

# “A limited focus on cancer rehabilitation” – A Qualitative Study of the Experiences from Norwegian Cancer Coordinators in Primary Health Care

## Abstract

**Objective:** The facilitation of complex cancer rehabilitation interventions in primary health care has become of growing importance to meet the bio-psycho-social needs of cancer survivors.

However, the delivery of cancer rehabilitation is debated and services are underutilized. Cancer coordinators (CCs) provide patients with coordinated services throughout the trajectory. Little is known about CCs' rehabilitation-focused tasks. This study's objective was to explore Norwegian CCs' experiences with cancer rehabilitation interventions in primary health care.

**Methods:** Data were obtained via two focus group interviews with 12 participants, analyzed using thematic analysis and discussed using Salutogenesis, a theory for health promotion.

**Results:** The analysis revealed three themes: 1) ‘A missing link’ to cancer rehabilitation in primary health care, 2) Aiming to put cancer rehabilitation ‘in the spotlight’, 3) The need to build a system for rehabilitation service delivery.

**Conclusion:** CCs experience a lacking focus on and missing systems for cancer rehabilitation in primary health care. CCs aim to improve local practices by advocating patients' needs and educating professionals. CCs must be supported via education and training in system-level work, an increased policy focus and resources for cancer rehabilitation. More research is required into how CCs may facilitate cancer rehabilitation in primary health care.

**Key words:** cancer rehabilitation, cancer coordinator, cancer navigation, primary health care, coordinated care, Salutogenesis

## Introduction

With increasing numbers of cancer survivors and their risk of physical, psychosocial and economic consequences from cancer and its treatment, multidimensional or complex cancer rehabilitation has become a pressing public health issue (Alfano, Ganz, Rowland, & Hahn, 2012; Dalton, Bidstrup, & Johansen, 2011; Hellbom et al., 2011; Thorsen et al., 2011). Cancer rehabilitation is commonly defined as a goal-oriented, coordinated and multidisciplinary health promoting process supporting the individual to obtain best possible functioning and participation in the physical, psychosocial and vocational life domains, relieve symptom burden, enhance independence and Quality of Life (QoL) (Hellbom et al., 2011; Jensen, Piester, Nissen, & Pedersen, 2004; Reigle et al., 2017). Complex interventions typically combine elements of physical activity, nutrition, psychoeducation and goal setting, peer support and individual follow-up. Research indicates that tailored, multidimensional rehabilitation interventions have better outcomes on physical functioning, fatigue, psychological distress and QoL than single approaches (Fors et al., 2011; Mewes, Steuten, Ijzerman, & van Harten, 2012; Scott et al., 2013).

Internationally, multidimensional cancer rehabilitation is mainly provided in cancer care centers in the secondary, tertiary and private sector (Hellbom et al., 2011; Stubblefield et al., 2013). Little attention has been given to how comprehensive rehabilitation interventions may be provided in primary health care (Bober et al., 2009; Faithfull, Samuel, Lemanska, Warnock, & Greenfield, 2016; Ugolini et al., 2012). Systems for cancer rehabilitation in primary health care are often fragmented and poorly developed, and patients are frequently lost to follow-up at the interfaces of care sectors

(Bober et al., 2009; Faithfull et al., 2016). Patients are therefore at risk of missing rehabilitation services, unmet rehabilitation needs, psychological distress and reduced QoL (Miller et al., 2016; Thorsen et al., 2011; Veloso et al., 2013.)

Norway is a unitary state, comprising 18 counties and 422 municipalities, which are the political and administrative subdivisions of the country. Primary health care is provided at the municipal level. Due to the sparse population of the country, the municipalities are geographically diverse and vary in size, infrastructure, and the organization of primary health care services (Helse- og omsorgsdepartementet, 2011; Vattekar, 2015). Following a re-organization of health care services in 2012, Norwegian municipalities are in charge of providing rehabilitation and follow-up care, and patients with complex needs are legally entitled to rehabilitation and an individual care plan (Helse- og omsorgsdepartementet, 2011). In cancer care, however, responsibilities for initiation and coordination of complex rehabilitation interventions are often unclear, which can yield fragmented and poorly coordinated services in primary health care (Helsedirektoratet, 2012). To facilitate comprehensive care and improve service coordination, including rehabilitation, in 2012 the Norwegian Cancer Society created 130 cancer coordinator (CC) roles in 215 municipalities (Vattekar, 2015). Resembling international coordinator functions, Norwegian CCs usually have a nursing background and operate at both the patient- and the system-level to address barriers to care (Monterosso, Platt, Krishnasamy, & Yates, 2011; Reigle, Campbell, & Murphy, 2017; Smith, 2016; Vattekar, 2015). The role of Norwegian CCs has been explored in previous research, showing that they execute diverse tasks in accordance with the various municipal frameworks (Lie, Hauken & Solvang, 2017; Lie, Solvang & Hauken, 2018).

