

Providing Patient-Centered and Coordinated Care: A Qualitative Study of Norwegian Cancer Coordinators' Experiences of Enacting Their Role in Primary Health Care

Nataskja-Elena Kersting Lie

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Nataskja-Elena Kersting Lie



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Department of Physiotherapy
Faculty of Health Sciences
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ABSTRACT

The cancer coordinator (CC) role was initiated by the Norwegian Cancer Society to meet the growing need for patient-centered and coordinated care in primary health care. Norwegian CCs shall adopt a dual focus on both patient- and system-level work, to address patients in all stages of the cancer trajectory, thus enacting a broad range of tasks. However, there is little in-depth knowledge of CCs' own experiences of enacting their role to deliver patient-centered and coordinated care. Based on the identified research gap, the overall aim of the present thesis is to increase knowledge of Norwegian CCs in primary health care own experiences of enacting their role to deliver patient-centered and coordinated care. Consequently, the first aim of this thesis was to study CCs' own experiences of their role (paper I). The second aim was to investigate in CCs' experienced barriers and facilitators for system-level work (paper II). The third aim was to examine CCs' experiences with the delivery of cancer rehabilitation interventions in primary health care (paper III).

For all papers a qualitative method was applied using a hermeneutic research design. In paper I and II, data were obtained via semi-structured, individual in-depth interviews with 26 CCs. In paper III focus groups were conducted, with seven, respectively five CCs. Data were analyzed using thematic analysis and the findings discussed in light of Antonovsky's salutogenic theory.

Paper I focused on the CCs' experiences of enacting their role. The findings indicated 'Providing coordinated care' as an overarching topic for CCs' experiences of how they enacted their role. This topic was elaborated in the following three main themes: (1) 'Finding their place and creating their function', (2) 'Meeting the needs of patients and helping them to cope', and (3) 'Promoting well-functioning cancer care systems'.

Paper II focused on CCs' experiences of barriers and facilitators for their system-level work. Here, the analysis revealed three main themes: (1) 'Understanding the role and local cancer care', (2) 'Systems for care delivery in primary health care', and (3) 'Commitment to collaboration'. Where present, the themes could represent important facilitators, where their absence could depict notable challenges to CCs' system-level work. Over time, CCs gradually seemed to turn initial challenges into facilitators.

Paper III focused on the CCs' experiences with the delivery of cancer rehabilitation interventions in primary health care. The analysis illuminated three main themes: (1) 'A missing link to cancer rehabilitation', (2) 'Trying to put cancer rehabilitation in the spotlight', (3) 'The need to build a system for rehabilitation service delivery'.

The findings from the three studies indicate that CCs delineated both patient- and system-level activities. CCs encountered initial challenges, as they expressed that they had to develop and implement the role in a time-consuming process and with little perceived support or guidance. Role flexibility enabled them to adjust the role to the distinct contextual frames and settings they worked in. However, the role's diversity challenged the implementation and external role recognition. CCs outlined a high degree of case-based, patient-level work, emphasizing the importance of a holistic approach, patient involvement and comprehensive needs assessments. Although CCs were available to patients in each phase of the continuum, the majority seemed to focus most on providing palliative care, and less on e.g. cancer rehabilitation. The broad range of tasks were perceived as work overload, hence, system-level work seemed to be sidetracked. Here, CCs encountered important topics, such as role recognition, common procedures and professional collaboration that could act as both barriers and facilitators for their system level work. The CCs expressed a missing focus on cancer rehabilitation in the municipalities. Although the CCs suggested a holistic approach to complex cancer rehabilitation, they perceived current practices to contrast this concept. Further, CCs accounts of rehabilitation- and treatment-focused tasks seemed to be blurred. In light of salutogenic theory, the findings indicate that CCs adopted a salutogenic view in their work as they focused on resources that could enhance comprehensibility, manageability and meaningfulness to achieve positive developments both at the patient- and the system-level.

The findings show that CCs ask for enhanced support from the municipal management and a better facilitation of system-focused work, in terms training, resources, multidisciplinary teams and cross-sectoral communication systems. This study suggest CCs and municipalities to adopt a stronger focus on cancer rehabilitation. Work-overload of CCs may be counteracted in assigning them a more overarching function with a focus on capacity building of health professionals and on local practice development. More research into the role is needed, particular on its effects, system-focused aspects and CCs' role in facilitating rehabilitation in municipalities. There is a need for quantitative and qualitative research into CCs' role from the perspectives of the patients and their families, CCs' superiors and collaborating partners.

SAMMENDRAG

Kreftforeningen har etablert kreftkoordinatorer (KK) for å møte det økende behovet for pasientrettet og koordinert omsorg i primærhelsetjenesten. KK skal ha et todelt fokus og jobbe både på pasient- og systemnivå og med pasienter i alle faser av kreftforløpet, som representerer en stor bredde av arbeidsoppgaver. Det er gjort lite forskning på KKs egne erfaringer med å utøve rolle for å gi pasientrettet og koordinert omsorg.

Det overordnede målet med denne studien er å øke kunnskap om norske KKs egne erfaringer med å gi pasientrettet og koordinert omsorg i rollen. Derfor er det første målet å undersøke KKs erfaringer med rollen (Artikkel I). Det andre målet er å belyse KKs erfaringer med hemmende og fremmende faktorer for å jobbe på systemnivå (Artikkel III). Det tredje målet er å få innsikt i hvordan KK opplever sin rolle innen kreftrehabilitering i primærhelsetjenesten (Artikkel III).

Denne studien bruker kvalitativ metode med et hermeneutisk forskningsdesign. I studie I og II ble dataene samlet inn gjennom semi-strukturerte individuelle dybdeintervjuer med 26 KK. I studie III ble det gjennomført to fokusgruppeintervjuer med henholdsvis syv og fem KK. Tematisk analyse ble brukt for å analysere dataene og funnene ble diskutert i lys av Antonovskys salutogene teori.

Artikkel I undersøkte hvordan KK opplever rollen sin. Funnene indikerer at 'Å gi koordinert omsorg' var et overordnet tema for KKs opplevelse av rollen. Dette ble utdypet i tre hovedtemaer: (1) 'Finne sin plass og utvikle rollen', (2) 'Møte pasientenes behov og bidra til mestring' og (3) 'Fremme godt fungerende systemer for kreftomsorg'.

Artikkel II undersøkte KKs erfaringer med hemmende og fremmende faktorer for sitt systemrettede arbeid. Analysen viste tre hovedtemaer: (1) 'Forståelse av rollen og kreftomsorg', (2) 'Systemer for å gi kreftomsorg i primærhelsetjenesten' og (3) 'Satsing på samarbeid'. Dersom temaene var til stede, kunne disse representere fremmende faktorer for KKs. Dersom de manglet kunne det gi utfordringer i KKs arbeid på systemnivå systemrettede arbeid. Funnene indikerer at KK over tid gradvis omgjorde det som innledningsvis var utfordringer til ressurser for systemrettet arbeid.

Artikkel III undersøkte KKs erfaringer med å levere kreftrehabiliteringstilbud i primærhelsetjenesten. Analysen viser tre hovedfunn (1) 'En manglende lenke til kreftrehabilitering', (2) 'Prøve å rette søkelyset mot kreftrehabilitering' og (3) 'Nødvendigheten av å lage gode systemer for å gi rehabiliteringstilbud'. 2)

Funnene fra de tre studiene indikerer at KK-rollen er kompleks og innebærer pasient- og systemrettet arbeid. KK møtte innledningsvis på utfordringer, fordi de ga uttrykk for at de måtte utvikle og implementere rollen i en tidskrevende prosess, med lite opplevd støtte og få føringer. Rollens fleksibilitet muliggjorde at KK kunne tilpasse rollen til de forskjellige kontekstene, rammene og omgivelsene de jobbet i. På en annen side ga rollens variabilitet utfordringer i forhold til implementering og rolleforståelse. KK viste til en høy andel av pasient-rettet arbeid og at de jobbet fra sak til sak. KK understreket viktigheten av en holistisk tilnærming, brukermedvirkning og en uttømmende kartlegging av pasientenes behov. Selv om KK var tilgjengelig for pasienter i alle faser av forløpet, indikerte mesteparten et hovedfokus på palliativ omsorg og mindre på blant annet kreftrehabilitering. KK opplevde den store bredden av oppgaver som en overbelastning, slik at systemrettede oppgaver kunne havne på sidelinjen. I den forbindelse viste KK til viktige temaer, som rolleforståelse, felles prosedyrer og profesjonelt samarbeid som kunne representere både hemmende og fremmende faktorer i KKs systemrettede arbeid. KK ga uttrykk for at det manglet et fokus på kreftrehabilitering i kommunene. Selv om KK utpekte en holistisk tilnærming til kreftrehabilitering gjennom hele forløpet, opplevde de at dette stod i motsetning til aktuelle praksiser i kommunen. Videre var det tilsynelatende uklare grenser mellom det KK beskrev som oppgaver knyttet til rehabilitering og behandling. I lys av den salutogene teorien indikerer funnene at KK fulgte en salutogen tilnærming i arbeidet sitt, med fokus på ressurser som kunne øke begripelighet, håndterbarhet og meningsfullhet for å fremme en positiv utvikling på pasient- og systemnivå.

Funnene fra denne undersøkelsen viser at KK etterspør økt støtte fra kommunal ledelse og en bedre tilrettelegging av systemrettet arbeid gjennom opplæring, ressurser, tverrfaglige team og kommunikasjonssystemer på tvers av sektorer. En overbelastning av KK kan motvirkes ved å gi dem mer overordnende oppgaver med fokus på kompetanseutvikling hos helseprofesjonelle og på praksisutvikling. Det er behov for mer forskning, spesielt på effekten av KK, KKs systemrettet arbeid og KKs rolle i å tilrettelegge for kreftrehabilitering i kommunene. Det er behov for både kvantitativ og kvalitativ forskning som belyser KKs rolle ut fra perspektivene til pasientene og familiene deres, KKs ledere og samarbeidspartnere.

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LIST OF PAPERS

Paper I: Lie N-EK, Hauken MA, Solvang PK. Providing Coordinated Cancer Care-A Qualitative Study of Norwegian Cancer Coordinators' Experiences of Their Role. *Cancer Nursing*. 2017. DOI: 10.1097/NCC.0000000000000504. [Epub ahead of print] (Appendix I)

Paper II: Lie N-EK, Solvang PK, Hauken MA. From challenges to resources-A qualitative study of cancer coordinators' experiences with barriers and facilitators for enacting their system-focused tasks. *Cancer Nursing*. 2018. DOI: 10.1097/NCC.0000000000000617. [Epub ahead of print] (Appendix II)

Paper III: Lie N-EK, Solvang PK, Hauken MA. We need to focus more on cancer rehabilitation - Experiences from Norwegian Cancer Coordinators in Primary Health Care. *Submitted for publication*. (Appendix III)

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ABBREVIATIONS

CC – Cancer coordinator

GP – General practitioner

GRRs – General resistance resources

GRDs – General resource deficits

IOM – Institute of Medicine

NCS – Norwegian Cancer Society

QoL – Quality of life

SOC – Sense of Coherence

SSR – Specific resistance resources

TA – Thematic analysis

WHO – World Health Organization

DEFINITIONS OF CENTRAL TERMS

- **Cancer control continuum**

“the various stages from cancer etiology, prevention, early detection, diagnosis, treatment, survivorship, and end of life.”¹

- **Cancer rehabilitation**

“is commonly defined as a goal-oriented, coordinated and multidisciplinary health promoting process that assists the individual to obtain maximal physical, psychological, social and vocational functioning within the limits created by cancer and its treatment.”^{2,3}

- **Care coordination**

“the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient’s care to facilitate the appropriate delivery of health care services. Organizing care involves the marshalling of personnel and other resources needed to carry out all required patient care activities, and is often managed by the exchange of information among participants responsible for different aspects of care.”⁴

p.5

- **Health promotion**

“the process of enabling people to increase control over their health and its determinants, and thereby improve their health. It is a core function of public health and contributes to the work of tackling communicable and non-communicable diseases.”⁵

- **Patient navigation**

“a community-based service delivery intervention designed to promote access to timely diagnosis and treatment of cancer and other chronic diseases by eliminating barriers to care”.^{6, p.2}

- **Primary health care**

“the first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process.”⁷

- **Specialized care**

“is delivered by specialized clinicians and in hospitals (secondary care), or in larger hospital with sub-specialties or intensive care facilities (tertiary care), usually upon referral by primary health care professionals.”⁸

1. INTRODUCTION

This thesis focuses on the experiences of Norwegian CCs in primary health care with enacting their novel role to deliver patient-centered and coordinated care. There were several reasons for this focus:

Although the number of new annual cancer cases is increasing, progress in treatment and research has shown that cancer patients are living longer and more frequently surviving cancer.⁹⁻¹¹ However, cancer and its treatment can cause considerable consequences and have a significant impact on patients' physical and mental health, their family and social relations, and their work and quality of life (QoL) both during and after cancer treatment.¹²⁻¹⁴ This requires complex cancer care along the entire cancer trajectory that addresses the whole range of a patient's needs to help them manage both physical and psychosocial side- and late effects of cancer and its treatment.¹⁵ However, comprehensive cancer care requires a significant amount of care coordination and continuity.¹⁶⁻¹⁸

To date, the current systems for cancer care are often accused for being fragmented and lack of coordination.^{19,20} Accordingly, patients and providers can be overwhelmed by navigating the complex health care system, and many patients report having unmet support needs.²¹⁻²³ Considering the demographic trends and advanced knowledge of these patients' complex needs, the demand for comprehensive and coordinated cancer care is expected to rise.^{24,25} Hence, there is an increasing need for establishing models for coordinated care delivery within primary health care and across sectors.²⁶⁻²⁹

In recent years, clinicians and researchers have increasingly looked into cancer coordination to facilitate continuity in cancer care. However, cancer coordination is as a young, developing practice addressing individual- and system barriers to improve cancer care before, during and after treatment.³⁰⁻³³ In Norway, cancer coordinators (CCs) have been introduced to primary health care by the Norwegian Cancer Society (NCS) in 2012. Similar to international CC functions^{32,34,35}, Norwegian CCs are required to engage at both the patient- and the system level to address barriers to care, covering a very broad spectrum of tasks and responsibilities. Furthermore, the CCs work in various geographical areas and primary health care settings, and some of them work across municipal borders (inter-municipal CCs).³⁵ The municipalities were assigned the responsibility of determining the particulars of developing

and implementing this new role. Hence, the CC role has developed diversely in different municipalities.³⁶ Likewise, internationally, there is no common definition of the role, its label, setting, responsibilities and its time-point in the patient care pathway varies around the globe. Calls have therefore been made to increase knowledge of how CCs work to promote cancer care coordination.^{30,32} In particular, there seems to be a gap related to in-depths knowledge of CCs' experiences of enacting the role and what they experience as barriers and facilitators for operationalizing their system-focused tasks. Furthermore, based on an increasing survival rates and a national focus on cancer rehabilitation, respectively, there is a need to explore how CCs describe their contribution to cancer rehabilitation interventions in primary health care.^{9-11,26}

Based on the considerations above, the overall purpose of this thesis is to increase understanding of and knowledge of Norwegian CCs' own experiences of enacting their role to deliver patient-centered and coordinated care in primary health care. This may generate important insights and knowledge that can clarify the CC role, its contribution and challenges regarding patient-centered and coordinated cancer care.

The thesis is structured around nine chapters, where an overview and the rationale is provided in the beginning of the chapters. Chapter two provides a brief overview of the context in which the CCs operate. Chapter three addresses previous research into coordinated cancer care and the role of CCs. The study is based on a salutogenic approach, and this theoretical framework is presented in chapter four. Based on previous research, the study aim and research questions are specified in chapter five. Following the research questions, chapter six outlines the study methods and materials and the rationale behind these choices. The findings from the three papers and presented in chapter seven, where the findings also are regarded in connection to each other. As the findings from each paper are discussed in the respective papers, the discussion of chapter eight focuses on the overall findings, followed by methodological reflections. The main conclusions of the studies, clinical implications and suggestions for further research are presented in chapter nine.

