 (giving and receiving emotional support) and 6 (coping and resilience) enhance both the perceived long-term need PSS and that which is gained by visiting Kraftens Hus. Similar unmet psychosocial needs are described by Arroyo *et al*,[34] who also report that even if the meaning of life is slowly restored for most, the need for help to move forward with

life seems to remain for those with a cancer diagnosis. For some individual long-term survivors, the PSS needs were described as being chronic. Many cancer diagnoses are also increasingly referred to as chronic, with psychological burden remaining high, and patients reporting ongoing experiences of difficulties accessing support and services.[35] Viewing cancer as a chronic disease indicates a need for new initiatives for chronic PSS. Kraftens Hus constitutes an example of such an initiative. Because Kraftens Hus is a free service, where no referral from any cancer treating clinic is required, visitors can easily access ongoing and relevant PSS in a new setting not previously found in Sweden.

One kind of support that the initiating Kraftens Hus patients emphasised that was not highlighted by the respondents in the present study was the more work-related support channels such as the Swedish public employment service and the Swedish social insurance agency. Very few ideas in the concept map referred to practical matters regarding employment and social insurance. These areas may still need further attention in future studies and similar initiatives.

The creation of Kraftens Hus illustrates the shift in perspective and scope moving from a medical-oriented/disease-oriented perspective to a person-oriented/life-oriented perspective. As a social innovation, it can meet social, emotional and practical needs; create meaningful new relationships; and form new collaborations between both private and public actors in society. Organised as a patient-led NPO, Kraftens Hus has the legal structure that makes collaboration between public and private sectors easier. This shared responsibility between private and public actors is innovative within the Swedish context of tax-funded public healthcare, as well as a prerequisite for the integration of society's resources. Kraftens Hus offers an essential and much needed supplement to the hospitals' cancer care within the cancer rehabilitation continuum. This user-centred collaborative model has fostered much interest and has been recognised in national and international innovation awards. Kraftens Hus' design parameters and complementing role in the welfare system can be adapted to and implemented[36] in other geographical contexts.

The Kraftens Hus case also illustrates an interesting example of how a national cancer strategy with directives toward greater patient-oriented and integrated cancer care can lay the groundwork for innovative grass-root initiatives on a micro level. By applying codesign methodology combined with a person-centred approach,[18] policy documents and plans might be easier to put into action, something that is always a challenge.[37]

Study limitations

The idea generation phase of the study is based on answers from 33 individuals. While the number of unique visitors to Kraftens Hus during the study period is not known, there were 303 visits registered during this period. It should be noted that Kraftens Hus is a relatively small pilot organisation targeting a selected group of individuals. CM methodology allows for groups of different sizes to participate[26] and, despite a seemingly small sample, our stress value was within accepted boundaries.[29] In addition to 33 the idea generators a number of individuals were recruited for the sorting task alone. Thus, the number of participants in the study is well within the range presented in by Rosas & Kane.[38]

As the initial data-collection was posted partly on social media, response rate and thus representativeness cannot be fully established. Also, some stakeholders found CM too complicated and burdensome, and, despite assistance from a member of the research team, chose not to participate.

One can note that distances between points within the same cluster can appear greater than distances between points in separate clusters. This is an artefact of the hierarchical nature of the clustering method applied. The impact of different clustering methods could be a topic for future studies.

A limitation of our study is the limited engagement of stakeholders throughout all steps of CM. Although we engaged Kraftens Hus stakeholders in defining a focus prompt, generating ideas (and interpreting the responses (sorting step), the research team conducted the statistical analysis, including the selection of the six-cluster solution. Ideally, CM is conducted in a participatory manner throughout all steps of the process.[39] CM methodology can involve an additional rating step where respondents rate all responses on one or more Likert-type scales for importance, feasibility, etc.[40] Although this rating step can provide additional data about priorities and variations in value among different stakeholder groups and comparisons of different dimensions (eg, importance vs feasibility), this step was omitted here because our purpose was to explore common, overarching perspectives across Kraftens Hus stakeholders. As Kraftens Hus evolves, future research and evaluation studies will formally engage stakeholders not only in codesign of study plans and research questions but also in data collection, analysis and dissemination. Such involvement in the research process corresponds with the patient-led, collaborative care model of Kraftens Hus.

In this study, we did not collect demographic data on the race/ethnicity of participants. The importance of both external (not having a place) and internal (not having a say) exclusion based on race/ethnicity in developing healthcare services has been highlighted in previous research.[41] Moreover, race/ethnicity is likely to intersect with other categories which may reinforce inequities in cancer care, access and so forth.[42] Further, three options on gender were available: male, female or other. No participant chose other, but if a more advanced method for collecting gender had been used, we might have a different, more diverse gender distribution.[43]

Clinical implications

In this study, Kraftens Hus visitors reported that they gained new knowledge and experience through conversation, activities and lectures offered at Kraftens Hus. This has given them a stronger self-esteem, ability to self-care and concrete tools that lead to better functioning in everyday life. The results from this study were presented to regional authorities as an evaluation of Kraftens Hus. The concept map visualised the meaning, role and experience for the stakeholders visiting Kraftens Hus, and consequently, regional funding has been continued. Further, a new Kraftens Hus is under development in another city (and more are in the planning phase), drawing on the results and using the clusters for inspiration. Venues similar to Kraftens Hus can be used to complement existing cancer rehabilitation initiatives without draining healthcare resources.

CONCLUSION

By applying a life-event perspective[21] on cancer, a view emerged focusing on life instead of the disease, including more than traditional healthcare and stretching across organisational boundaries in the welfare system. When cancer-affected individuals designed the services provided by Kraftens Hus, emphasis was put on social, emotional and practical support. The current evaluation suggests that PSS should encompass a broad sense of health and well-being for those affected by cancer. The concept map highlights the importance of meeting other people with similar experiences in addition to receiving and giving support to each other. Further, Kraftens Hus provides value through its creative, knowledge sharing and inspirational activities. The social innovation (Kraftens Hus), regarded as a new collaborative care model, has the potential to be implemented in other similar contexts in the welfare system.

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Contributors FS is the guarantor for the study. FS and AH were in charge of writing the manuscript, but all authors provided text and made amendments. EE did the individual interviews. KAG and AG did the statistical analysis. CM contacted participants. LV was the senior methodological advisor. All authors designed the study and participated in the analysis.

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