Internationally, there has been growing interest in using professionals in navigating roles to facilitate coordinated cancer care. Research shows that professionals in navigating roles can

reduce barriers to care, harness the skills of local professionals and facilitate coordinated, multidisciplinary services across sectors (Freijser, Naccarella, McKenzie, & Krishnasamy, 2015; Lie et al, 2017; Monterosso et al., 2011; Smith, 2016). Accordingly, CCs may represent one possible model to ensure the delivery of complex cancer rehabilitation interventions. However, previous research has focused on understanding and evaluating the role of coordinators in general rather than in the context of cancer rehabilitation (Freijser et al., 2015; Monterosso et al., 2011; Smith, 2016). Other research has indicated that cancer rehabilitation appears to have a marginal role in CCs' work (Lie et al, 2017;2018). Hence, little is known about how professionals in primary health care work to accommodate cancer patients' rehabilitation needs despite a widespread request for such research (Bergholdt et al., 2013; Dalton et al., 2011; Helsedirektoratet, 2012; Vattekar, 2015).

#### Theoretical framework

Salutogenesis, a theory of health promotion by Aaron Antonovsky's (1979, 1987) was chosen as theory for interpreting and discussing this study's findings. In line with the principle of cancer rehabilitation, Salutogenesis adopts a holistic perspective on health and health-promoting processes in individuals and settings (Antonovsky, 1987). The theory is centered around factors that impact health (of cancer patients) and health promoting interventions, such as cancer rehabilitation. According to Salutogenesis, a patient's ability to improve or maintain health (called "sense of coherence") is influenced by three core components. These include the situation's comprehensibility (e.g. information), manageability (care coordination) and meaningfulness (e.g. psychosocial support) (Antonovsky, 1979). The same principles apply to facilitate interventions at a system level, e.g. the delivery of cancer rehabilitation. For instance, health professionals' ability to deliver complex interventions is influenced by the degree to which

they perceive the task as comprehensible, manageable and meaningful (Antonovsky, 1987). In this study, we apply the theory in the discussion of the findings, as it can facilitate a more nuanced understanding of CCs' experiences with the delivery of cancer rehabilitation services.

### Study Aim

To bridge the aforementioned research gap, this paper focuses on Norwegian CCs' experiences with the delivery of cancer rehabilitation interventions in primary health care. In so doing, we seek to answer the following research question: 'What are Norwegian CCs' experiences with the delivery of complex cancer rehabilitation interventions in primary health care?'

### Methods

To gain an in-depth understanding of CCs' experiences related to cancer rehabilitation, we applied a qualitative, hermeneutic approach based on the work of Gadamer (Gadamer, 1976, 1989; Koch, 1996). Within this approach, new knowledge and understanding is generated in a dialectical process between the investigator and the informants ("hermeneutic circle") until a common understanding about the phenomenon is reached (Gadamer, 1976, 1989; Koch, 1996). Because this process is shaped by the context, prior knowledge and subjective experiences, the authors discussed how these factors may have impacted the interpretation of results (Gadamer, 1989; Koch, 1996). With backgrounds in health promotion, cancer nursing and sociology, all authors had some preconceptions of the topic and these were made explicit and critically discussed during the research process. This facilitated awareness and reflexivity and allowed the researchers to approach the topic faithfully (Koch, 1996).

## Sampling Procedure

The eligibility criterion for this study was ‘being a CC funded by the Norwegian Cancer Society and working in the municipality’. Based on literature guidelines for focus groups, we aimed to conduct two focus groups with five to ten participants (Kitzinger and Barbour, 1999; Morgan, 1997). To generate a diverse sample, we used purposive maximum variation sampling. Based on available data from Statistics Norway, websites of the Cancer Society and Norwegian municipalities (Kreftforeningen, 2012; Statistisk sentralbyrå, 2014), we selected 20 CCs from heterogeneous municipalities of different age, gender, full-time equivalent and work experience. The CCs were approached and invited by e-mail with information about the study. Due to great traveling distances and time constraints, 14 out of 20 CCs declined to participate. Using convenience sampling (Creswell, 2013; Morgan, 1997), we consecutively recruited CCs based close to focus group locations. In line with the recommended sizes for focus groups (Kitzinger and Barbour, 1999; Morgan, 1997), we completed recruitment after 14 CCs had given consent. From these 14 CCs, two had to cancel the appointment at short notice due to illness. The final sample resulted in two focus groups with seven and five participants, respectively. No participant was turned away.

## Interview Procedure

The focus group interview procedure was planned and conducted based on the guidelines of Kitzinger and Barbour (1999) and Morgan (1997). The focus groups were held in conference rooms in the two largest towns of Norway. They were moderated by the first author, supported by a co-moderator who acted as an observer. An independent researcher co-moderated focus group 1 and the second author co-moderated focus group 2. The interviews were conducted using a semi-structured interview guide, as shown in *Table 1*. Interview questions were based on the identified

knowledge gap, designed in discussions in the research team and in accordance with established guidelines for interview guides (Creswell, 2013; Morgan 1997). The questions targeted CCs' experiences with the delivery of complex rehabilitation interventions in primary health care, allowing participants to raise additional topics. The interviews lasted 120 minutes, were audiotaped and transcribed verbatim.

#### Ethical considerations

The Oslo Metropolitan University and the Norwegian Centre for Research Data approved the conduct of our study (Pr.no.38673). All participants gave informed and written consent, and the researchers followed established guidelines in preserving anonymity and secure data handling (World Medical Association Declaration of Helsinki, 1964).