2. CONTEXTUALIZING THE STUDY

Because the Norwegian CCs operate in complex and diverse settings, addressing patients in all phases of the cancer trajectory, this chapter provides a brief overview of this context. First, an overview of cancer in Norway is given. Thereafter, current provision of cancer care in primary health care is outlined, followed by a presentation of the NCS initiative to implement CCs in Norwegian primary health care. Finally, the cancer control continuum is presented as a relevant model to provide insights into the different phases and relevant issues for cancer patients that CCs may encounter.

2.1 Cancer in Norway

‘Cancer’ is a generic term for a large group of diseases characterized by abnormal and rapid cell division beyond their ordinary boundaries, and ability to metastasize to other organs.³⁷ Cancer is one of the leading causes of morbidity and mortality globally, with approximately 14 million new cases and 8 million cancer-related deaths worldwide.¹⁴ Up to 58% of all new cancer cases occur at age 65 or older.³⁸ Cancer incidence rates are increasing, reflecting a real increase in numbers and a growing and aging population.³⁹ However, it is estimated that, with effective cancer control, more than 40% of all cancer can be prevented and common cancer types such as breast -, colorectal - and cervical cancer can be cured.²¹ The total annual economic impact of cancer is enormous and equivalent to 2% of the total global gross domestic product.¹⁴ Additionally, these costs are increasing, and it has been proposed that an increased focus on prevention, early detection and treatment could significantly reduce the burden.^{ibid}

In Norway, 32.827 new cases were registered in 2016, including 17.763 men (54%) and 15.064 women (46%). The most frequent cancer types were prostate cancer, breast cancer, lung cancer, colon cancer and malignant melanoma. Three out of four cancer patients were 60 years old or older. In 2016, more than 262.000 surviving individuals had a previous diagnosis of cancer. The 5-year survival rates are increasing as a result of advances in screening, detection and treatment.^{40,41}

Modern cancer treatments are often complex and long-lasting and involve a combination of invasive interventions, such as surgery, chemotherapy and radiotherapy, each of which can

produce considerable side-effects. Furthermore, based in increasing survival, research documents that cancer survivors suffer from notable and long-term impact on their physical and psychosocial health and well-being.^{42,43} Likewise, advances in treatment have prolonged the palliative phase for patients with incurable cancer, who also require for comprehensive long-term support.^{12,14} Hence, the current trends in disease patterns bring along an increasing need for more comprehensive follow-up of patients during the different phases of the cancer trajectory. Consequently, primary health care systems are challenged by the requirement posed by a growing number of patients with complex needs.^{10,14,27}

2.2 Cancer care at the primary health care level

The provisioning of cancer care is ensured within the frames of the broader health care system, which includes primary, secondary and tertiary care.⁴⁴ In Norway, the health care system is semi-decentralized in that the state holds responsibility for specialist care, while municipalities are responsible for primary health care. In all, 85% of the total health expenditure (not including dental care) is financed via public sources, while 15% of costs are covered by patient deductibles.⁴⁵ Access to required health and social services is a legal right for Norwegian inhabitants, irrespective of the level of care required.^{29,46-49}

A cancer diagnosis and subsequent treatment most often involve highly technical interventions that are accessed in secondary and tertiary care centers and administered with the aim of saving or prolonging the patients' life.^{44,50,51} However, the fact that survival has increased indicates that cancer has shifted into a chronic disease and that cancer patients therefore undergo treatments for longer period of times and have to deal with the long-term effects of these treatments.^{44,51} In Norway, hospital stays are getting notably shorter and treatment is increasingly provided in polyclinics.²⁶ This has brought along a greater requirement for cancer care in primary health care.

Norwegian primary health care involves the day-to-day health care services provided by general practitioners, occupational therapists, physiotherapists, and speech therapists and is often combined with acute care, rehabilitation offers and intensive care, including that provided by nursing homes, sheltered housing and homecare teams.²⁹ Even if Norway's health care system is ranked high internationally⁴⁵, efforts to ensure equal access to health care is challenged by geographical diversity. Hence, collaboration and coordination between

primary health care and specialized care physicians ought to be improved.^{45,52} Consequently, the Coordination Reform⁵³ was released to strengthen primary health care and improve collaboration and service coordination among the relevant sectors. Thereby, primary health care received increased responsibility for patient follow-up after hospital discharge and during rehabilitation and end-of-life care.

In accordance with international developments, the national policies emphasize an increased need for holistic, patient-centered and coordinated care that is aimed at prevention, early intervention, early diagnosis, treatment, follow-up and rehabilitation.^{26,47,48,53,54} This requires specific skills, competencies, and care coordination^{19,50,51} that often surpass a generalist approach, adding to the needs of all other patient groups that primary health care professionals address.^{26,55}

2.3 Norwegian CCs in primary health care

To meet the challenges of providing comprehensive and coordinated care, in 2012, the NCS invited Norwegian municipalities to take part in a pilot program to establishing CCs in primary health care. The NCS allocated 30 million NOK funding for the initiative, offering 75% financial coverage of the costs of a CC position in the first year. The NCS outlined to gradually reduce this coverage over four years to encourage municipalities to fully finance their CCs after the project pilot period.^{35,36} As a result of this initiative, approximately 130 municipal CCs have been established in part-time and full-time positions since 2012, with the number per region depending on size and number of inhabitants within the municipality, the ability of the municipality to co-finance the role and the requests they made.^{35,36} For instance, Norway's largest municipality, Oslo, employs several CCs throughout the county, whereas other, typically smaller municipalities have allied with each other to employ a shared CC, who is then referred to as an inter-municipal CC.³⁶ The Norwegian CCs are distributed all over Norway as shown in Figure 1.

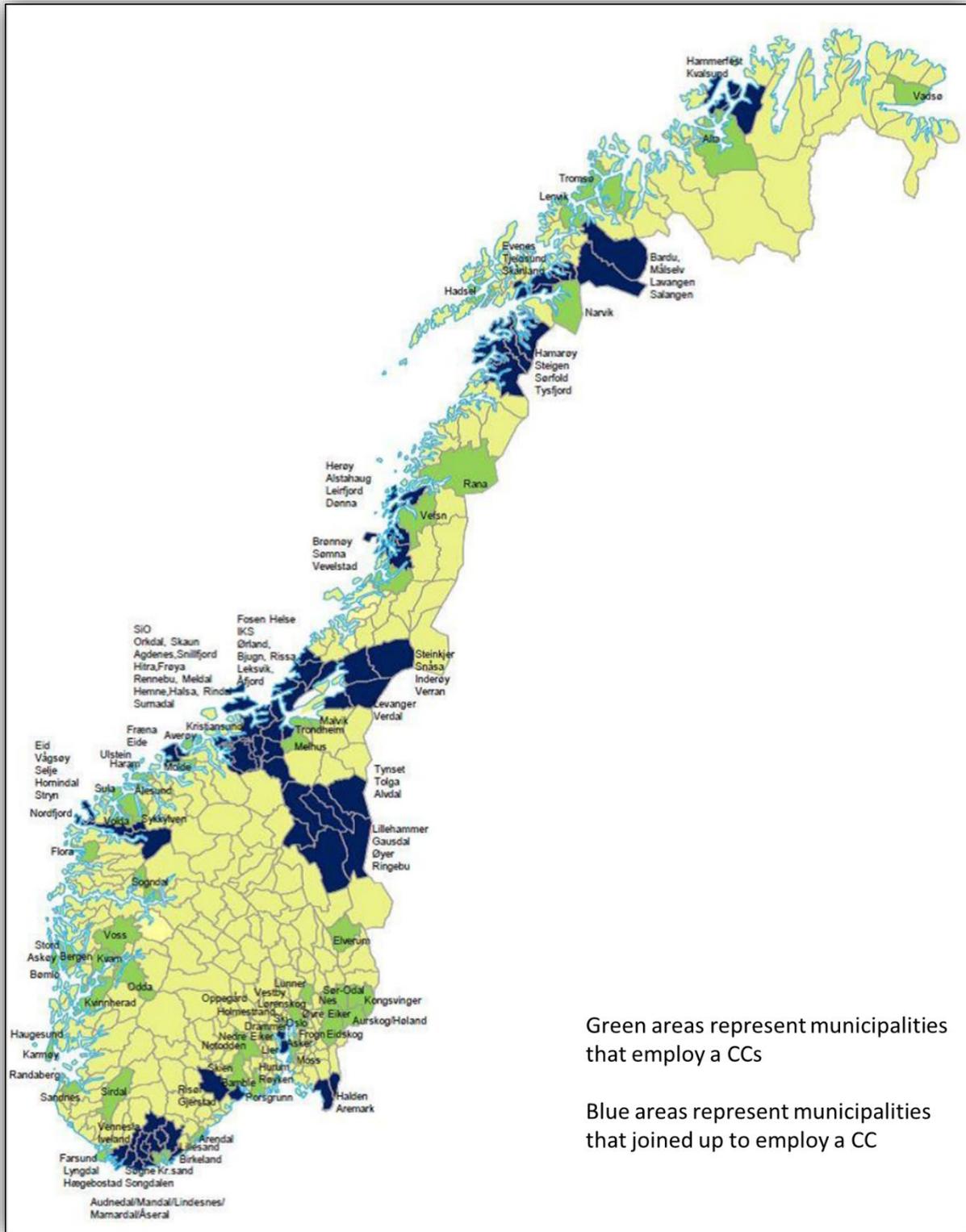


Figure 1: Distribution of the overall CC population in 2013. Derived from Hernes, Lindseth³⁵. The map is based on the Norwegian Mapping Authority. Reprinted with permission from the copyright owner.

The NCS did not specify the professional background for the role. However, most municipalities employed CCs with a background in nursing or cancer nursing, many of whom work as local nurses in addition to holding a part-time CC role.^{35,36} The NCS assigned municipalities the responsibility of developing and implementing the role in accordance with the context and needs of the municipalities.³⁶ Consequently, the NCS did not provide any clear description of the role, but presented only very broad guidelines and examples of work tasks, as shown in Table 1.

Table 1: The Cancer Society's Guidelines and Examples of Work Tasks for Norwegian Cancer Coordinators (see paper I)

Guidelines and examples of work tasks for Norwegian Cancer Coordinators

CC shall have an overview over:

- all cancer patients in the municipality
- relevant offers and services in the municipality
- patient associations and volunteers and collaborate with them

CC shall disseminate and promote their function through:

- leaflets and information on the municipality's home page.
- visibility and accessibility to persons affected by cancer and their next-of-kin
- visibility and accessibility to the specialized health services
- collaboration with the local general practitioners, cancer nurses and the patient coordinator in hospitals

CC shall have a patient-directed function, including:

- advice and guidance for patients and relatives on matters related to the diagnosis, treatment, rehabilitation, palliative and terminal care
- individual case management
- follow-up of children and young next-of-kin
- establishing good routines for contact with and follow-up of bereaved

CC shall have a system-level function, including

- implementing routines for cooperation and interaction within the municipality and across sectors, e.g. procedures, check lists or patient transfer between primary and specialized care
 - competence building in the municipalities, such as information, education and supervision of health care professionals and other relevant agencies in the municipality
 - periodic collaboration meetings with resource nurses and general practitioners and with health professionals in the hospitals
 - implementing routines for interdisciplinary and cross-sectoral work.
 - provide feedback on what works and does not work in the health system
-

As the NCS' guidelines suggests, the CCs are assigned a novel role in primary health care, adopting both a patient- and a system focus which involve a broad range of tasks.^{35,36}

However, the aims, tools and strategies used to implement, acquire quality measurements of or evaluate the role are not described in the guidelines.^{35,36} As a result, the CC role is highly diversified across the country. Currently, there is scarce evidence on CCs' work apart from semi-annual evaluations and at some gatherings of all CCs.^{35,36,56,57} The CC themselves express a need for more precise guidance for how to define, implement and sustain their navigating role in primary health care.^{26,35}

2.4 The cancer control continuum

As indicated by the NCS' guideline, Norwegian CCs are supposed to facilitate care for patients in all phases of the cancer trajectory. In line with this, the WHO^{21,24,58} underscores the need to adopt a comprehensive framework that describes and organizes prevention, early detection, diagnosis, treatment, rehabilitation and palliative care, and accounts for patients' physical and psychosocial needs in all phases, referred to as cancer control. Based on this, several models^{2,44,59} have been developed to illustrate the distinct phases of the cancer trajectory. However, in this thesis, the cancer control continuum model (Figure 2) by the Institute of Medicine (IOM)¹⁵, was considered as particularly relevant because it incorporates all the phases of the trajectory as well as the relevant issues patients face, accordingly. As patients treatment increasingly is provided in polyclinics, and hospital stays are shorter, CCs increasingly meet patients at all stages of the cancer control continuum.²⁶ The framework is widely used and demonstrates particularly well the complex field CCs navigate and the many issues they may have to address via their role.

As shown in Figure 2, the IOM model includes: etiology, prevention, detection, diagnosis, treatment, survivorship and end-of-life care.¹⁵

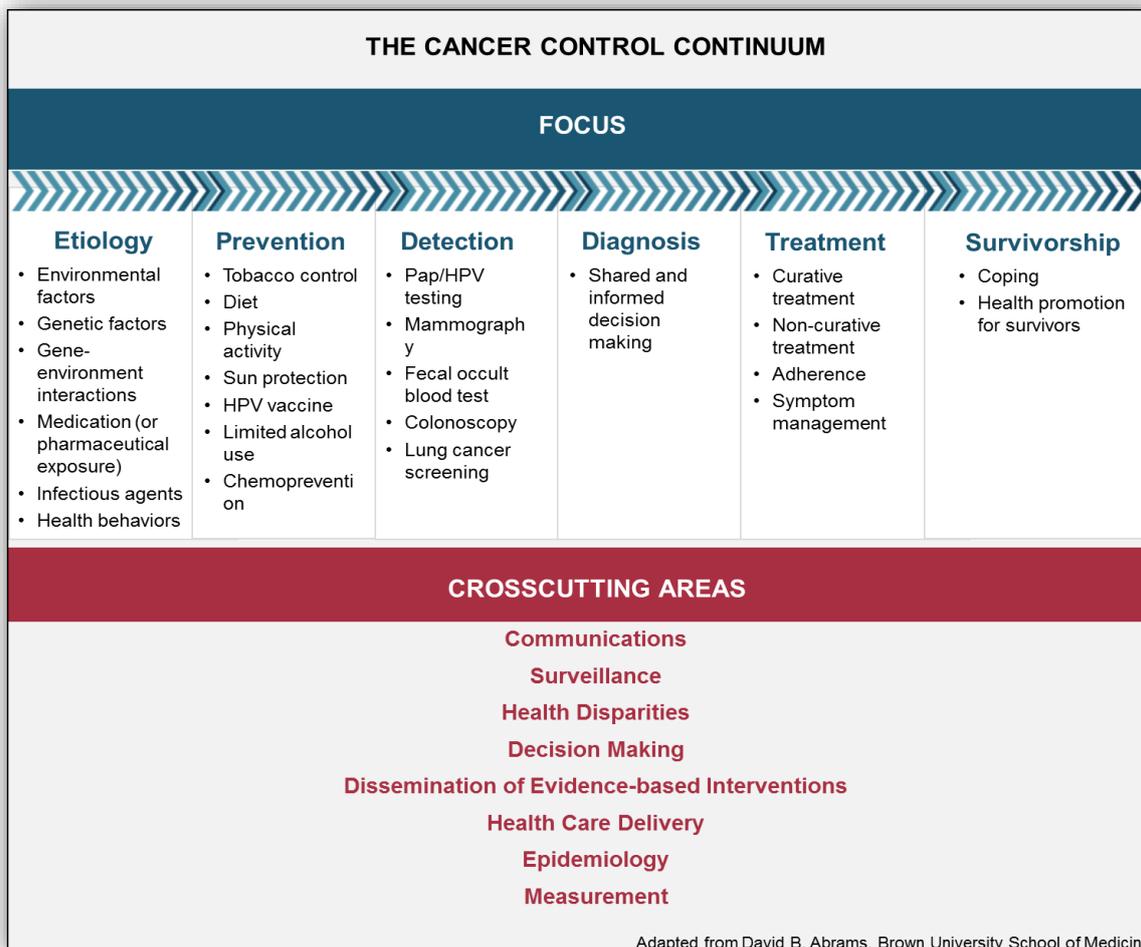


Figure 2: Illustration of the cancer care continuum. The National Cancer Institute 1. This figure is freely available for reprint.