#### Data Analysis

The data were analyzed using six steps to thematic analysis (TA) by Braun & Clarke (2006). TA is widely used in health research and across a range of qualitative methods and research designs. As knowledge is generated in a circular process, it fits the tenets of hermeneutic research. (Braun & Clarke, 2006, Gadamer, 1976). First, the authors familiarized themselves with the data. Second, entering the hermeneutic circle of pre-understanding and understanding, the interview transcripts were re-read and coded by the first author, using the coding software NVIVO to organize the rich material (QSR NVivo, 2007). Third, the codes and data extracts were organized into preliminary themes. The authors discussed the codes and themes while critically considering their own presumptions. Fourth, the authors re-immersed themselves in the data, contextualizing, reviewing and refining the themes. The process was finalized when the researchers had reached a consensus on all the findings. Fifth, three main themes were identified and labeled, which represented a coherent and comprehensive picture of Norwegian CCs' experiences with the

delivery of cancer rehabilitation interventions in primary health care. Sixth, the findings are presented and discussed, as follows. Quotes from the interviews are provided to add meaning to the text. The quotes were first translated to English, and the translated back to Norwegian to ensure that original meaning was captured.

## Results

The characteristics of the final study sample are outlined in *Table 2*. The mean age of the participants in the focus group study was 51 years (range 31–62), 92% were female. All participants were nurses, where 83% were specialized as cancer nurses. 67% worked in full-time positions. CCs were organized as part of either the health and social services (50%), the home care services (25%), the medical service center (17%) or the municipal administration (8%). The mean inhabitant number of the participants' municipalities was 33768 (range 7806 – 84476). The characteristics of the study sample mirror the characteristics of the overall population to a high degree (Vattekar, 2015). However, with 92% of CCs employed in one municipality/capital district there was an underrepresentation of CCs working in two or more municipalities. The majority of CCs were from East and West Norway, while CCs from South and North Norway were underrepresented.

The group interaction was dynamic and complementary in both focus groups, requiring minimal moderator involvement (Creswell, 2013; Morgan, 1997). However, in focus group 1, one participant tended to dominate the discussion, leading the moderator to encourage other participants to share their experiences as well (Morgan 1997).



The analytical process led to three main themes: (1) ‘A missing link’ to cancer rehabilitation in primary health care; (2) Aiming to put cancer rehabilitation ‘in the spotlight’; (3) The need to build a system for rehabilitation service delivery.

Theme 1: ‘A missing link’ to cancer rehabilitation in primary health care

Theme 1 reflected the CCs’ experiences of the current delivery of cancer rehabilitation services in primary health care. Most participants outlined a vision of complex interventions that addressed cancer patients’ bio-psycho-social rehabilitation needs throughout the care trajectory.

This contrasted their experiences of current practices in primary health care, where services were scarce and mainly provided as single, post-treatment interventions such as physiotherapy. The CCs noted that the municipalities had focused on facilitating palliative care and that they perceived a missing link to cancer rehabilitation interventions during patients’ cancer trajectory.

CC1: ‘What I perceived all the way is that there is a missing link. We have cancer rehabilitation centers; we have [general] community rehabilitation services the patients could be linked to.’ CC5: ‘Yes, I think it is very fragmented and there is no system [cancer rehabilitation].’ (Focus group [FG]1)

The CCs described that health professionals’ knowledge appeared to be limited to their own medical field, yielding a limited understanding of patients’ overall bio-psycho-social rehabilitation needs. CCs perceived a lack of common conceptualization of cancer rehabilitation and unclear responsibilities for its delivery, particularly in patients’ transitions between health care sectors.

CC2: ‘I don’t know if anybody has made a plan for rehabilitation – everybody is working in their medical bubbles...’ CC1: ‘Yes, the specialized services often provide a brochure

and that's it. Well, I don't think they are very good at it and many general practitioners (GPs) know little about rehabilitation. It's up to the patients to make an appointment with the GP after their treatment, and often they don't do it. The municipality doesn't do it either.'(FG1)

The CCs perceived working with cancer rehabilitation as difficult, as primary health care providers did not routinely engage in patients' follow-ups and seldom referred them to the CCs after their hospital discharge. CCs raised concerns regarding unequal access to cancer rehabilitation interventions, as its delivery seemed to depend on the engagement of the patients, their families or dedicated professionals.

Theme 2: Aiming to put cancer rehabilitation 'in the spotlight'

Theme 2 comprised CCs' accounts of how they operated to facilitate rehabilitation interventions in primary health care. The participants described acting as patients' advocates, educating professionals on their bio-psycho-social needs and promoting a focus on multidisciplinary rehabilitation interventions throughout the trajectory. Most of them noted gradual changes in health professionals' ideas of cancer rehabilitation over time.

CC7: 'When I started working, there was a widespread idea of that, if the patient couldn't get better, there was no use for rehabilitation. And *that* has changed.' CC11: 'The idea is that most patients should stay at home as long as possible.' CC8: 'Yes...rehabilitation [means now]...maintaining the current level of functioning and coping in daily life.'(FG2)

To enhance coping and participation, the CCs promoted patients' involvement in the planning of their rehabilitation course, considering individual values, goals and resources as opposed to a sole focus on their problems and limitations.