The figure underscores the notion that the physical, cognitive, emotional and social consequences caused by cancer and its treatment can evolve from the point of detection and may persist throughout the cancer control continuum.^{42,43,60,61} Further, the model underscores that CCs' support required by each patient will vary based on genetic, environmental, medical and behavioral factors and on the particular phase they are in.¹⁶ Thus, the model underscores that the delivery of cancer care is influenced by a complex set of factors the CCs must consider in their work. It exemplifies that CCs may work with prevention, for instance, in providing information and education to the public. The CCs may also support to patients

during the detection phase, where patients will have to undergo diagnostic tests and procedures that require timely and coordinated services.^{62,63} Following a diagnosis, patients and their families have a particularly urgent need for information about cancer, where CCs may be assigned the task to facilitate the provisioning of information and education on treatments and its consequences to patients.^{55,64} During treatment, CCs may address common issues including system gaps, barriers to care, treatment adherence, symptom management and early rehabilitation from the treatment sequelae.^{15,65} Patients' support needs may, among other, include the management of and adjustments made to treat fatigue, pain, physiological and sexual dysfunction, cognitive deficits, and mental health issues, such as depression, anxiety, and fear about the future, death, the recurrence of cancer and decreased QoL.^{60,66-74} Health professionals might require education on cancer-related issues or care procedures, among other. In the IOM model, survivorship is associated with a need for support that addresses physical and mental long-term consequences in addition to problems with employment, insurance, social re-integration and participation.^{42,43,75,76} Here, coping and health promotion are important topics that need to be addressed by health care providers, e.g. the Norwegian CCs. Cancer rehabilitation is considered a part of treatment and is provided to help patients adjust to treatment sequelae, while issues and long-term-consequences arising after treatment are addressed within the frame related to survivorship.^{15,77} Furthermore, patients' network and family, who are often the patients' primary health caregivers, may also require support. As underscored by the WHO, the model also demonstrates that some of these issues are cross-cutting, (e.g. the need for information, communication, shared and informed decision-making, the dissemination of evidence-based interventions, coping, health care delivery and quality of care).^{78,79} As such, the model illustrates a need to focus on both the patient-and system level to facilitate coordinated and patient centered care.

3. PREVIOUS RESEARCH

As described in the foregoing chapters, cancer care coordination is a complex field, involving various actors, services and sectors. Therefore, this chapter seeks to provide an overview over previous research into cancer patients' need for comprehensive and coordinated care, the challenges they face at the interface between primary and specialized care, and how navigation roles operate to improve coordinated cancer care.

3.1 The need for patient-centered and coordinated cancer care

Providing quality care to patients requires that health care systems both ensure health benefits in the form of treatment and that they address the adverse effects of treatment by providing adequate interventions and support throughout the care continuum.⁸⁰ Accordingly, in cancer care, there is an increasing focus on providing services for patients include optimal biomedical and psychosocial health care so that patients, their families and health professionals can better manage sequelae and thereby promote health and wellbeing.⁸¹ Primary health care interventions that aim to support cancer patients may therefore include multidimensional services, such as information and counselling, physical exercise and psychosocial support.^{78,82} Evidence shows that patients are positively impacted when information and support are provided from the time of diagnosis, suggesting that integrating education and support with self-management and self-care may help patients better cope with their disease and enhance self-efficacy.^{83,84} Furthermore, some evidence indicates that there are economic advantages to providing adequate follow-up, perhaps because it can prevent avoidable hospital re-admission and reduce consultation rates, thereby resulting in cost savings.^{83,85}

However, while the necessary biomedical treatments are currently delivered at a high level, there seems to be a failure to target the psychosocial challenges faced by patients and their families, despite the range of available services.⁸¹ Consequently, there is an increased call for a new and multidimensional or holistic standard of care that emphasizes the need to focus on psycho-social support in addition to biomedical services.^{78,81,84}

3.2 Challenges at the interface of primary and specialized health care

The IOM⁸⁶ proposes six key dimensions that the health care system should aim to achieve to meet patient needs: “safe, effective, patient-centered, timely, efficient and equitable health care”.^{86, p.6} The literature suggests that the optimal way to organize cancer care is to promote clear aims, responsibilities, roles, and communication patterns among professionals both within and across sectors.^{20,51,87} However, there are notable challenges to achieving these aims, particularly those at the interface between specialized and primary health care.^{64,65} A comparative investigation of international health systems has shown that collaboration and coordination between primary health care and specialized care physicians is a notable challenge in several countries, including Norway.⁵² This is often because of a lack of communication and unclear responsibilities between primary and specialized care providers.^{64,65} As a consequence, services are often fragmented and uncoordinated, and this puts patients at risk of missing out on the support they need.^{19,55} In particular, post-treatment and long-term follow up care, rehabilitation, management of late effects, preventive care and health promotion are frequently underutilized in cancer care.^{15,16,65}

Primary health care is often expected to assist patients in navigating their way through the system, and it is highly desirable to ensure the coordination and continuity of a patient’s contact persons.^{17,88,89} However, research shows that while primary health care providers are often involved in diagnosing a cancer patient, they are frequently unaware of the patient’s treatments and the other multidimensional challenges they face, such as psychosocial issues or concerns with their sexuality or employment.^{65,85} Thus, primary health care providers regularly become disconnected from their patient as soon as the patient transitions to specialized care. It is common for patients to not be referred back to their primary health care providers after hospital discharge, leading to a lack of awareness about the patient’s care trajectory on the part of the provider.^{44,87} This consequentially results in the follow-up needs of the patient going unmet.^{15,44,65} In addition, the effectiveness of primary health care appears to be impacted by a growing number of care tasks, and this limits its ability to adequately assist patients in managing their challenges.¹⁹ As a consequence, primary health care providers often have too little time to spend with their patients, and time-consuming tasks, such as information gathering, shared decision-making and cancer care coordination, consequently become sidetracked.^{20,51,88,89}

The literature underscores the notion that system fragmentation, discontinuity in care and missing service delivery impose a substantial burden upon patients.^{19,55} When providers fail to effectively interact, follow-up often falls to the patients themselves to receive test results and referrals and make new appointments.⁵⁵ However, the need to undertake such considerable navigation tasks on top of dealing with the burden of their sickness can impose a considerable amount of added stress, uncertainty and confusion on the patients.^{55,64} The variety of treatments and the need to undergo several transitions between sectors and settings can be overwhelming⁶⁴, particularly when the patient experiences geographic, socioeconomic or cultural barriers^{45,90} or has a low level of health literacy or education.^{91,92} When a patient cannot effectively navigate through the health care system, the consequences can include inefficiency and poorer outcomes caused by care delays, a failure to receive treatments and proper care, or an increase in expenses because services are received at an expensive location, such as an emergency room.^{19,55} As a consequence, the patients' psychosocial, family and information needs can remain unmet from diagnosis through treatment.^{16,64} This can have considerable consequences for the patients, whose unmet needs and poor health following cancer treatment can prevent the patients from social and workforce participation both during and for years after treatment.⁴³

There is an urgent need to strengthen primary health care and improve its integration with specialized health care systems to improve the quality and continuity of care.^{15,50,51,85} However, systems aimed at ensuring a satisfactory level of quality and continuity of care throughout the care continuum are scarce.^{20,93} There is therefore a need to develop and test models for care coordination throughout the cancer control continuum.^{20,93} Such models must involve strategies aimed at promoting the role of primary health care professionals in managing the multidimensional challenges faced by cancer patients and survivors to achieve patient-centered, coordinated care.²⁰ However, it remains unclear which strategies and models can best accomplish these tasks.¹⁹

3.3 Using navigating roles to facilitate coordinated cancer care

In recent decades, there has been an increased interest in using patient navigators, such as CCs, to better meet the requirement for coordinated, patient-centered care.¹⁸ The first patient navigation program was introduced in the US in the 1990s and was focused on reducing inequality in access to health care and providing more individualized follow-up services to

patients.⁶ This program established a paradigm for subsequent programs because it focused on low-income, underserved minorities and their perceived barriers to care and consequentially increased access to care and follow-up in this population.^{94,95} Since then, different models for patient navigation have been introduced that have expanded its scope to meet the needs of patients in distinct settings^{18,96}, including both primary and tertiary care, and to target all stages of cancer care.^{32,95-98} Previously established programs have addressed, among other things, educational, cultural, and language barriers to screening and treatment.³² However, research documents that most programs target particular tumor streams, care settings or particular phases of the trajectory, whereas cancer patients' rehabilitation needs seem to be marginalized.^{25,32,99}

3.3.1 Organization and scope of the role

Cancer navigation programs are often established with the support of local, state or federal government grants, private organizations, local initiatives by community-based clinics and cancer care centers and philanthropy.³² These navigation programs can involve the work of individuals or a team of individuals who can act as both health care professionals and social workers in addition to functions performed by non-professionals who are trained to carry out tasks within the frames of system navigation.^{96,100} Professionals in navigating roles, who are interchangeably referred to as patient navigators, cancer care or cancer nurse coordinators, have been established internationally and, recently, in the frames of the NCS CC position in Norwegian primary health care.^{99,101-106} Hence, the specific organizational structure and purposes of a function varies between distinct settings.⁹⁶

Because such diversity has evolved in CC functions around the globe, several studies have been performed to clarify and define the scope of the role. Several literature reviews published over the last decade^{32,96,100} have demonstrated that there is no consistent definition of navigation programs in cancer care even though some attempts have been made to describe its primary features. For instance, Valaitis et al.⁹⁶ identified three motivators that prompted the implementation of patient navigation roles. These included improving the delivery of health care and social services, supporting and managing particular health- or population-level needs, and enhancing patients' QoL and well-being.

Other studies have suggested, more specifically, that a set of overarching activities should be performed by professionals in navigating roles. These include identifying and eliminating patient- and system-level barriers to care^{96,100}; facilitating patient and caregiver access to health-related services; facilitating the effective and efficient use of the health system by patients, caregivers and providers; promoting and facilitating care continuity^{96,100} and health education; and providing emotional and psychosocial support or referring patients to alternative sources of such support.

However, Dohan & Schrag³² emphasized that a service-focused definition of CCs may lack specificity because, for example, administrative, emotional and social support can also be provided by other health professionals. Instead, they suggest the use of a barrier-focused definition that underscores the notion that CCs should distinguish themselves from other professionals in cancer care so that they can adopt a flexible, reactive approach to addressing perceived barriers to care rather than a role in which they provide a predetermined set of services to their patients. This manner of defining the scope of the role allows the role to be clarified while preserving its flexibility, as was requested by Freijser et al¹⁰⁷ and acknowledged by other scholars.⁵⁵

3.3.2 Implementation and outcomes of CC roles

Early patient navigation programs generated preliminary evidence of their benefits but had limited reproducibility because they focused on single-site interventions and employed different definitions of navigation.¹⁸ Currently, despite interest in navigating roles in cancer care, the topic remains understudied, and evidence for how to best implement such processes to achieve the best outcomes are scarce.^{32,55,96,100,107}

Freijser et al¹⁰⁷ identified some factors that influenced the implementation of the CC role, including that the scope of the role must be clearly defined and understood and that CCs' mandate for enacting specific tasks should be supported by management and other stakeholders. Other key factors include peer support and networking, professional development and methods to evaluate the role. However, little additional evidence is available on factors that impact the implementation of primary health care navigation.^{96,107}

Regarding the patient-, provider-, and system-level outcomes of the CC role, someone more extensive information is available in the literature. Previous studies indicate that patient

navigation can increase access to care, screening and follow up; promote the successful flow of information; provide assistance with financial, employment and health claims; support the logistical aspects of care coordination and improve overall patient satisfaction.^{32,33,96,108}

Furthermore, the literature suggests that improving patient navigation leads to better communication between services or providers, increases the skills and knowledge of providers, and enhances trust between providers and patients.^{32,96,109} However, Freijser et al.¹⁰⁷ demonstrated that CCs' activities have also led to unforeseen outcomes, such as issues related to equity, in that some patients received support from CCs while others did not or there was an increase in demand that exceeded available resources.

At the system level, it has been suggested that cancer care coordination supports effective case management, the use of standardized treatment protocols and better use of appropriate hospice care.¹⁰⁰ Valaitis et al⁹⁶ further noted that improving patient navigation in primary health care can help facilitate patient transitions between organizations and health care providers and thereby improve the efficiency of care coordination among multiple health care providers. Furthermore, research indicates that cancer navigation can reduce emergency visits and hospital admissions and readmissions and prevent premature institutionalization and the use of avoidable testing^{100,108,110}, each of which would produce cost savings.¹⁰⁰ However, few published studies have systemically evaluated or explored the effects of cancer navigation. Previous studies have been criticized for their lack of rigorous research design and their methodological limitations, such as a small sample sizes, the use of limited comparative data or a lack of control groups.^{32,100} Consequently, the current results at best suggest opportunities for further investigations.³² Likewise, knowledge of barriers and needed prerequisites for CCs system-level work and professional collaboration to improvement cancer care systems remains scant.^{28,30,100,107} Hence, there is a clear need to enhance what is currently known about navigating roles in cancer care.^{32,100,107}

3.4 What this study adds

The foregoing literature review shows that there exists a considerable amount of literature on CCs internationally, but limited in a Norwegian context. Moreover, most of the international studies have generated descriptive information on particular patient navigation initiatives, while only some qualitative studies have provided insights into the experiences of CCs, health care providers and patients.¹⁰⁰ Accordingly, there seems to be a lack of in-depth knowledge of CCs experiences of enacting the role. Furthermore, most research has focused on particular aspects of the role, such as its implementation, CC activities regarding single aspects of care or stages of the trajectory. Thus, there seems to be very little evidence on CCs' experiences of the entire process of care coordination, including the implementation of their role, its enactment at a patient- and system level, and in how far the various stages of the cancer care continuum, including rehabilitation, are approached. Therefore, the present study seeks to address this research gap in providing comprehensive, in-depth insights into CCs' own experiences of enacting their role. Thereby, a nuanced understanding may be generated that can help inform further research and the development of care coordination onwards.

4. THEORETICAL FRAMEWORK

The CC role may be studied in light of different theoretical perspectives, such as role theory, organizational theory, coping theory and many others. In this thesis, the salutogenic theory was chosen because Salutogenesis is a framework to guide understanding of factors and processes that impact how groups, organization or systems manage challenges, achieve health and positive outcomes.¹¹¹⁻¹¹³ Therefore, a salutogenic perspective was considered a suitable framework to aid the understanding of CCs' experiences of their role in the discussion of the findings. For this study it was exactly the applicability various levels that yields Salutogenesis a powerful framework for understanding CCs' experiences of enacting their role to deliver patient-centered and coordinated care.

In the following section, the context of salutogenic theory within the field of health promotion and its relevance to cancer care will be outlined. This is followed by a presentation of the origin of and main concepts underlying Salutogenesis and its development into an orientation that can be used to guide investigations into health-promoting processes and initiatives at the group-, society- or organizational level.

4.1 Salutogenesis: A theory for health promotion in cancer care

Health has for a long time been conceptualized in terms of a deficit model, with an emphasis on illness and disability, its causes and risk factors.^{114,115} Within Pathogenesis (from Greek: pathos = disease, genesis = origin) health and resources stand in a dualistic, mutually exclusive relationship with disease and risks.¹¹⁵ This approach has been subject to fundamental critique, reflected in the WHO Ottawa Charter for health promotion, adopting a bio-psycho-social approach to health with an emphasis on its internal and external determinants.¹¹⁶ Its principles involve a focus on creating health-promoting environments as well as to enable people to gain control over their health determinants and thereby to improve their health.^{5,116} The WHO²⁷ highlights that health care systems, particularly so primary health care, must increasingly look into health promotion in addition to viable disease prevention and management strategies. The role of health professionals can thus be seen as supporting people in decision making, to identify and point out determinants or resources for health and support people in making use of them.¹¹⁷ Accordingly, health promotion has become an

important and integral component of the cancer control continuum¹ and of high relevance for CCs in primary health care.