CC11: 'Putting the patients in the spotlight has been very important. (...) We may think that pain is the problem (...), but it may be something else that matters more.' (FG2)

CC11: 'It is always positive when you start to talk about rehabilitation with the patients. (...) Placing emphasis on the resources. (...) What is rehabilitation for you?' CC8: 'Yes! We have a project in our municipality, with needs assessments, where we ask: 'What matters to you right now?'' (FG2)

Several CCs mentioned working towards facilitating local rehabilitation services, by linking patients to services for mixed patient groups or establishing, for instance, walking groups, patient cafés and meeting points in collaboration with volunteer organizations. This could also alleviate the family caregivers' burden, which was described as an important aspect of cancer rehabilitation.

Theme 3: The need to build a system for rehabilitation service delivery

Theme 3 related to CCs' perspectives on further facilitating cancer rehabilitation in primary health care. The CCs emphasized a need for systematic needs assessments and collaborative action to ensure equal access to cancer rehabilitation in the municipalities. Both focus groups emphasized the GP as a key provider and collaborating partner in cancer rehabilitation.

CC1: 'There needs to be a system to reach out to [patients with rehabilitation needs]. (...) This needs to be taken care of and I cannot see that this can be done by anyone other than the GP who receives all the medical records and needs to be a hook to catch these patients.' (FG1)

The CCs expressed that, as municipalities progressively established systems for palliative care, more attention might be focused on cancer rehabilitation in future. However, the CCs highlighted

the need for adequate resources in the municipalities, including electronic systems, alongside the establishment of early needs assessments, individual cancer rehabilitation care plans and systems for cross-sectoral communication and coordination. Moreover, the CCs indicated the need for future national and local policies to promote comprehensive cancer rehabilitation in the municipalities.

## Discussion

To our knowledge, this is the first study to explore CCs' experiences with the delivery of complex cancer rehabilitation interventions in primary health care.

Many of our findings of underutilization and fragmentation of cancer rehabilitation in Norway are consistent with international studies (Bober et al., 2009; Helsedirektoratet, 2012; Mewes et al., 2012; Scott et al., 2013). Only some countries (e.g. Denmark) appear to provide cancer rehabilitation in the primary health care sector, while several other European countries and the US have not yet integrated rehabilitation into the standard medical care of all cancer patients (Handberg, Thorne&Maribo, 2018; Hellbom, 2011, Stubblefield et al., 2013). Our participants indicated that, in Norway, a main focus on palliative care and patients with the most urgent needs might have sidelined cancer rehabilitation in primary health care. The literature supports this, elaborating that health professionals often assign cancer rehabilitation a low priority as they were faced with acute, more pressing tasks (Handberg et al., 2018; Monterosso et al., 2011; Silver et al., 2015).

This study highlights the need for primary health care professionals' knowledge gaps and confusion about their responsibilities for rehabilitation service delivery to be addressed in order to improve equality of access to these services. The CCs emphasized that, so far, cancer

rehabilitation programs in primary care were lacking and that GPs did not regularly provide multidimensional interventions. Similar issues were found in the US, where the aforementioned challenges have yielded significant differences in service delivery (Bober et al., 2009, Stubblefield et al., 2013). Our participants' call for assigning GPs a central role in cancer rehabilitation is widely supported (Bergholdt et al., 2013; Blanch-Hartigan et al., 2014; Grunfeld & Earle, 2010). In the US, GPs are supported via training, education (e.g. e-learning programmes), internships in cancer rehabilitation clinics or participation in specialized programs. (Nekhlyudov, O'malley&Hudson, 2017; Stubblefield, 2013). It is crucial, however, that new initiatives be accompanied by effective communication among professionals to avoid fragmented health care delivery (Handberg et al., 2018; Nekhlyudov et al., 2017).

Our study shows that, although municipalities have been assigned with responsibility for rehabilitation, progress seems to be very limited in implementing complex cancer rehabilitation interventions in primary health care. Research shows that suboptimal success with implementing policy decisions can often be linked to professionals' lack of ownership and understanding of the new approach (Handberg et al.2016, Lie; 2018; Sommerbakk et al., 2016). This is in line with salutogenic theory, where low level of comprehensibility (knowledge gaps), manageability (fragmented systems) and meaningfulness (a low priority of cancer rehabilitation interventions) can pose significant challenges to the implementation of interventions or policies (Lindström&Eriksson, 2006). These challenges represented a common theme in both focus groups, although CCs' municipalities and working environments varied. Handberg et al. (2018) suggest that such challenges arise when policies are executed without consideration for health professionals, patient context, workplace priorities and practice culture. Lindström & Eriksson (2009) addressed this problem in the framework of a salutogenic case study, involving politicians

and clinicians throughout the policy-making process, with the aim of discussing how health policy and its implementation can be made comprehensive, manageable and meaningful to all involved. Our study, supported by others, suggests a need for policies to clarify responsibilities in cancer rehabilitation and the continuous involvement of health professionals in the implementation process (Handberg et al., 2018; Lindström & Eriksson, 2009).