The salutogenic theory of health^{118,119}, developed by Aaron Antonovsky, has influenced health promotion research notably.¹²⁰⁻¹²² Salutogenesis (from Latin: *salus* = health and Greek: *genesis* = origin) is a resource-based, problem solving theory that works on the basis of asking which factors and processes create health, rather than exclusively investigating the limitations and causes of disease.^{118,119} Rather than classifying people as either sick or healthy, Antonovsky suggested health as a continuum with health and dis-ease reflecting the respective endpoints, as shown in Figure 3.

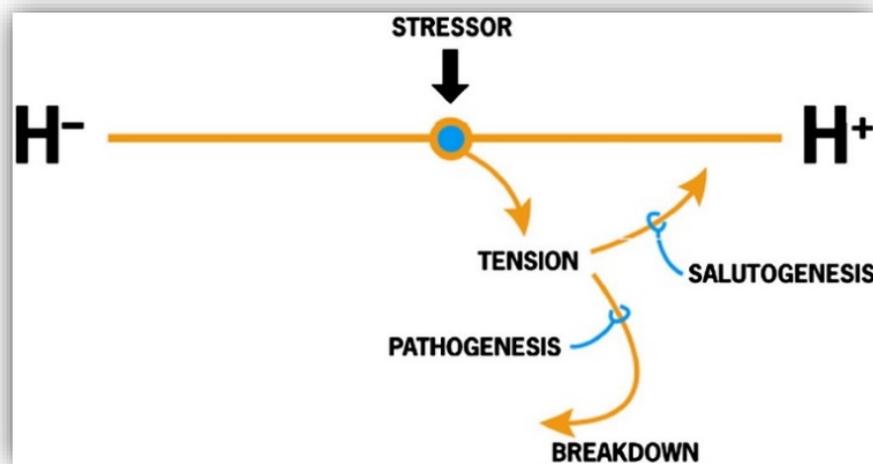


Figure 3: Antonovsky's health- dis-ease continuum, Graphic: Bengt Lindström, Monica Eriksson, Peter Wikström. Derived from: Lindström, Eriksson¹²³. Reprinted with permission of the copyright owners.

As the figure shows, Salutogenesis suggests that one always has some degree of health, which can vary during the life course.^{118,124} Antonovsky's dynamic concept of health can be understood as an alternate philosophical stance to the medical view of homeostasis as a fundamental human condition. In homeostasis, a system is characterized by an equilibrium, which is occasionally disturbed by stressors causing tension, disorder or disease. Hence, stressors must be avoided or eliminated to restore or maintain the initial state of a system.¹²⁵ Antonovsky, however, pointed out that stressors, illness and disease are omnipresent and environments can never be completely stressors-free. Hence, he outlined health as a form of

dynamic homeostasis, which he called a “heterostatic disequilibrium”.^{119, p.130} Rather than mostly engaging in maintaining the initial state, a system is regarded as primarily engaged in adapting to new or changing circumstances and creating a new order.¹²⁶ In this view, stressors *per se* are not health diminishing but can be resolved via effective tension management, which is suggested as a key mechanism for moving into a positive direction. In contrast, prolonged failure to manage tension and re-establish equilibrium (/create order) is anticipated to lead to a breakdown of a system or organism.¹¹⁹ Hence, health may not merely be achieved through the elimination of stressors but requires people to adapt to stressful situations. This can be achieved by asking the salutogenic question: ‘What are the salutary (health-causing) factors that help people move towards the health-end of the scale?’^{119,124}

4.2 Main concepts in Salutogenesis

Antonovsky suggested that there are two main components of the resources people have at their disposal to manage imbalance or tension caused by stressors.¹²⁴ Those resources, referred to as general resistance resources (GRRs), encompass features that can help enhance an individual’s resistance to stressors and thus their ability to manage tension and maintain their health.^{118,119} Antonovsky¹¹⁸ provided a mapping sentence that can be used to define a GRR, as shown in Figure 4.

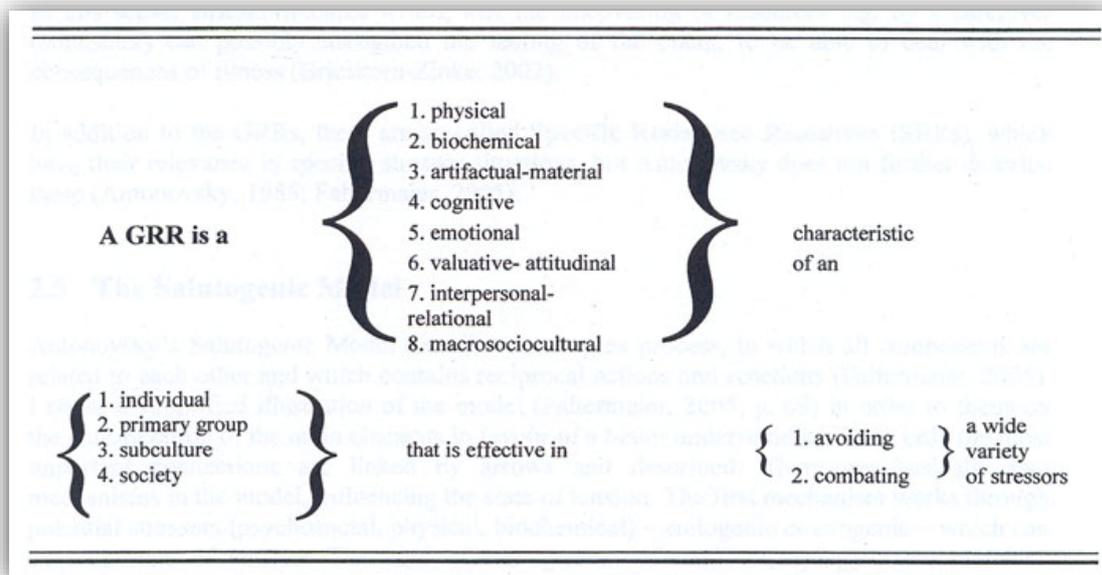


Figure 4: Mapping sentence for a GRR. Derived from Antonovsky¹¹⁸. Reprinted with permission of the copyright owner.

Figure 4 illustrates that the features of a GRR can vary and may include, for example, genetic or constitutional factors or psychosocial (social supports), material (money), cultural (cultural stability), or spiritual (religion) features, which can be identified at the individual level both within groups and in society. These characteristics can effectively circumvent or combat stressors.^{118,119,124} Specific resistance resources (SRRs) are closely related to GRRs and are frequently beneficial in particular situations.¹¹⁸ In turn, when resources are not available, a resource deficit (GRD) could occur that might impede tension management and thereby cause disease.¹¹⁹ In addition to being instruments useful for tension management and coping, GRRs can also provide positive life and feedback experiences to people, demonstrating that they are capable and worthy of achieving positive outcomes through their actions.¹²⁴ When repeatedly exposed to such experiences, people can develop a global sense that solutions are available. This orientation is called a Sense of Coherence (SOC), which is defined as follows:

“a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (1) the stimuli deriving from one's internal and external environments in the course of living are structured, predictable and explicable; (2) the resources are available to one to meet the demands posed by these stimuli; and (3) these demands are challenges, worthy of investment and engagement.”^{119, p.19}

As a strong life-orientation, the SOC orientation thus assumes that people's intrinsic driving force can improve and maintain their health. Its three main components are comprehensibility, manageability and meaningfulness, and these represent the cognitive, instrumental and motivational prerequisites, respectively, that enable people use available resources to deal with stressors.¹¹⁹

- Comprehensibility is defined as “the extent to which one perceives the stimuli that confront one (...) as making cognitive sense, as information that is ordered, consistent, structured, and clear”.^{119, pp.16-17}
- Manageability is defined as the extent to which an individual “perceives that resources are at one's disposal that are adequate to meet the demands posed by stimuli that bombard one”.^{119, p.17}
- Meaningfulness describes a perception that demands or challenges are “worth investing energy in, are worthy of commitment and engagement”.^{119, p.17}

Additionally, GRRs and the SOC can mutually impact each other because GRRs can enhance comprehensibility, manageability and meaningfulness and thereby strengthen an individual's overall SOC. A strong SOC, in turn, enables people to utilize the GRRs available to them to improve their health.^{115,119}

4.3 Salutogenesis – expanding the concept

Salutogenesis originates from research into individuals' health, stress and coping.^{118,119} However, the salutogenic paradigm has broadened its scope and application to investigate topics beyond individual health.¹²⁷ Equating health with functioning and survival, the salutogenic paradigm can be applied to examine the processes which promote well-functioning and positive outcomes in various systems and settings.^{113,128} Vinje, Langeland & Bull¹²⁹ note that the SOC concept, which has been influenced by system theory and the concepts of order and disorder, might be employed to explore how a systems copes with its reality. Replacing a perspective on how individuals deal with challenges, a group or system oriented SOC explores the interaction between individuals and their (social) environments.^{119,128} However, Salutogenesis can also be applied to investigate salutary factors in systems, without explicitly referring to the SOC.^{130,131} Consequently, Salutogenesis has become an umbrella term for 'strengths' or 'assets'-based approaches and has gained notable research interest in the field of psychology, educational sciences, occupational and organizational health.^{113,123,128}

Vaandrager & Kennedy¹³² highlight that Salutogenesis can be applied to a community setting to explore how communities make use of available resources to manage tension and determine whether an outcome will be salutary. By applying the concept of a collective SOC, the authors show that collective action can be viewed as a salutogenic mechanism that facilitates movement towards the health-end of the continuum and to gather GRRs.

Lindström & Erikson¹¹¹ even applied a salutogenic approach to the making of healthy public policy with the aim of improving health outcomes at the population level. Other studies^{128,133-135} have shown that when it is applied to an intervention setting, Salutogenesis can be useful for capturing both the negative and positive aspects of the intervention process and promoting and identifying which GRRs are needed to achieve the desired outcomes.

4.4 The salutogenic orientation used in the present thesis

In this thesis, the salutogenic theory was applied to investigate the role of CCs in Norwegian municipalities because it was considered that it may generate valuable insights into the mechanism, challenges and resources that influenced CCs' ability to achieve improved care coordination. This orientation may yield new knowledge of the challenges and resources that CCs experience.

The salutogenic theory is used throughout this thesis. In paper I, Salutogenesis was considered a useful framework with which to improve understanding of how CCs work to facilitate coordinated care and determine what resources they use to improve cancer patients' health. In paper II, this framework was used to generate insights into the challenges experienced and resources used by CCs to create healthy collaborations and achieve well-functioning systems in cancer care. In paper III, Salutogenesis was used as a framework to understand to identify the challenges CCs experience and the resources they use during to facilitate its delivery. Hence, in this thesis, Salutogenesis provides the theoretical framework for discussing the findings.

5. STUDY AIM

Based on the identified research gap, the overall aim of the present thesis is to increase knowledge of Norwegian CCs in primary health care own experiences of enacting their role to deliver patient-centered and coordinated care. The first aim was to study CCs' own experiences of their role. The second aim was to investigate in CCs' experienced barriers and facilitators for system-level work. The third aim was to examine CCs' experiences of their role in cancer rehabilitation in primary health care.

Consequently, this thesis seeks to answer the following research questions:

- 1.) How do CCs experience their role, and how do they undertake it to enhance coordinated cancer care? (paper I)
- 2.) What do CCs experience as barriers and facilitators for operationalizing system-focused tasks? (paper II)
- 3.) What are CCs' experiences with the delivery of cancer rehabilitation interventions in primary health care? (paper III)

6. METHODS AND MATERIALS

The methods adopted in this study were based on previous research and identified knowledge gap, the study's aim and research questions. These methods and materials and the rationale behind this are elaborated this section.

6.1 The study's perspective and method

Knowledge of CCs' role may be generated using different methods and designs. Considering the complexity of the setting CCs operate in, their role could be investigated from different perspectives, for example from the perspective of the patients and their next of kin, other healthcare professionals operating in the same field, the management etc., or a combination of these. Combining such perspectives were judged as being too comprehensive considering the frames of this thesis. Based on the fact that Norwegian CC role is novel, has broad assignments and operates in highly diverse contextual frames (chapter two), and the evident research gap of in-depth insights into CCs' own experiences from enacting this role (chapter three), a choice was made to focus on the CCs' perspective in this thesis.

Furthermore, the CC role also may be investigated using different research methods. For instance, quantitative research into effects and effectiveness is highly requested.^{32,100} However, existing international quantitative studies have indicated scant results due to e.g. methodological limitations and small sample sizes.^{32,100,107} Accordingly, quantitative studies on Norwegian CCs might be premature due to a lack of a clear understanding of the role and its tasks, which may be needed as a baseline for quantitative research outcomes. Considering this, the evident research gap and the research questions, a qualitative method was considered to be the most suitable method to investigate CCs' own experiences (hence their life-world) with operating the role, challenges and facilitators for system-focused work and the delivery of cancer rehabilitation in primary health care.

6.1.1 A qualitative method

Qualitative research allows insight into individual's experiences and provides an in-depth understanding of a topic that would be difficult to achieve via quantitative approaches.^{136,137} Traditionally, quantitative research was the predominant method to investigate health sciences and medicine, aiming to generate objective data, searching for causes and effects and

obtaining generalizable results though.^{138,139} However, based on a growing acknowledgement that today's health professionals operate in a highly complex context, qualitative methods are increasingly used to generate knowledge of health and health services.¹⁴⁰⁻¹⁴²

Qualitative research is associated with the use of a constructivist inquiry to generate knowledge. This approach anticipates that there are multiple, subjective realities, each of which is mentally constructed. Knowledge is created via an interactive process that takes place between the researcher and the researched.¹³⁹ Consequently, qualitative research refrains from separating subjects and objects because the objects are always viewed subjectively by the individual who regards them.^{143,144} Qualitative research methods focus on subjective and non-quantifiable parameters, and the insights gained from such projects are grounded in participant narratives, experiences and contexts.^{139,145} Hence, the aim of qualitative research is not to define a singular, independent reality but to capture how reality is regarded by individuals.^{137,138} By exploring individuals' lived or life-world experiences, qualitative approaches seek to provide a detailed and in-depth understanding of how individuals experience a topic and the value and meanings they attach to it.¹⁴⁵ Hence, the goal of knowledge gained via qualitative approaches is to reflect the shared or common views a group of individuals has of a phenomenon and reveal the contrasts in their perceptions.¹⁴⁶ However, as for quantitative research, several different design exist within qualitative research, whereby this thesis adopt a hermeneutic research design.

6.1.2 A hermeneutic research design

The choices that constitute a study's design depends on the philosophical assumptions it departs from.¹⁴⁷ The present study is based on a philosophical assumption of ontological relativity and epistemological constructivism.^{137, p.97} Ontological relativity^{137,148} anticipates that statements made by an individual depend on a human world view, by which experiences are interpreted and meaning is created. Thus, there is no absolute reality or universal truth, but there are instead multiple perspectives of what is real. Hence, the perceptions that different people have of the same empirical world can contrast one another dramatically.¹⁴⁸ Epistemological constructivism anticipates that life world is not real in an absolute sense but is shaped by socio-cultural constructs.¹³⁷ Consequently, when studying humans, truths or knowledge are formed based on consensus among those who construct the reality in question.¹⁴⁹

Based upon these philosophical assumptions, the present studies applies a hermeneutic design oriented towards the school of Gadamer.^{150,151} The oldest hermeneutic school involves a descriptive phenomenology that builds upon writings by Edmund Husserl and other important scholars^{137,152} associated with a positivistic paradigm.¹⁴⁴ It suggests that although reality cannot be separated into subjects and objects, qualitative research can maintain objectivity if the researcher steps aside from pre-conceptions (bracketing).^{143,144} Further developing this, Gadamerian scholars refrained from a positivist paradigm by anticipating that all knowledge is influenced by the researchers' pre-conceptions.¹⁵⁰ Understanding or obtaining the meaning of a phenomenon rather than a description of it is the center of attention.¹⁵³ Gadamer placed particular emphasis on the study of text and language. Applied in health sciences, learning from and understanding any action made, product produced or meaning expressed by an individual is regarded as analogous to interpreting a text.¹⁵⁴ Hermeneutics underscores the notion that understanding is generated from a certain perspective and is situated in a cultural, historical or situational context.¹³⁷ Pre-understanding is both impossible to set aside and a fruitful and necessary part of active interpretation because it enables the researcher to contextualize, frame and understand the phenomenon under investigation. The hermeneutic process resembles a dialogue in which understanding is generated through a circular process of interpretation between the researcher and the data (e.g., the narrative of a person or a text), called the hermeneutic circle.^{141,151}

Hermeneutics anticipates that gaining a new or different understanding requires personal involvement by the researcher, which makes him or her the instrument of the research.¹⁵⁵ On entering the hermeneutic circle, the researcher must remain open to the meaning held by another person.¹⁵⁶ During the interpretative course, it should become clear whether preunderstandings or anticipations made by the researcher facilitate or obstruct understanding, the latter of which lead the researchers to detach from them.¹⁵⁶ The researcher then adjusts his or her understanding according to the new insight and re-encounters the qualitative inquiry with a new set of preunderstandings. This hermeneutic process goes on until the horizon of the interpreter and the data are combined to form a new, common understanding.^{155,156} Kvale¹⁵⁷ notes that a hermeneutic interpretation is, in principle, an infinite process wherein interpretation ends when "a sensible meaning and coherent understanding that is free of inner contradictions has been reached".^{157, p.62} Gadamer¹⁵⁰ himself emphasized that reaching an understanding is not equivalent to understanding something better (e.g., in terms of clarity)

but can mean that one understands something in a new way. He argued that the focus of hermeneutics is therefore not to identify one single method or technique to gain understanding but to instead reveal the processes and contextual, personal, historical and social circumstances under which understanding takes place.¹⁵⁶ Reflexivity is thus necessary throughout the process to both ensure trustworthiness and enable the researcher to portray the meaning held by another against his or her own pre-understanding.^{143,150}

Following the hermeneutic design used in the present thesis, data were collected by individual in-depth interviews and focus groups interviews, to which a thematic analysis (TA) was applied to analyze the generated data in an interpretive, dialectic process. This will be elaborated in the following chapters. In summary, the thesis' positioning within philosophy of science can be illustrated as shown in Figure 5:

The position of this thesis within philosophy of science

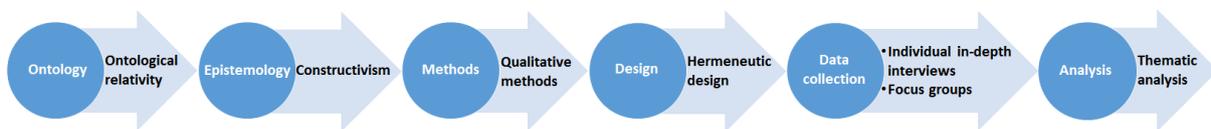


Figure 5: The position of this thesis within philosophy of science

6.2 Participants

In the following, the eligibility criterion, sampling procedure, participant recruitment and the study sample will be presented. The recruitment and data collection were undertaken parallel, between April 22nd 2014 and December 12th 2015.

6.2.1 Eligibility criteria and sampling procedures

This thesis embraces two study samples; one sample for individual in-depth interviews (paper I and II) and one for the focus group interviews (paper III). The following criterion was

applied to select participants for both samples: “Being an NCS-funded CC in Norway”. Because the nature of the role requires that CCs are Norwegian speaking adults, and the goal of the research was to gain insights into nuanced perspectives, no exclusion criteria were applied. To recruit a sample representing CCs with various background, a careful preliminary mapping was undertaken to inform the selection of participants. At this time, spring 2014, 130 CCs were established and listed at the webpages of the NCS.¹⁵⁸ Using this list, the web-pages of each of municipalities and statistical information (regarding number of inhabitants, localization, organization, CCs responsibility for one/several municipalities and their personal characteristics such as age, gender, time of employment and full-time equivalent) were undertaken for each CCs. Data were plotted into an excel sheet, providing an overall overview on the context for the role in the different municipalities.

To maximize differences of the study population in order to reflect different perspectives, a purposeful maximum variation sampling¹⁴⁵ was performed based on the preliminary criteria and initial mapping. The literature suggests that qualitative studies using individual in-depth interviews should embrace between 10 and 25 participants, depending on their availability, the frames of the research project and the richness of the material.¹³⁸ Consequently, 25 potential participants who differed notably based on the chosen criteria were selected to participate in in-depth interviews for paper I and II, in addition to three participants who participated in pilot interviews. The selected participants were approached by mail with an invitation and information about the study, alongside a consent form (appendix IV and V). They were also provided a brief recommendation of the study by the NCS (appendix VI). After two weeks, a reminder was sent to participants who had not responded.

For focus group interviews, the literature recommend between three and 14 participants.¹⁵⁹ Hence, from the total sample, 20 CCs were selected for two focus group interviews according to the same procedures as described above. The information letter also included a tentative date and place for the interviews, and offering re-imburement for travel expenses and one night of accommodation, assistance in organizing the journey, and catering subsequent to the interview. For the focus group interviews, 14 of the 20 invited CCs declined to participate in the study, mostly because of long travel distances and time pressure. Consequently, convenience sampling^{145, p.127} was performed as an alternative strategy for additional recruitment whereby participants that were most accessible were recruited.^{137,145} To

reach more participants and maintain some degree of variation, they were invited into two different cities (one in Eastern and one in Western Norway), both of which were easy to access via public transport and by car.

6.2.2 Participants

For the individual in-depth interviews, 28 invitations were sent out. One participant did not reply, and one participant did not wish to participate in the study, as the CCs just had started and did not perceive enough experience to contribute to the study. The final study sample consisted of 26 participants, including the three CCs who took part in the pilot interviews. This final sample represented 18 out of the 19 counties in Norway, and the characteristics of the participants are presented in Table 2.

Table 2: Overview of the study sample (individual interviews). Taken from paper II.

| Variables | Participants n (% of total n) |
|--|--------------------------------------|
| Gender | |
| Female | 25 (96%) |
| Male | 1 (4%) |
| Profession | |
| Nurse | 25 (96%) |
| Additional specialization as cancer nurse | 21 (81%) |
| Additional specialization in palliative care | 2 (8%) |
| Other than nurse | 1 (4%) |
| Worked as a CC since | |
| 2012 | 15 (58%) |
| 2013 | 5 (19%) |
| 2014 | 6 (23%) |
| Full-time equivalent | |
| Full time (100%) | 15 (58%) |
| Part- time (50%) | 11 (42%) |
| Organization of the position (Placement) | |
| Administration (e.g. service office) | 8 (31%) |
| Specialized services (e.g. local hospital) | 3 (12%) |
| Inter-municipal (commuting between municipalities) | 1 (4%) |
| Number of municipalities covered | |
| One municipality / one capital district | 21 (81%) |
| Two or more municipalities | 5 (19%) |
| Number of inhabitants covered (range) | 6163 – 267960 |

For the two focus groups interviews, 14 of the 16 invited participants agreed to participate. No participant was turned away. However, the final sample embraced seven, respectively, five CCs in two focus groups, as two CCs had to cancel the appointment on short notice due to illness. These CCs were from Eastern and Western Norway, and their characteristics are summarized in Table 3.

Table 3: Overview of the study sample (focus group interviews). Taken from the paper III.

| Participant characteristics | Focus group 1 | Focus group 2 | Total |
|--|-----------------------|----------------------|----------------------|
| Gender | | | |
| Female | 5 (100%) | 6 (86%) | 11 (92%) |
| Male | - | 1 (14%) | 1 (8%) |
| Age | | | |
| Mean (Range) | 50 (31 – 57) | 52 (38 – 62) | 51 (31 – 62) |
| Profession | | | |
| 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%) |
| Worked as a CC (months) | | | |
| Mean (range) | 24 (11-32) | 24 (13-29) | 24 (11-32) |
| Full-time equivalent | | | |
| Full time (100%) | 3 (60%) | 5 (71%) | 8 (67%) |
| Part- time (50%) | 2 (40%) | 2 (29%) | 4 (33%) |
| Organization of the position | | | |
| 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%) |
| Number of municipalities covered | | | |
| One municipality / one capital district | 5 (100%) | 6 (86%) | 11 (92%) |
| Two or more municipalities | - | 1 (14%) | 1 (8%) |
| Number of inhabitants covered | | | |
| Mean (Range) | 28097 (10397 – 48062) | 37819 (7806 – 84476) | 33768 (7806 – 84476) |

6.3 Data collection

In qualitative research, data can be collected by several means, as for example from observation, documents, in-depth interviews and focus group interviews.¹³⁷ Based on the research questions, the choice of methods, the research design and the available time frame in-depth interviews were chosen to be most suitable to investigate the CCs' own experiences with operating the role and their experienced challenges and facilitators for system-focused work (paper I and II). However, focus group interviews were judged to be more appropriate in focusing on cancer rehabilitation (paper III) as this is a relatively new and upcoming topic in primary health care. In the following, the data collection using individual in-depth interviews will be presented, followed by a presentation of focus-groups interviews.

6.3.1 Individual in-depth interviews

Individual in-depth interviews are widely used in both health and health service research because they can provide nuanced in-depth insights into the participants' worldview and the context of a given topic.¹⁴⁰⁻¹⁴² In this study, the individual interviews were conducted as semi-structured interviews because it allows conversation to circulate freely within the frames of the issue of interest. The questions in the interview guide help the researcher focus the topic and explore or probe what the participants share during the interview.¹³⁷ According to literature¹³⁷, the interview guides in paper I and II were designed under careful consideration of their wording and the questions they contained, and questions were phrased in an open-ended manner to ensure a free flow of information during the interviews.

The first interview guide (appendix VII) was used to investigate into the first research question: 'How do CCs experience their role, and how do they undertake it to enhance coordinated cancer care?' (paper I). This topic embraced six main questions. The introduction question addressed the background and context of the CC role in the participants' municipality. The following questions targeted the CCs' experiences in establishing the role, the tasks they perform, professional cooperation, as well as their perspectives on what primary role they played in local cancer care. The closing question addressed whether there was any relevant issue the CCs would like to add that had not been discussed in the framework of the interview. All main questions embraced optional follow-up questions.

The second interview guide (appendix VIII) was used to investigate the second research question: ‘What do CCs experience as barriers and facilitators for operationalizing system-focused tasks?’ (paper II). The main question of the interview guide was: ‘Can you please tell me about your experiences of implementing the CC function and establishing collaborations with professionals in your municipality/ies?’. Follow-up question addressed CCs experiences with challenges and facilitators regarding the establishment of the position, their working relationships and collaboration, improving services in the municipalities and their reflections on the way forward.

In line with recommendations¹⁴⁵, each of the individual interviews was held in quiet surroundings that were free from distractions. Out of 26 interviews, 18 were conducted face-to-face at the CC’s work site. It was anticipated that a familiar environment would provide a safe and conducive interview frame in which the participants would feel comfortable. Eight interviews were conducted via phone because time constraints or geographical distances. The candidate interviewed the participants in accordance with Kvale’s ‘traveler metaphor’^{160,p.4}, wherein the interviewer journeys with the participants and uses questions to entice them to provide stories about their individual life-world.¹⁶⁰ This approach is aligned with the constructivist research perspective and fits the hermeneutic underpinnings of this study.^{160,161} To maintain flow during the interviews, a conversational neutral question was used as starting point.¹⁶² The candidate was attentive towards the use of clear language and let the participants talk freely while refraining from inappropriate rushing or interrupting and keeping the conversation within the frames of the interview. Particularly relevant or unclear topics were explored with probing questions.¹⁶³ In all interviews, room was provided for the participants to raise additional topics. Subsequent to the interview, the candidate conducted an informal debriefing¹⁶⁰ in which the participant was thanked for their time and their willingness to participate in the study and invited to talk about the interview and how it had gone. The interviews lasted between 60 and 120 minutes. All interviews were audiotaped and the records were transcribed verbatim.

6.3.2 Focus groups

As cancer rehabilitation in primary health care has been given increased attention in national policies, while it is a relatively new and unexplored issue in Norwegian primary health care, focus groups seemed a more appropriate method for exploring CCs’ perspectives

on that topic than individual interviews. Focus groups are a viable method for examining group understandings of illness and health and are often used in health service research¹⁶⁴⁻¹⁶⁷, and are particularly suitable for exploring relatively new or unexplored issues.^{161,168} Focus group can support the exploration of new phenomenon as a given topic is mutually discussed among the participants. By capitalizing on group interactions, focus groups can help participants to clarify their views and explore issues in a way that would be more difficult to talk about for the length of an individual interview.^{165,168,169}

The focus group discussions were oriented using a semi-structured interview guide. The focus group interview guide (appendix IX) was used to investigate the third research question: ‘What are CCs’ experiences with the delivery of cancer rehabilitation interventions in primary health care?’ (paper III). This approach embraced two main questions that targeted the CCs’ experiences with the delivery of cancer rehabilitation interventions in their municipality and their experiences of working with cancer rehabilitation in their municipalities. Each question embraced potential sub-questions for follow-up.

The focus groups were held in conference rooms free from distractions.¹⁵⁹ The candidate moderated both interviews and was assisted by a co-moderator. In the first interview, the co-moderator was an independent researcher. In the second interview, the co-moderator was the main supervisor of the candidate. The focus group interviews were conducted in accordance with the literature recommendations for focus group interviews.^{168,170} The conversation was proceeded by a round of introductions, which was followed by a broad opening question about the CCs’ conceptualization of rehabilitation. This led to the more specific questions from the interview guide as the conversation became fluent. To maintain a conversational flow during the interview, the candidate made sure that the participants could engage equally in the conversation and were free to speak freely.¹⁵⁹ The candidate focused on keeping the role of moderator and not to engage but to guide the discussion to keep the conversation within the frames of the interview.^{171,172} Particularly relevant or unclear topics were explored with probing questions, and the interviewer opted to allow the participants to raise additional topics.¹⁶³ Subsequent to the interviews, the candidate thanked the participants for their time and willingness to participate in the study. The participants were invited to a lunch for an informal debriefing¹⁶⁰ and to continue any conversational topic of interest. Both focus-group interviews lasted 120 minutes and were audiotaped¹³⁷. The co-moderators took field notes to

support their subsequent reflections on the interview. These were intended to be used as a back-up in case of technical problems. The interviews were transcribed verbatim.^{137,167}

6.4 Data analysis

Qualitative data can be analyzed by using a variety of methods^{137,145} The individual interviews and the focus group interviews were all analyzed using thematic analysis (TA) as suggested by Braun & Clarke.¹⁷³ TA was chosen because it is widely used in health and health service research¹⁷⁴ as it offers a flexible approach to identify themes that capture the story presented by the data. Furthermore, TA differs from other qualitative approaches to data analysis in that it is not bound to a theory and epistemology, and can be used across a range of descriptive or interpretative methods and designs in qualitative research.¹⁷³ As knowledge is generated in a circular process, the TA procedure aligns well with the hermeneutic tenets and was considered a suitable analytical method for the present study. Based on her previous knowledge and experience of TA from her bachelor and master thesis, it was also viable to exceed this competence. The candidate undertook the analysis of each interview and was assisted by her supervisors, who analyzed some of the interviews to promote a mutual discussion and ensure the trustworthiness of the results.