The CCs seemed to work salutogenically by enhancing resources for local cancer rehabilitation, e.g. the provision of professionals' education, service establishment and the promotion of multidisciplinary interventions. Similarly, CCs in Australia are involved in health professionals' development and aid the improvement of collaboration (Monterosso et al., 2011; Smith, 2016). Despite these similarities, the cited literature describes a main focus on treatment-related issues, while Norwegian CCs include a focus on rehabilitation. Our findings may thus indicate an untapped potential for advancing CC roles to facilitate cancer rehabilitation in primary health care.

Norwegian CCs call for more resources and support to enable larger scale system-level work. Strikingly, none of the main themes discussed in the focus groups involved systematic approaches to rehabilitation interventions, but instead focused on CCs' case-based approaches and single services. Our findings reiterate debates on CCs' work-overload and limited capacity to engage in larger scale system-level tasks (Lie et al., 2017, 2018; Monterosso et al., 2011; Smith, 2016). The findings may also imply that CCs require additional training or formal education to undertake system-level work. Salutogenesis supports this, emphasizing that CCs need sufficient resources to be able to cope with the demands placed on them (Antonovsky, 1979).

Research supports our CCs' calls for adequate frameworks and resources to carry out both patient and system level work (Freijser et al., 2015; Monterosso et al., 2011). Our study suggests that tools, such as electronic systems, systematic needs assessment and cancer rehabilitation care

plans, could help facilitate the coordinated delivery of rehabilitation interventions. Positive outcomes have been shown in the US, amongst others, where health professionals are provided with guidelines for the follow-up of cancer survivors in primary health care (Nekhlyudov, O'malley&Hudson, 2017). Other literature demonstrates that cancer rehabilitation care plans and needs assessments can facilitate coordinated care and equal access to it (Barry & Edgman-Levitan, 2012; Blanch-Hartigan et al., 2014; Charles et al., 1997, Handberg at al., 2018).

#### Limitations and trustworthiness of the study

The use of focus groups has its limitations. Data produced in focus groups may provide less detailed accounts than individual interviews. However, they have the advantage of stimulating discussions and facilitate nuanced perspectives on the topic (Morgan, 1997). The participants' exchange of ideas may be influenced by the involvement of a moderator and participant interaction. In this study, moderator bias was accounted for by minimal moderator involvement and a focus on open questions (Creswell, 2013). A dominant participant in focus group 1 may potentially have inhibited other participants in disclosing their opinions. However, the moderator encouraged the other participants to engage in the discussion, so that dynamic and complementary interaction could be facilitated in both focus groups.

Trustworthiness in qualitative research can be assessed in terms of credibility and transferability. Credibility can be ensured by providing a detailed, transparent account of the research process and reflexivity concerning one's own preconceptions (Koch, 1996). To ensure credibility, each step of the present research has been described and presented in detail. Further, the researchers' continuous discussion of their presumptions enhanced their reflexivity throughout the research process. Due to difficulties in recruitment, in the current study sample, CCs from North and South Norway were under-represented, so that their potentially distinct perspectives may not be

reflected. However, the study sample represents CCs with diverse backgrounds and municipalities, which may enhance the findings' transferability to other municipal settings.

#### Conclusion and implications for research and clinical practice

Norwegian CCs acknowledge the importance of holistic cancer rehabilitation in primary health care. However, they described the delivery of current rehabilitation interventions as low priority, one-dimensional and difficult to access. Identified barriers were professionals' lacking knowledge of and missing systems for rehabilitation service delivery. CCs outlined a need for further training of health professionals and a strengthening of GPs' roles in cancer rehabilitation. Health care providers should place greater emphasis on patient involvement and needs assessments. The CC role may improve cancer rehabilitation in promoting patients' needs and multidisciplinary interventions. However, they may benefit from further education and training to better facilitate system-level action. Political strategies are needed to clarify systems and responsibilities for cancer rehabilitation. Health professionals' involvement in implementation processes may aid the translation of policies into clinical practice. More research is required to identify best practices for cancer rehabilitation and how CCs may contribute to facilitate cancer rehabilitation in primary health care.