TA was undertaken following a six-step process to develop codes and themes. The first step was to become familiarized with the data.¹⁷³ Prior to this, the candidate and supervisors reflected upon their pre-conceptions with the aim of becoming aware of how they might impact their understanding of the interviews.^{143,155}

To become familiar with the data, the candidate listened to the interviews after they were conducted. In addition, the focus group interviews were subsequently discussed with the co-moderator. In recalling the interviews directly after holding them, the candidate reflected upon the process and the content and assessed the data in terms of its usefulness, accuracy and authenticity.¹³⁷ Further familiarization was facilitated during the transcription of the interviews. In the subsequent analytic course, the candidate recaptured the interview situation to increase awareness concerning self-expectations and conceptions. Thereafter, each transcript was read and re-read by the candidate.^{143,147} The re-reading was characterized by the candidate's focused attention because a first impression had been gained in the first

reading. This allowed the candidate to re-encounter the data with an enhanced and altered pre-understanding.

In the second step, the candidate coded each transcript¹⁷³ using the software NVivo¹⁷⁵ to facilitate a systematic approach to perform the coding and to subsequently organize themes. The coding was undertaken to identify features of the data that might be important to answer the research question. Data extracts were collated for each code, and all codes with their relevant data extracts were collated for subsequent phases of the analysis.¹⁷³ The supervisors read, re-read and coded some of the interviews independently from each other and the candidate to facilitate subsequent discussions of codes and themes.

In the third step, the candidate and supervisors independently engaged in a search for themes by reviewing the codes and data extracts to identify overarching patterns of meaning (possible themes) that were relevant to the research question. Themes were labelled preliminary, and the codes and data extracts were gathered for each theme.^{ibid}

In the fourth step, the themes and codes were reviewed in relation to the coded data extracts and the entire data set. The latter involved re-engaging with the data set and contextualizing the themes therein with the aim of determining whether the themes recaptured the story of the data and whether that story was one that answered the research question in a consistent and coherent way.^{ibid} The candidate and supervisors then gathered to mutually discuss the codes and themes. Within the frames of the discussion, a reflective process was facilitated as each of them became aware of how their interpretation may be different from those presented by the others' and how this may have impacted their encounter with the data.^{143,155} In terms of the review and discussion of themes, the candidate refined or re-labelled, split, merged, or discarded the themes during the course of the ongoing reviewing process. The aim of this procedure was to ensure that the generated themes were true to the data and recaptured the story both accurately and authentically.¹⁷³

In the fifth step, the candidate defined and labeled the final themes. This involved re-immersing with both the data extracts and the data to achieve an ongoing, comprehensive analysis of each of the themes. Here, the scope and focus of each theme was determined, and the theme was labelled in a way that best reflected its story. This involved keeping the initial labels of some themes and giving some other themes a more accurate label. This process was

performed until each theme had received its final label. The candidate reviewed and discussed the themes with the supervisors as a final check of the themes' consistency and authenticity until all of them agreed that the final worksheet captured a rich and detailed picture of the findings.^{ibid} This discussion cycle supported an ongoing reflexive process between the candidate and supervisors.¹⁴³

In the sixth step, the findings were presented. This included weaving the themes and quotations from the data extracts together in an analytical narrative, then contextualizing and discussing them in relation to previous studies and the theoretical framework.¹⁷³

6.5 Ethical considerations

The study was approved by the Oslo Metropolitan University (former Oslo and Akershus University College of Applied Sciences) and the NSD (appendix X). As this study does not fall into the scope of the health research law, the approval of the regional ethical committee was not required. The study was conducted in compliance with the Helsinki Declaration and requirements for data processing.¹⁷⁶

Qu & Dumay^{162, p. 252-254} emphasize the following four specific ethical issues that require careful consideration when undertaking projects consisting of qualitative interviews: (1) impose no harm, (2) use relationship-based ethics, (3) disclose the research intent and (4) ensure the right to privacy and confidentiality. Based on Cresswell,^{145, p.142-143} (5) storing data was added as a fifth particular ethical issue related to the procedures in this thesis. In the frames of the study, these ethical issues were considered and managed as follows:

The candidate sought to diminish any risk of subtle injury, such as the decreasing a participant's self-esteem or exposing a participant to undue stress via experiences or moral conflicts during the interview. Complying with these issues involved the candidate's awareness of and reflection about the fact that interview situations can be sensitive because the participant is asked to open up and to share behaviors, knowledge, experiences, thoughts and feelings with the researcher, and some of these disclosures may be emotionally challenging.¹³⁷ Therein lies a potential power imbalance because the participants may expose themselves and thereby make themselves vulnerable to a greater or lesser extent.¹⁴⁵ Therefore,

all interviews were conducted after careful consideration of these issues and following the principles described in section 6.3.1 and 6.3.2.

To ensure the dignity and welfare of the participants, the candidate communicated to the participants that their participation was valuable and appreciated and made sure that the participants were treated in a considerate and humble way. This involved interacting with the participants in a polite manner, providing encouragement for them to speak and respecting the participants' personal boundaries.^{145,162} Additionally, this required the interviewer to provide safe and comfortable interview frames, as described in section 6.3.1 and 6.3.2.

Study participation was voluntary, and no participant was coerced into study participation.¹⁶⁰ The candidate disclosed the research intent to the participants both in writing and verbally and emphasized that participation was voluntary before and, if required, during the interviews. The candidate made sure the study was understood and gave the participants room to ask questions and make comments before obtaining the participants' written informed consent to participate in the study. The participants' right to privacy and confidentiality¹⁷⁷ ensured throughout the research process by anonymizing any recognizable information regarding the CCs' identities or their municipality in the transcripts, the papers and this thesis.

Anonymization was performed by masking names, inhabitant numbers and all information that could potentially illuminate the municipalities of the participants or otherwise inform their identity.

Safe data storage^{145,178} was ensured as follows. The sound recorder used to record the original interviews was stored in a locked filing cabinet. Recordings that were converted to mp3 files that were held securely, were password-protected, and could be accessed only by the candidate, as were the anonymized interview transcripts.

7. FINDINGS

In this section, the findings of the three papers are presented.

7.1 Paper I: 'Providing Coordinated Care'

The aim of paper I was to gain an understanding of how CCs experience their role and how they perform it to enhance coordinated care based on 26 individual interviews. The findings showed that the Norwegian CCs evolved in very different ways by adapting to the needs and circumstances of their municipalities. 'Providing coordinated cancer care' was identified as an overarching topic and common aim of the CC role. This topic was elaborated by three main themes.

The first theme was 'Finding their place and creating their function', which embraced the CCs' experiences of entering a new and unknown role. The CCs needed to put major efforts into developing a position description and promoting it among professionals and in the municipalities. This was frequently done in an independent and self-sufficient manner and with little management support and was often described as a full-time job in itself.

The second theme was: 'Meeting the needs of cancer patients and helping them cope'. The participants acted as a contact person for patients and their families to support them in all their needs. This theme was elaborated upon in three sub-themes that described the ways in which CCs explained their approaches their patients. These included 'Mapping the entire situation', 'Providing psychosocial support', and 'Providing practical support and access to appropriate services'. 'Mapping the entire situation' reflected the process by which the CCs expressed that they took a holistic approach to their patients' needs. They regarded the patients as a part of their context and actively involved them in the mapping of their resources and support needs. The two latter subthemes elaborated upon the comprehensive support provided by the CCs, which could involve psychosocial support (e.g., supportive conversations or referrals to other support offers, such as support groups) as well as practical help in terms of navigating the system, delivering needed services or providing assistive devices.

The third theme was: 'Promoting well-functioning cancer care systems'. This was elaborated upon in the following subthemes: 'Filling system gaps' and 'Fostering collaborations'. 'Filling system gaps' describes CCs' experiences of disconnected services that they attempted

to coordinate or bridge in several ways. In particular, CCs perceived current cancer care systems as focusing primarily on providing care for palliative patients, which meant that insufficient or missing systems were available to accommodate the needs of curative patients or to deliver cancer rehabilitation. 'Fostering collaborations' outlines the CCs perception that they had to build a network for cancer care and engage in alliances with other relevant professionals in cancer care. CCs system-focused activities involved activities such as establishing common procedures for patient transferal, follow-up and care, interacting with upskill professionals and enhancing local offers in cancer care.

These findings suggest that CCs adopt a holistic, salutogenic approach in which they aimed to provide their patients with the cognitive (e.g., information), instrumental (e.g., practical support, assistive supplies, and health or social services) and motivational (e.g., psychosocial support) resources they need to handle their situation. This may enhance their SOC. Most CCs experienced numerous tasks that exceeded their capacity, causing them to select the most relevant tasks and indicating they need better support from their management.

7.2 Paper II: 'From Challenges to Resources'

The aim of paper II was to obtain an understanding of CCs' experiences with the barriers and resources they face when operating their system-focused tasks, based on 26 individual interviews. The analyses revealed three main themes, which were elaborated upon in subthemes related to CCs' encounters with operating system-focused work.

The first theme was the following: 'Understanding the role and local cancer care'. This was explained by two subthemes: 'Clarity of the CC role' and 'Cancer-related knowledgeability of collaborating partners'. 'Clarity of the CC role' refers to the extent to which the CCs and their collaborating partners clearly understand their role and its associated tasks. The 'Cancer-related knowledgeability' of collaborating partners addresses local professionals' knowledge concerning cancer patients' bio-psycho-social support needs and the actors and services available in cancer care.

The second theme was: 'Systems for care delivery in primary health care'. This theme embraced the following four subthemes: 'Integration of the CC role', 'Common procedures', 'Communication across sectors and disciplines' and 'Local resources'. 'Integration of the CC

role' involved taking a planned approach to integrating the role and to organizing and localizing the role in an effort to make the CCs visible and provide them with access to professional work arenas and databases. 'Common procedures' included routines for cooperation, communication and care delivery, e.g., via standardized tools, checklists or training. 'Communication across sectors and disciplines' addressed whether there were sufficient meeting points and shared electronic systems for information exchange across and within sectors. 'Local resources' referred to the degree to which budgets, offers and services were available for cancer care in the municipalities.

The third theme was 'Commitment to collaboration', which included the following two subthemes: 'Acknowledging work relations' and 'Shared ownership and responsibilities'. 'Acknowledging work relations' related to trusting work relations and maintaining an ongoing dialog between professionals and the CCs. 'Shared ownership and responsibilities' addressed the degree to which professionals felt formally or informally committed to, and therefore how actively they engaged in, collaborations with CCs to improve systems for cancer care delivery in the municipalities.

These themes represent both facilitators and challenges in the CC work system. When present, these themes represent important facilitators for CCs' system-focused work, whereas their absence could present notable challenges to CCs' system-focused work. The results indicated a positive trend over time, suggesting that CCs pursue a salutogenic approach to become more able to mobilize resources, and this has helped to gradually turn initial challenges into facilitators in the context of system-level work. These findings suggest that the work CCs perform to enhance system-level resources may contribute to enhancing the collective comprehensibility, manageability, and meaningfulness of CCs system-focused tasks in cancer care.

7.3 Paper III: 'We need to focus more on cancer rehabilitation'

The aim of paper III was to obtain an understanding of CCs' experiences with the delivery of cancer rehabilitation interventions in primary health care. The findings were based on two focus group interviews performed with 12 CCs. The analysis revealed three themes that reflected CCs' experiences with the delivery of rehabilitation services in primary health care.

The first theme was ‘A missing link to cancer rehabilitation’. This theme embraced that CCs envisioned a holistic approach to cancer rehabilitation in primary health care. However, CCs reflected on that their holistic conceptualizations of cancer rehabilitation were contrasted by the practices currently used in primary health care. Often, the CCs interacted with professionals who had a limited knowledge of their patients’ complex rehabilitation needs and respective services. Furthermore, the CCs perceived that the municipalities had only a limited focus on and resources for providing patients with complex rehabilitation services. The CCs explained that missing systems had led to a failure of cancer rehabilitation to be routinely delivered to all patients and that there was often only a low-level of multidisciplinary.

The second theme was ‘Trying to put cancer rehabilitation in the spotlight’. This theme represents the CCs’ accounts of how they operated to facilitate complex rehabilitation in primary health care. This involved, among other things, upskilling, informing other professionals about rehabilitation and increasing local offers. CCs emphasized a need to focus on patients’ involvement in their rehabilitation course, for instance via needs assessments focused on address patients’ values, goals and resources.

The third theme was ‘The need to build a system for rehabilitation service delivery’, in which the CCs stated that they promoted a need to establish a systemic delivery and equal access to complex cancer rehabilitation interventions in the municipalities. The general practitioner was identified as a key person and collaborating partner for CCs. CCs underscored the need for adequate resources and facilities in the municipalities, for instance electronic systems or individual cancer rehabilitation care plans. Moreover, the CCs indicated the need for future national and local policies to increase the focus on cancer rehabilitation and promote changing practices in cancer care.

These findings suggest that CCs adopt a holistic, salutogenic approach to cancer rehabilitation because they emphasized available resources promoted a move towards complex, holistic cancer rehabilitation interventions during each phase of the cancer control continuum. The findings indicate that the CCs pursued and promoted a salutogenic orientation to cancer rehabilitation, in and promoting a development towards a holistic approach to cancer care.

7.4 Summary of the findings

Summing up the findings, the three papers are connected to each other terms of a process (Figure 6). The findings from paper I identify the CCs' experiences of developing, establishing and current experiences from operating the role. The findings from paper II illuminate the CCs' experiences of meeting the quest for system-focused work in primary health care, where they provide a comprehensive picture of their experienced barriers and facilitators for this work. Then, the findings of paper III provide insight into CCs' experiences with the delivery of cancer rehabilitation interventions in primary health care, which, in light of current trends in cancer and its treatment and national policies^{26,179}, can be considered an issue of increasing importance for CCs to address further on.

Connection of the three papers:

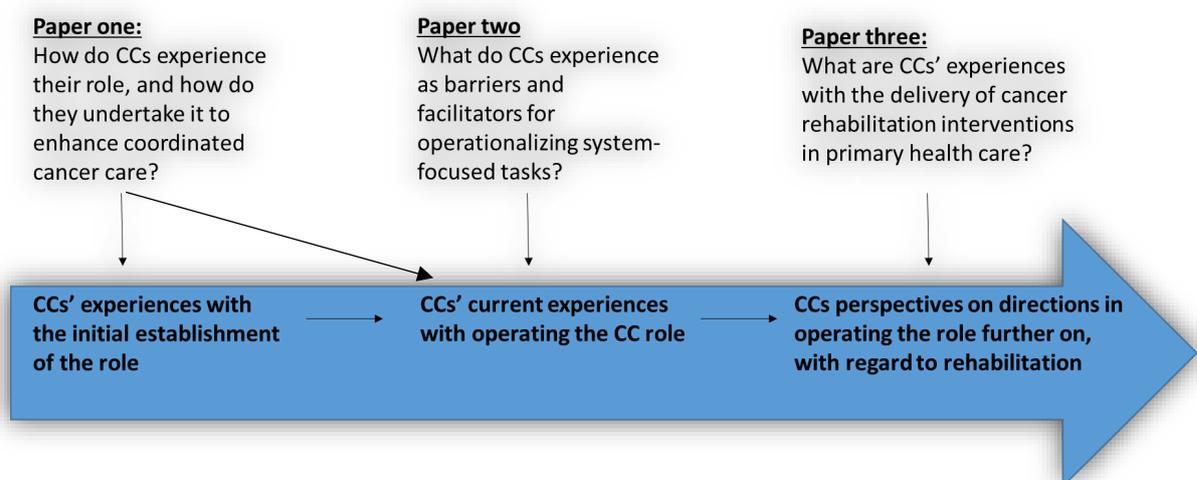


Figure 6: Connection of the three papers

The findings from the three studies indicate that CCs delineated both patient- and system-level activities. CCs encountered initial challenges, as they expressed that they had to develop and implement the role in a time-consuming process and with little perceived guidance or support. Role flexibility enabled them to adjust the role to the distinct contextual frames and settings they worked in. However, the role's diversity challenged the implementation and

external role recognition. CCs outlined a high degree of case-based, patient-level work, emphasizing the importance of a holistic approach, patient involvement and comprehensive needs assessments. Although CCs were available to patients in each phase of the continuum, the majority seemed to focus most on providing palliative care, and less on e.g. cancer rehabilitation. The broad range of tasks were perceived as work overload, hence, system-level work seemed to be sidetracked. Here, CCs encountered important topics, such as role recognition, common procedures and professional collaboration that could act as both barriers and facilitators for their system-level work. The CCs expressed a missing focus on cancer rehabilitation in the municipalities. Although the CCs suggested a holistic approach to complex cancer rehabilitation, they perceived current practices to contrast this concept. Further, CCs accounts of rehabilitation- and treatment-focused task seemed to be blurred. In light of the Salutogenic theory, the findings indicate that the CCs adopted a salutogenic view in their work as they focused on resources and assets that could enhance comprehensibility, manageability and meaningfulness to achieve positive developments both at the patient- and the system-level.