## References

- Alfano, C. M., Ganz, P. A., Rowland, J. H., & Hahn, E. E. (2012). Cancer Survivorship and Cancer Rehabilitation: Revitalizing the Link. *Journal of Clinical Oncology*, *30*(9), 904-906. doi:10.1200/jco.2011.37.1674
- Antonovsky, A. (1979). Health, stress, and coping. San Francisco: Jossey-Bass.
- Antonovsky, A. (1987). Unraveling the Mystery of Health - How People Manage Stress and Stay Well. San Francisco: Jossey-Bass.
- Barry, M. J., & Edgman-Levitan, S. (2012). Shared decision making—the pinnacle of patient-centered care. *New England Journal of Medicine*, *366*(9), 780-781.
- Bergholdt, S. H., Søndergaard, J., Larsen, P. V., Holm, L. V., Kragstrup, J., & Hansen, D. G. (2013). A randomised controlled trial to improve general practitioners' services in cancer rehabilitation: Effects on general practitioners' proactivity and on patients' participation in rehabilitation activities. *Acta Oncologica*, *52*(2), 400-409. doi:10.3109/0284186X.2012.741711
- Blanch-Hartigan, D., Forsythe, L. P., Alfano, C. M., Smith, T., Nekhlyudov, L., Ganz, P. A., & Rowland, J. H. (2014). Provision and Discussion of Survivorship Care Plans Among Cancer Survivors: Results of a Nationally Representative Survey of Oncologists and Primary Care Physicians. *Journal of Clinical Oncology*, *32*(15), 1578-1585. doi:10.1200/jco.2013.51.7540
- Bober, S. L., Recklitis, C. J., Campbell, E. G., Park, E. R., Kutner, J. S., Najita, J. S., & Diller, L. (2009). Caring for Cancer Survivors A Survey of Primary Care Physicians. *Cancer*, *115*(18), 4409-4418. doi:Doi 10.1002/Cncr.24590
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101.
- Charles, C., Gafni, A., & Whelan, T. (1997). Shared decision-making in the medical encounter: what does it mean?(or it takes at least two to tango). *Social Science & Medicine*, *44*(5), 681-692.
- Creswell, J. W. (2013). Qualitative inquiry and research design: Choosing among five approaches (3rd ed.) Los Angeles: Sage.
- Dalton, S. O., Bidstrup, P. E., & Johansen, C. (2011). Rehabilitation of cancer patients: Needed, but how? *Acta Oncologica*, *50*(2), 163-166. doi:doi:10.3109/0284186X.2010.550315
- Faithfull, S., Samuel, C., Lemanska, A., Warnock, C., & Greenfield, D. (2016). Self-reported competence in long term care provision for adult cancer survivors: A cross sectional survey of nursing and allied health care professionals. *International Journal of Nursing Studies*, *53*, 85-94. doi:10.1016/j.ijnurstu.2015.09.001
- Farrell C, Walshe C, Molassiotis A. (2017). Are nurse-led chemotherapy clinics really nurse-led? An ethnographic study. *International Journal of Nursing Studies*, *69*, 1-8. doi:10.1016/j.ijnurstu.2017.01.005
- Fors, E. A., Bertheussen, G. F., Thune, I., Juvet, L. K., Elvsaa, I. K., Oldervoll, L., Anker, G., Falkmer, U., Lundgren, S. & Leivseth, G. (2011). Psychosocial interventions as part of breast cancer rehabilitation programs? Results from a systematic review. *Psychooncology*, *20*(9), 909-918. doi:10.1002/pon.1844
- Freijser, L., Naccarella, L., McKenzie, R., & Krishnasamy, M. (2015). Cancer care coordination: building a platform for the development of care coordinator roles and ongoing evaluation.

- Australian Journal of Primary Health*, 21(2), 157-163.  
doi:<http://dx.doi.org/10.1071/PY13037>
- Gadamer, H.-G. (1976). *Philosophical Hermeneutics* (D. E. Linge, Trans. D. E. Linge Ed.). Berkeley: University of California Press.
- Gadamer, H.-G. (1989). *Truth and Method* (2 ed.). London: Sheed and Ward.
- Gamble, G. L., Gerber, L. H., Spill, G. R., & Paul, K. L. (2011). The future of cancer rehabilitation: emerging subspecialty. *American Journal of Physical Medicine & Rehabilitation*, 90 (5 Suppl 1), 76-87. doi:10.1097/PHM.0b013e31820be0d1
- Grunfeld, E., & Earle, C. C. (2010). The interface between primary and oncology specialty care: treatment through survivorship. *Journal of the National Cancer Institute Monographs*, 2010(40), 25-30.
- Handberg, C., Thorne, S., & Maribo, T. (2018). When a policy decision meets practice realities: The case of cancer survivorship care and rehabilitation needs assessment. *European Journal of Oncology Nursing*, 33, 70-77.
- Hellbom, M., Bergelt, C., Bergenmar, M., Gijzen, B., Loge, J. H., Rautalathi, M., . . . Johansen, C. (2011). Cancer rehabilitation: A Nordic and European perspective. *Acta Oncologica*, 50(2), 179-186. doi:doi:10.3109/0284186X.2010.533194
- Helsedirektoratet. (2012). Rehabiliteringstilbudet til pasienter med kreft. Kartlegging og anbefalinger. Oslo: Helsedirektoratet. [Health Directorate. Rehabilitation services for patients with cancer. Mapping and recommendations. Oslo: Health Directorate.]
- Helse- og omsorgsdepartementet (2011). *Forskrift om habilitering og rehabilitering, individuell plan og koordinator*. Oslo: Helse- og omsorgsdepartementet. [Ministry of Health and Care Services. Regulations on Habilitation and Rehabilitation, Individual Plan and Coordinator. Oslo: Ministry of Health and Care Services.]
- Hewitt, M., Greenfield, S., & Stovall, E. (2006). *From cancer patient to cancer survivor: lost in transition*. Committee on cancer survivorship: improving care and quality of life, institute of medicine and national research council: Washington, DC: The National Academies Press.
- Jensen, M., Piester, C., Nissen, A., & Pedersen, K. (2004). *From needs to offers. Rehabilitation of cancer patients*. Denmark: The Nordic Cancer Union.
- Johansen, C. (2007). Rehabilitation of cancer patients—research perspectives. *Acta Oncologica*, 46(4), 441-445.
- Kitzinger, J., & Barbour, R. (1999). *Developing focus group research: politics, theory and practice*: Sage.
- Koch, T. (1996). Implementation of a hermeneutic inquiry in nursing: philosophy, rigour and representation. *Journal of Advanced Nursing*, 21, 827- 836.
- Kreftforeningen. (2012). Kreftkoordinatorer i kommunene. [The Norwegian Cancer Society. Cancer Coordinators in municipalities].  
<http://www.ks.no/PageFiles/22180/Kreftkoordinatorer%20Kjernerdokument%2025012012.pdf> (last accessed 15 September 2016).
- Lie, N.-E. K., Hauken, M. A., & Solvang, P. K. (2017). Providing Coordinated Cancer Care-A Qualitative Study of Norwegian Cancer Coordinators' Experiences of Their Role. *Cancer Nursing*. doi:10.1097/NCC.0000000000000504
- Lie N-EK, Solvang PK, Hauken MA (2018). From challenges to resources-A qualitative study of cancer coordinators' experiences with barriers and facilitators for enacting their system-focused tasks. *Cancer Nursing*. DOI: 10.1097/NCC.0000000000000617.

- Lindström B, Eriksson M. (2009) The salutogenic approach to the making of HiAP/healthy public policy: illustrated by a case study. *Global health promotion*, 16(1):17-28.
- Mewes, J. C., Steuten, L. M., Ijzerman, M. J., & van Harten, W. H. (2012). Effectiveness of multidimensional cancer survivor rehabilitation and cost-effectiveness of cancer rehabilitation in general: a systematic review. *Oncologist*, 17(12), 1581-1593. doi:10.1634/theoncologist.2012-0151
- Miller, K. D., Siegel, R. L., Lin, C. C., Mariotto, A. B., Kramer, J. L., Rowland, J. H., . . . Jemal, A. (2016). Cancer treatment and survivorship statistics, 2016. *CA: A Cancer Journal for Clinicians*, 66(4), 271-289. doi:10.3322/caac.21349
- Monterosso, L., Platt, V., Krishnasamy, M., & Yates, P. (2011). Evaluation of the Western Australian Cancer Nurse Coordinator Role. Final Report. Western Australia: Health Department Western Australia.
- Morgan, D. L. (1997). Focus groups as qualitative research (2 ed. Vol. 16). Thousand Oaks, California: Sage publications.
- Nekhlyudov, L., Aziz, N. M., Lerro, C., & Virgo, K. S. (2013). Oncologists' and primary care physicians' awareness of late and long-term effects of chemotherapy: implications for care of the growing population of survivors. *Journal of oncology practice*, 10(2), e29-e36.
- Nekhlyudov, L., O'malley, D. M., & Hudson, S. V. (2017). Integrating primary care providers in the care of cancer survivors: gaps in evidence and future opportunities. *The Lancet Oncology*, 18(1), e30-e38.
- Nielsen, R. (2011). Kreftpasienters behov, bruk og vurdering av rehabiliteringstilbudet. Oslo: Helsedirektoratet. [Cancer patients' needs, use and assessment of rehabilitation offers. Oslo:Health Directorate.]
- Reigle, B. S., Campbell, G. B., & Murphy, K. B. (2017). Cancer Rehabilitation and the Role of the Rehabilitation Nurse. A White Paper by the Association of Rehabilitation Nurses Association of Rehabilitation Nurses. Chicago, USA: Association of Rehabilitation Nurses.
- Scott, D. A., Mills, M., Black, A., Cantwell, M., Campbell, A., Cardwell, C. R., . . . Donnelly, M. (2013). Multidimensional rehabilitation programmes for adult cancer survivors. In L. JohnWiley & Sons (Series Ed.) Vol. 3. Cochrane Database Syst Rev (pp. 1-48). doi:10.1002/14651858.CD007730.pub2
- Silver, J. K., Raj, V. S., Fu, J. B., Wisotzky, E. M., Smith, S. R., & Kirch, R. A. (2015). Cancer rehabilitation and palliative care: critical components in the delivery of high-quality oncology services. *Supportive Care in Cancer*, 23(12), 3633-3643. doi:10.1007/s00520-015-2916-1
- Smith, L. (2016). The Cancer Nurse Coordinator Initiative Evaluation. Final report. Wellington, New Zealand:Litmus.
- Sommerbakk, R., Haugen, D.F., Tjora, A., Kaasa, S., Hjermsstad, M.J., (2016). Barriers to and facilitators for implementing quality improvements in palliative care - results from a qualitative interview study in Norway. *BMC Palliative Care* 15 (1), 61.
- Statistisk sentralbyrå.(2014). Folkemengde og befolkningsendring [Statistics Norway. Population and population changes.] [Database]. <http://www.ssb.no/befolkning/statistikker/folkendrkv/kvartal/2013-08-16?fane=tabell#content> (last accessed 20 June 2014).
- Stout, N. L., Silver, J. K., Raj, V. S., Rowland, J., Gerber, L., Cheville, A., . . . Chan, L. (2016). Toward a National Initiative in Cancer Rehabilitation: Recommendations From a Subject