The findings show that CCs ask for enhanced support from the municipal management and a better facilitation of system-focused work, in terms training, resources, multidisciplinary teams and cross-sectoral communication systems. CCs' and municipalities' stronger focus on cancer rehabilitation seem to be needed. Work-overload of CCs may be counteracted in assigning them with a more overarching function with a focus on capacity building of health professionals and on local practice development.

8. DISCUSSION

The aim of the current study was to generate knowledge of the experiences of Norwegian CCs in primary health care with enacting their role to deliver patient-centered and coordinated care. In the following, the study's main findings related to the role implementation, their patient - and system work are first discussed. Thereafter, reflections on the role of the NCS as initiator and co-under of the CC initiative are provided. Subsequently the findings are discussed in light of the salutogenic theory, followed by methodological considerations.

8.1 Implementing the CC role

The findings indicate that CCs' experienced the implementation of their role to be challenging, especially due to the very broad guidelines for the role. Moreover, the CCs perceived that a position description and orientation to the role was missing in most of the municipalities. Thus, based on the broad role description provided by NCS, most informants had to develop a more specific position description to determine the scope of the role and its tasks on their own. Similarly, the literature^{28,98,103,104} highlights that CCs can encounter problems in terms of an inadequate description for the CC role. CCs elsewhere¹⁰⁵ found it helpful to consult with other professionals in their role orientation. This was difficult for the informants, as their role was novel and unknown to both themselves and other professionals in Norwegian primary health care. Consequently, the role development was described as a time-consuming task, deterring CCs from operationalizing their intended cancer-care related tasks. Further, the CCs perceived limited support from their superiors or a team in implementing the role. Similarly Nilsen¹⁸⁰ et al found that nursing leaders in primary health care perceive a missing link between them and their superiors, which could deter their goal attainment. However, the same study suggests where management support was missing, peers could provide a certain degree of support, which is in line what the present CCs asked for.

Findings from paper I indicate that CCs perceive that the broad guidelines for the role also brought along the flexibility to adjust their work to the needs and the frameworks provided by municipalities in various geographical areas and primary health care settings. While the CCs perceived this as a benefit, both paper I and paper II indicate that the resulting variability of the CC role can bring forward a role confusion. Hence, CCs pointed to difficulties in professional collaboration, especially with the specialized services. This might be explained

by that professionals in specialized care collaborate with CCs from several municipalities, all of which might have developed and promoted their role in different ways. The literature confirms that a lacking role recognition can challenge the establishment of CC and their collaboration with other professionals.^{28,98,104,105}

The present findings and national reports^{35,36,56,98} indicate that in Norway, it can be particularly difficult to distinguish the CC role from that of a cancer nurse. Looking at the national curriculum for cancer nursing¹⁸¹, one can see that the tasks for cancer nurses align with several of the tasks for CCs identified in paper I and II. Further, national reports^{35,36} issue that some of the CCs initially enacted nursing tasks, particularly part-time CCs who also worked as a local nurse. Therefore, both the present CCs and national evaluations underscore the necessity to refrain from nursing tasks in the frames of the CC role. Moreover, it must be noted that the CC role is a position, whereas the role of cancer nurses also describes a specific specialization. This gives them, for instance, the qualification to administer medicines and undertake care procedures, such as wound care.¹⁸¹ In turn, a CC position does not authorize professionals to operate nursing tasks, and those tasks are also excluded from CCs' role description. Only few municipalities have earmarked positions for cancer nurses, and most cancer nurses appear to work in specialized care after their education.¹⁸² Accordingly, one might say that a cancer nurse education may prepare CCs sufficiently to execute many of the potential tasks outlined in the NCS guidelines.

Another important difference between CCs and cancer nurses is that health care services usually need to be assigned to patients via the health care system, hence, not all cancer patients receive support from a local cancer nurse or a home care team. In turn, paper I underscores that CCs' services and support are free-of-charge and do not require referral. The CCs valued that thereby, their services are available and easy to access, sparing patients and their families for the need to apply for services, such as home care teams. Accordingly, a recent national report¹⁸³ shows that the CCs can help patients manage their everyday lives longer without home care services, for instance, by providing them with appropriate assistive devices at their homes. Furthermore, CCs may distribute their time self-sufficiently, a finding highlighted in paper I. This allows them to provide patients with extensive practical and psycho-social support, compared to nurses who can face time constraints as they often have to enact nursing tasks and provide medical tasks in addition. Hence, the CC role correspond with national guidelines²⁹ outlining the necessity to increase health professionals' availability to

the patients as well as low-threshold offers in primary health care. Lastly, the guidelines for CCs involve system-level assignments and the CC role may include their involvement into local policy making.^{98,183} For instance, national reports^{98,183} suggest that CCs contribute to the development of local health care plans and strategies for particular phases of the cancer continuum or diagnosis groups in cancer care.

Consequently, one might say that although the work profile of cancer nurses and the CCs align, cancer nurses may have a narrower work profile, in which system-level and political work often plays a smaller role. However, this study, supported by prior research^{16,83,184}, suggests that the CC role requires a clearer demarcation in order to avoid duplication or blurring of tasks. The findings suggests that CCs would benefit from support in the development of the position descriptions and its implementation. There is a need to disseminate more particular position descriptions than the NCS guidelines offer, so that collaborating partners achieve a common understanding of the CC role. This might be particularly relevant to support CCs' collaboration with health professionals in specialized care, who are connected with several CCs who might execute the role in different ways. The findings, supported by the literature^{33,98,107,180}, indicate that such support could be provided by both management of CCs and other local professionals. Other programs¹⁸⁵ have, for instance, developed toolkits, providing a definition of the program, key tasks and messages, as well as a role description, among others. Such a toolkit could also be valuable for Norwegian CCs, as it could prevent CCs from developing this independently in a time-consuming process. Thereby a clarification of the role and tasks could be ensured, while, at the same time, the role remains flexible to some adjustments.

8.2 A main focus on patient-level work

A main finding from paper I indicated that the CCs had a predominant focus on patient-level work and outlined a holistic approach to support patients. The CCs highlighted comprehensive needs assessments as an important starting point for patient-centered services. Further, they outlined a high degree of patient involvement to facilitate their patients' coping and independence in everyday life. In doing so, the CCs appeared to work in line with the IOM⁸⁶ recommendations for quality care delivery, emphasizing patient-centeredness as an important dimension. Prior research^{186,187} confirms that patient involvement and shared

decision making is crucial in facilitating patient-centered care, and that this can increase patients' participation and progress in their treatment course.

The CCs delineated several assignments in their patient-level work. In line with other CCs^{103-105,188,189}, our participants placed emphasis on offering both practical help and psychosocial support to patients and their families. Research underlines the importance of an integrated approach to care and a focus on the families, who often are patients' primary caregivers and may have a range of own support needs.^{78,79,188} In engaging in coordinating activities in their patients' treatment course and offering continuous follow up, CCs appeared to meet the widespread request for timeliness and continuity of care. Research^{4,81,188,190,191} shows that support that targets both the physical-, psychosocial and information needs can enhance patients' coping and healthy functioning. A recent study by Guldhav, Jepsen, Ytrehus, Grov¹⁹¹ found that the availability of a CC could facilitate personalized counselling and information, and may have a positive impact on patients in a primary health care setting.

This study illustrates that CCs perceived the broad range of tasks as a work overload, which they managed by focusing on the most important needs in their municipalities. Supported by the literature^{31,32,94,188}, most CCs described a main focus on cancer patients with complex needs and those who were at risk of experiencing severe challenges during treatment. According to the CCs, this yielded a main focus on palliative patients, whose complex and changing needs could often exceed both the capacity and the competence of primary health care professionals. The literature supports that urgent matters often require providers' time and attention, which can sidetrack engaging in other important matters^{190,192}, for example the needs of patients at another stage of the cancer control continuum.

In particular, paper I and III reflect that the addressing patients' needs for cancer rehabilitation appeared to be sidetracked in CCs work. This is elaborated by findings in paper III, indicating that the CCs' lacked clarity concerning the concept and content of cancer rehabilitation in primary health care. The CCs aspired a holistic and multidisciplinary approach, where rehabilitation might be provided at each stage of the trajectory, as suggested in the cancer control continuum model and by previous research.^{15,59,193} However, the findings also indicate that CCs' delineated interventions regarding rehabilitation and treatment seemed to be blurred, illustrated by the finding that CCs referred to some patient-centered tasks interchangeably as treatment and rehabilitation work, respectively. Likewise, the cancer care

continuum model shows that some issues can be overlapping and do not distinguish clearly. The literature^{25,59,82,194} confirms that the blurred concepts can challenge the delivery of cancer rehabilitation interventions, particularly so in an outpatient setting. Therefore, our findings indicate the need to clarify the content and concept of cancer rehabilitation for instance in national policies. Further, a clarification of health professionals' roles and responsibilities, including the CCs, is needed to better facilitate a delivery of cancer rehabilitation interventions in primary health care. Recent national strategies¹⁷⁹ support this, outlining a systemic approach to cancer rehabilitation as an upcoming target.

Findings from paper I and III illuminate that CCs commonly referred to their supportive tasks as "holistic care". To date, holistic care is increasingly referred to by professionals across various disciplines.¹⁹⁵⁻¹⁹⁸ As there exists no common definition for the concept and its meaning can be interpreted individually, holistic care may represent as a popular rhetoric rather than as an actual practice.^{195,199} In cancer care, for instance, patients may not require comprehensive services despite their need for holistic care and support.^{22,23,81,200} Findings from paper III appear to support this, as CCs delineated linking patients to single rehabilitation services, which contradicts the idea of providing complex, multidisciplinary rehabilitation interventions. Accordingly, research^{194,201} shows that current rehabilitation interventions often have a narrow focus and do not provide the entire range of necessary services. Following this line of thought, one may argue that CCs' own interpretation of a holistic approach might divert notably from their patients' perspectives. This issue has been raised in previous studies, showing that both general practitioners and cancer nurses did not pursue the holistic approach they intended to.^{195,202,203} However, considering that the interpretation of holistic care can be individual, it would be up to the individual care recipient to consider whether or not care is being provided in a holistic manner. Consulting the NCS' patient surveys,⁵⁶ it can be confirmed that patients received a wide range of practical and psychosocial support from the CCs. Furthermore, the majority of the patients reported continuous consultations and high overall satisfaction with the CCs, all of which indicate that CCs address patients' needs in a comprehensive manner. However, those surveys provide only a first impression of patients' perspectives, and the reductionist data must be enhanced by in-depth insights to reach any conclusions. Therefore, qualitative investigations into patients' experiences are needed to confirm or revoke whether CCs work as holistically as they perceive.

8.3 Less focus on system-level work

Findings from this study suggest that even if most CCs primarily engaged in patient-related tasks, they also outlined system-level work as an important aspect of their role. Paper II identified a set of factors that CCs experienced to be influencing their opportunities to act at a system level. Findings from paper II indicate that CCs perceived some local professionals to be hesitant to collaboration, as they appeared to guard their roles and were unwilling to change routines. Literature^{204,205} shows that collaborative care can be challenging to achieve if health professionals' preferences for service delivery are inconsistent with innovation or changes. However, CCs outlined that over time, collaboration could be facilitated via an ongoing dialog with professionals where the role was clarified as a support and not a threat for existing roles in municipalities. The literature²⁰⁶ confirms that collaboration for care coordination can be achieved when the benefits of CC roles are understood, role boundaries are set. Supporting this, Valaitis⁹⁶ suggests that the development of strong professional relationships and consensual decision making approaches can encourage collaboration.

Findings from both paper I, II and III indicate that CCs perceived that local professionals at times demonstrated limited knowledge and competence in regard to cancer patients' support needs, care procedures and services throughout the cancer control continuum. Paper I elaborate that the CCs experienced limited knowledge of health professionals to challenge the delivery of palliative care. The findings of paper III suggests that this also applied with regard to the delivery of complex rehabilitation interventions. Accordingly, the findings indicated that the CCs worked to further educate local professionals in cancer care, highlighting this as an important facilitator for system-level work. This is in line with international CCs^{103,189,206} who outlined that upskilling other professionals through training, supervision and exchange of experiences could help to establish collaboration and implement new procedures. The present study indicates that CCs' attempted to promote more patient involvement and focus on patients' expressed needs and their coping when educating other health professionals. Although literature shows that international CCs work to enhance professionals' cancer-related knowledge, it is not made explicit whether this includes the promotion of patient involvement and coping.³² Instead, the literature suggest care coordination predominantly adopts a provider focus rather than a patient focus.²⁰⁶ In that regard, the Norwegian CCs

might be ahead of other CC programs, in making a notable contribution to incorporate the requested patient-centered dimension into the system level.

However, an important issue to consider is how the CCs might collaborate with other professionals to contribute patient-centered care for patients multimorbidities, that is the coexistence of two or more chronic conditions.²⁰⁷ Particularly in elderly patients, cancer may increasingly co-occur with other non-communicable diseases and medical conditions such as coronary heart diseases, diabetes, dementia, chronic obstructive pulmonary disease, depression, anxiety disorders and different geriatric syndromes.^{208,209} Each of these conditions alone may require notable coordination, and a combination of two or more chronic conditions requires thorough alignment.²¹⁰ In a scenario in which CCs and other disease-oriented health professionals would address the different conditions on their own, patients with multimorbidities could be at risk for excessive consultations and overtreatment, among others.^{208,211} Thus, an approach with multiple coordinators could be assumed to significantly enhance care complexity, raising the question whom health professionals in specialized care as well as patients themselves should approach for support. Hence, patients with multiple diseases might be exposed to a burden from multiple treatments, adding to their overall disease burden.²¹² Moreover, focusing on each of the conditions separately can potentially lead to patients perceiving that their overall situation and daily life is overlooked.²¹³ Hence, the literature^{210,211,214} underscores the need for a team-based approach, in which health care professionals from different specialties and patients should collaborate and identify strategies to reduce the overall disease burden, rather than its separate components. Goals, such as functioning, activities of daily living, QoL and well-being, must be placed in the foreground, rather than a specific diagnosis, e.g. cancer.^{208,215,216} Consequently, disease-focused care coordination might not fit the requirements of patients with multimorbidities. However, this does not imply that the very idea of CC roles should be discarded. Rather, the reflections above highlight that it is vital that the focus and the efforts of health care professionals must be targeted towards treating the patients, and not only their diseases. Hence, the discussed challenges might serve as a reminder that disease-focused roles must be introduced with caution. It must be ensured that an enthusiasm for such roles does not override health professionals' and policymakers' awareness that additional solutions, e.g. primary health care teams, are needed to facilitated adequate care for patients with multimorbidities. Furthermore, there seems to be a need for clarifying how CCs competencies can be best applied in such a

context. Both nationally and internationally, it is emphasized that both professionals with general and specialized knowledge are needed to appropriately manage pathways for patients with one or multiple chronic diseases. CCs may thus play an important role to facilitate care coordination for patients with multimorbidities by connecting them to the required services and providers. Having a nursing background and thereby general competencies, CCs are likely to respond adequately to patients with co-occurring diseases. This may also include identifying patients' needs for support in terms of a comprehensive care plan and linking them up with the coordination department, as requested by national guidelines.^{47,53,54}

Although the CCs indicated a need for integrating the role in multidisciplinary teams, this study suggests that CCs perceived low levels of facilitation for collaborative action and system-level work in the municipalities. Findings from paper I and II indicate that CCs elaborated that system fragmentation and lacking common procedures in cancer care could pose a particular challenge to collaboration, particularly at the interfaces of primary and specialized care. The findings show that CCs attempted to implement procedures, tools or checklists to improve systems for cancer care. However CCs perceived that health professionals' time constraints and a high professional turnover in the hospital setting hampered the implementation of new practices. This is confirmed by other research^{55,96}, showing that the effective operational processes and procedures are difficult to establish among different with health professionals and settings. Findings from paper II highlight that CCs' allying with health professionals in leading positions could support the dissemination and implementation of new procedures. Findings from paper I and II, supported by the literature²⁰⁶, suggest that collaboration for care coordination can be better facilitated when CCs are integrated into a multidisciplinary team. This is in line with research by Tulinus, Hølge-Hazelton²¹⁷ who highlight a need to establish an arena for shared experiences, as this can facilitate professional development and multi-professional cooperative practice. However, paper II indicates that CCs experienced the establishment of multidisciplinary teams to be a time-consuming process. This was particularized in term of a scarcity common meeting points and shared electronic systems for cross-sectoral communication, both of which the literature^{17,28,96,188,218} confirm to be important facilitators for cancer care coordination. However, the same literature shows that, while multidisciplinary teams are widely established around international CCs, these programs face similar and unresolved challenges regarding technological resources.