- Matter Expert Group. *Archives of Physical Medicine and Rehabilitation*, 97(11), 2006-2015. doi:10.1016/j.apmr.2016.05.002
- Stubblefield, M. D., Hubbard, G., Cheville, A., Koch, U., Schmitz, K. H., & Dalton, S. O. (2013). Current perspectives and emerging issues on cancer rehabilitation. *Cancer*, 119, 2170-2178.
- Thorsen, L., Gjerset, G. M., Loge, J. H., Kiserud, C. E., Skovlund, E., Fløtten, T., & Fosså, S. D. (2011). Cancer patients' needs for rehabilitation services. *Acta Oncologica*, 50(2), 212-222. doi:10.3109/0284186X.2010.531050
- Ugolini, D., Neri, M., Cesario, A., Bonassi, S., Milazzo, D., Bennati, L., . . . Pasqualetti, P. (2012). Scientific production in cancer rehabilitation grows higher: a bibliometric analysis. *Support Care Cancer*, 20(8), 1629-1638. doi:10.1007/s00520-011-1253-2
- Vattekar, E. (2015). Kreftkoordinatorersatsingen. Hovedrapport 2014. Oslo: Kreftforeningen. [Cancer Coordinator Initiative. Main Report 2014. Oslo: Norwegian Cancer Society.]
- Veloso, A. G., Sperling, C., Holm, L. V., Nicolaisen, A., Rottmann, N., Thyssen, S., . . . Hansen, D. G. (2013). Unmet needs in cancer rehabilitation during the early cancer trajectory—a nationwide patient survey. *Acta Oncologica*, 52(2), 372-381.
- World Medical Association Declaration of Helsinki (1964). Ethical Principles for Medical Research Involving Human Subjects. Helsinki: World Health Organization.

## Tables

**Table 1: The Semi-Structured Interview Guide**

<b>The semi-structured interview guide</b>	
<p><b>Main question</b></p> <p>Sub-questions</p>	<p><b>Can you please tell me about your experiences with the delivery of cancer rehabilitation interventions in your municipality?</b></p> <ul style="list-style-type: none"> <li>- How is cancer rehabilitation in your municipality provided?               <ul style="list-style-type: none"> <li>• When, how long and to whom does rehabilitation apply?</li> <li>• What kind of patients' needs or goals are addressed?</li> <li>• Who is responsible for needs assessments and service delivery?</li> </ul> </li> <li>- What challenges and opportunities do you perceive regarding the delivery of local rehabilitation services in your municipality?</li> </ul>
<p><b>Main question</b></p> <p>Sub-questions</p>	<p><b>Can you please tell me about your experiences of working with cancer rehabilitation in your municipality?</b></p> <ul style="list-style-type: none"> <li>- To what degree is rehabilitation part of your work as a CC?</li> <li>- In what way are you working with rehabilitation?               <ul style="list-style-type: none"> <li>• At the patient level</li> <li>• At the system level</li> </ul> </li> <li>- What challenges and opportunities do you perceive in working with the delivery of complex cancer rehabilitation interventions in your municipality?</li> <li>- What is needed to facilitate working with cancer rehabilitation as a CC in primary health care onwards?</li> </ul>

*Table 2: Overview of the Study Sample*

Variables	Study sample (% of study sample)		
	Focus group 1	Focus group 2	Total
<b>Gender</b>			
Female	5 (100%)	6 ( 86%)	11 ( 92%)
Male	-	1 ( 14%)	1 ( 8%)
<b>Age</b>			
Mean (Range)	50 (31 – 57)	52 (38 – 62)	51 (31 – 62)
<b>Profession</b>			
Nurse	5 (100%)	7 (100%)	12 (100%)
Additional specialization as cancer nurse	5 (100%)	5 ( 71%)	10 ( 83%)
Additional specialization in palliative care	2 ( 40%)	1 ( 14%)	3 ( 25%)
Other additional specialization	1 ( 20%)	1 ( 14%)	2 ( 17%)
<b>Worked as a CC (months)</b>	24 (11-32)	24 (13-29)	24 (11-32)
Mean (range)			
<b>Full-time equivalent</b>			
Full time (100%)	3 ( 60%)	5 ( 71%)	8 ( 67%)
Part- time (50%)	2 ( 40%)	2 ( 29%)	4 ( 33%)
<b>Organization of the position (Placement)</b>			
Home care	2 ( 40%)	1 ( 14%)	3 ( 25%)
Health and social services department	3 ( 60%)	3 ( 43%)	6 ( 50%)
Local medical service center	-	2 ( 29%)	2 ( 17%)
Administration	-	1 ( 14%)	1 ( 8%)
<b>Number of municipalities covered</b>			
One municipality / one capital district	5 (100%)	6 ( 86%)	11 ( 92%)
Two or more municipalities		1 ( 14%)	1 ( 8%)
<b>Number of inhabitants covered</b>			
Mean (Range)	28097 (10397 – 48062)	37819 (7806 – 84476)	33768 (7806 – 84476)