The findings from paper I and III suggest the urgent need for establishing systems for service delivery particularly with regard to cancer rehabilitation. In a primary health care setting, this seemed to be frequently sidetracked due to the urgent need for focusing on palliative care. The literature^{190,192} suggests that this may be due to the significant pressures on primary health care, resulting in the prioritization of acute care. Accordingly, care of patients with less acute, less complex or primarily rehabilitation needs may be neglected. Findings from paper III suggest that CCs experienced systems for complex cancer rehabilitation to be missing and that professionals mostly focused on physical rehabilitation. Similarly, recent research^{201,219} shows that professionals had limited training in cancer rehabilitation, and that the detection or treatment of adverse outcomes was low in outpatient settings. The findings from paper III indicate further that the CCs sought to promote complex rehabilitation and a focus on patients' rehabilitation needs in the municipalities. This is in concordance with literature recommendations^{194,219-221}, outlining that clinical practice requires tailored services and improved communication with providers to facilitate common practices in rehabilitation. Despite the aforementioned challenges, CCs' attempts to enhance local awareness and services can represent a first step towards better systems for the delivery of cancer rehabilitation in primary health care. Thus, Norwegian CCs might be ahead of some international programs which do not outline rehabilitation as a particular work focus of CCs.^{32,34,94,96,100}

8.3.1 CCs' case-based approach to executing their role

The findings from paper I and paper II indicate, in concordance with previous research^{18,96,100}, that CCs take a needs-oriented, case-based approach to their work. Thus, they primarily respond to challenges at the patient and system-level as they arise, rather than using pre-determined strategies to addressing them. In turn, national policies emphasize health professionals must orient their practices more towards research and the implementation of evidence-based approaches in primary health care.^{29,222} Taking into account that evidence-based practice involve a synthesis of research, empirical knowledge and user involvement²⁹, the findings indicate that CCs, with their focus on best practices and patient involvement, incorporate at least the two latter aspects into their day-to-day-work. However, it might be questioned whether CCs' focus on research needs to be strengthened to fully comply with national guidelines. Accordingly, research²²³ indicates that nurses have a long tradition of patient-focused, case-based work, and may need to adjust the role to increasing requirements for research-orientated practice. According to national guidelines^{29,222}, one strategy to

enhance a research-focus in primary care is to promote primary health care professionals to acquire a higher education. Examining CCs' backgrounds, one can see that most of them are nurses, many of whom are specialized in cancer or palliative care.^{35,36,98} As such, CCs usually hold a minimum of a bachelor's degree in nursing, often supplied by additional 60 ECTS or more from continuing education. Having a look at the national curriculum for cancer nursing¹⁸¹, one can note that the educational course involves the development of both specialized knowledge and broader skills, e.g. competency in collaboration, professional development and public health work with a focus on prevention. Considering this, one could thus argue that CCs' educational level and the depth and the breadth of their competency correspond with the national ambitions of capacity building. It is questionable whether further education such as a master's degree would lead to a stronger research-orientation in clinical practice or whether better facilitation in municipalities might be an adequate strategy. Looking at previous research²²⁴, it becomes clear that nurses, with educational levels ranging from diplomas to PhDs, underscore that research implementation into complex clinical settings can be difficult.

In the context of the present study, the difficulties in implementing new procedures, for instance, can be elaborated by CCs' perception of a high workload and working mostly on their own. Several studies²²⁴⁻²²⁷ confirm that implementation and dissemination of evidence-based approaches require a sufficient degree of collaboration with other professionals. Despite their perceived challenges, the present findings and national evaluations^{35,36,98,228} indicate that CCs already have contributed to capacity building, e.g. in terms of educating patients, their families and health care providers on cancer-related topics. The CCs also managed to implement and disseminate evidence-based guidelines in their municipalities.^{183,229,230} For instance, the literature²³⁰ shows that CCs have implemented and promoted the Edmonton Symptom Assessment Scale (ESAS), to assess and manage common symptoms in cancer patients over time. Considering that the optimal development of new professional roles is a process over time²²³, the given example indicates that a stronger orientation towards evidence-based approaches in CCs practice could be underway.

Consequently, the CCs' frequent nursing background with continuing education and the aforementioned activities comply in many ways with national ambitions of capacity building. However, there is a potential for CCs to adopt a stronger orientation towards research evidence and its implementation. This might be promoted, e.g., by providing CCs with

training as well as a better facilitation of evidence-based practices in primary health care. Such training is provided in terms of seminars or workshops on parts of the NCS, and well-received by the CCs.^{36,98} However, CCs demand more of these offers.⁹⁸ Alternative approaches have been suggested elsewhere; for instance, a multi-site study in the US¹⁰⁰ has presented a training curriculum that provides CCs with required knowledge and skills for undertaking the role.¹⁸⁵ Other programs have developed toolkits, including schemes for patient intake, needs assessments, treatment plans and evaluations.^{185,231} However, both the present findings and the literature¹⁸⁵ suggest that a focus on evidence-based practice and standardized routines should enhance, but not substitute, case-based approaches in CCs' work. It is important to acknowledge and preserve CCs' flexibility in responding to arising needs at a patient and system-level, which is valued by both patients and collaborating partners.^{56,228}

Last, but not least, the findings of this study indicate that the broad scope of their tasks often represented a work-overload and could not be entirely operated in the frames of the CC role. Providing such comprehensive support to all patients in the municipalities appears hardly manageable for one CC alone, particularly when patients have complex needs or co-occurring diseases. Accordingly, underscoring previous research¹⁰⁷, the findings from paper I indicate that there were unresolved equity issues. While CCs facilitated patient-centered, coordinated care for some patients, many patients were not linked to a CC and thus received no support from them at all. Consequently, the study indicates that the CC role may benefit from being re-organized in order to fulfil its full potential. The findings indicate that the advantages of the role lie with the CCs being highly knowledgeable professional in primary health care with a true dedication to meeting their patients' complex support needs. The drawbacks seem to lie within that systems around CCs are not developed in a way that appropriately supports them in working in both a patient- and system-focused manner. However, identified facilitators for system-level work include, among others, the CCs engagement in raising awareness and promotion of cancer care and rehabilitation in municipalities, further educating of other professionals, the establishment of procedures and routines and the identification of underutilized local resources for cancer care. Hence, this study suggests that the CC role may have greater impact on facilitating coordinated care if they were to engage more at a system versus using their expertise to facilitate coordinated, quality care for some patients at a patient level. This way, the CCs could e.g. pass on their knowledge and skills to build competence

networks and enable and educate other professionals to deliver holistic care at a patient-level, while using more time to identify and intervene in system gaps.

8.4 The NCS' role as initiator and co-funder of the CC initiative

Cancer patients depict a large patient group in Norway, and cancer is one of the leading causes for death in Norway. Therefore, cancer patients have received considerable attention in national strategies and in the media, and are represented by a powerful patient organization, the NCS. The NCS is one of the largest NGOs in Norway, dedicated to fight against cancer locally, nationally and globally through research, preventive measures, education, advice and lobbying. 28% of the overall annual budget has been provided to improve cancer care and to date approximately 213 million NOK has been provided to the CC initiative of 2012.^{183,232} Increased resources, political and public awareness on cancer provide undoubtedly an invaluable support to those who are affected by cancer. However, while such a strong NGO like the NCS establishes CCs to improve cancer care, some critical aspects must be considered.

First, cancer patients are a patient group that already receives resources, support and a high level of public awareness.^{233,234} One may thus raise the question in how far it appears rightful to enhance support to a patient group that already receives a notable amount of resources, while smaller patient groups with less resources do not have such powerful ambassadors to support them. Hence, introducing CCs in primary health care may be accused for contributing to inequity issues across patient groups in primary health care. Likewise, the issue of disease prestige hierarchies must be considered, where some diseases, including cancer, are ranked highly both within health care and the society.^{233,234} High prestige patient groups receive high levels of social acceptance, empathy, engagement and support, typically due to well-organized and well-funded initiatives involving public education, awareness campaigns and fundraising.^{234,235} In turn, diseases such as psychiatric disorders, among others, may be less supported and explained, undermining public support or creating public stigma and low acceptance and support for these patient groups.²³⁴ Following this line of thought, and potentially amplifying it to some extent, the CC initiative may strengthen the disease prestige of cancer, and unintentionally contribute to a stronger gap between the different patient groups.

Second, it can be regarded as a critical issue that the NCS is not fully financing the CC position, but requires municipal resources to co-finance the position. In addition, the NCS particularly state that they expect municipalities to establish the CC role subsequent to the funding period.⁹⁸ This illustrates that the NCS, through their financial incentives, exerts power that is likely to impact political and clinical directions in primary health care. The establishment of CCs appears to inevitably give rise to municipalities directing their attention and resources particularly towards cancer care and its coordination. Hence, it can be questioned whether the municipalities, based on the opportunity to receive NCS funding, may allocate parts of the local budget to the co-financing of the CC position, which otherwise might have been applied to other public health matters.

On the other hand, it must be considered that cancer is an important public health issue and affects a considerable part of the Norwegian population. Therefore, the NCS complies with national and international calls^{21,26,27,29} for strengthening primary health care and facilitating that the needs of this growing patient group are adequately addressed. The WHO²¹ has explicitly encouraged countries to ally both governmental and NGOs in order to take action to strengthen cancer care and health care systems. This may be due to the widespread acknowledgement that activities of powerful NGOs, such as establishing CCs in primary care, challenge the status quo in existing systems. In doing so, established structures can be pushed open and opportunities for a positive change are created.^{236,237} Further, in a discussion paper²³⁸ and the resulting Shanghai declaration¹³, the WHO underscores the need for ‘a whole of society engagement’, where NGOs can make a notable contribution to health promotion in the countries. In that regard, the NCS can be regarded as a valuable stakeholder, as its incentives facilitate opportunities for coordinated, patient-centered care to patients that municipalities otherwise might not be able to offer. Accordingly, the CC initiative has also been shown to contribute to reduce municipalities’ costs related to overdue discharges, short-term stays at institutions, use of home care services, nursing home admission and home death.

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In Norway, collaborative action between governmental and non-governmental organizations has for a long time been outlined as an important way of progressing national, regional and local health care.^{29,53} Thus, the NCS can contribute considerably to advancing cancer care in Norway through their incentives and lobbyism of cancer, providing expert advice and education of health professionals. Thereby, the NCS may contribute to the progressive

development of local professionals' skills and competency, as called for by both national and international policies.^{13,238} Accordingly, the literature indicates that the CC initiative contributes notably to the development of cancer-related competence in municipalities, facilitates cancer care strategies and increases coordinated care. The NCS has, for instance, contributed to directing the attention of national policies²⁶ towards the need to improve care coordination, resulting in the introduction of standardized 'cancer packages', in order to reduce waiting times and service fragmentation from the detection phase and throughout the treatment. In the most recent national cancer strategy¹⁷⁹, CCs are also encouraged to adopt a central role in the 'home cancer packages', which seek to ensure that patients routinely receive the needed follow-up and rehabilitation offers in municipalities.

Further, it may be argued that initiatives of NGOs such as the NCS can benefit parties other than their own target group, as they put important issues on the agenda that otherwise might remain silent.²³⁷ For instance, the CC initiative exemplifies and promotes patient-centered care and follow-up in primary care as important values in patients' treatment courses. In establishing CCs, the NCS thus puts the need to improve local health care in the foreground which can contribute to enhancing a general consciousness about opportunities for improving service delivery in primary health care. Thereby, the NCS' CC initiative may facilitate action and lobbying for a more patient-centered and coordinated primary health care in ambassadors of other patient groups, too.^{236,237}

Historically, this has been proven right, for instance, with regard to palliative care. In Norway, the organization and the content of palliative care had initially been put in the spotlight in order to provide quality care for cancer patients, among others, in collaboration with the NCS.²³⁹ The developments and guidelines resulting from the work on palliative care for cancer patients apply today to palliative patients regardless of their disease.²³⁹ Likewise, the LCP plan was originally developed as an interdisciplinary protocol to ensure dignified and individualized palliative care for cancer patients.²⁴⁰ To date, the protocol has been internationally tried out, evaluated and adjusted to provide end-of-life care to cancer patients and non-cancer patients.^{98,240} In a similar way, the CCs' initiative may be regarded as a stepping stone towards better care coordination for cancer patients, which might bring along important lessons to learn and practical implications transferable to other patient groups.

From this perspective, the NCS plays an important role in responding to the WHO's calls and national ambitions of strengthening primary health care and its offers. However, it is important to acknowledge and be aware of the aforementioned and other critical issues connected to the role of NGOs, such as the NCS, so that potential conflicts of interests can be managed if they arise.²³⁸

8.5 Discussion in light of Salutogenesis

In the following, the findings will be placed into the theoretical framework, regarding first the patient and subsequently the system-level work of cancer coordinators in light of Salutogenesis.

8.5.1 A salutogenic perspective of CCs' patient-level work

At the patient level, CCs focused on providing patients with cognitive resources (e.g. information and advice regarding cancer, cancer treatment and the sequelae), instrumental resources (e.g. access to services, service coordination, assistive devices) and motivational resources (e.g. psychosocial support) in order to help them manage the treatment and their day-to-day life. In light of salutogenic theory, these findings indicate that the CCs worked to facilitate the health resources (GRRs) to enhance patients' ability to manage their challenges (SOC) and thereby improve their health and well-being. This is in line with the literature²⁴¹, emphasizing that assisting people in their search for appropriate GRRs can facilitate successful tension management and increase SOC. Enhancing patients' SOC is of relevance in cancer care, as patients with a high SOC report fewer symptoms of distress, anxiety and depression.²⁴²⁻²⁴⁴

This study showed that CCs aided patients in gaining an overview of the cancer care process, providing structure and help with coping with their situation. From a salutogenic perspective, CCs supported patients in creating 'order out of chaos' regarding a fragmented health care system and incisive changes in patients' lives. The literature shows that re-establishing consistency and load balance can increase the SOC and is an important first step towards better health and well-being.^{124,125} This study, supported by literature²⁴¹, indicates that health professionals should support patients' ability to understand their situation, as this can empower them to identify and use adequate resources for health.

Several CCs expressed that, at times, even a single consultation during which they discussed the situation, provided advice and the required resources could enable patients to move on self-sufficiently. Consequently, it seems that the CCs helped patients manage both their acute challenges and strengthened their ability to approach challenges ahead. This is referred to as indirect mechanisms to increase SOC, describing that people can re-establish consistency and a load balance during stressful events, which enables them to actively acquire and use more GRRs.²⁴¹ Thus, early consultations and support by CCs may increase the likelihood that patients adjust to cancer and need less support or health services onwards. Prior research^{15,245} confirms that health professionals' focus on social support can enhance meaningfulness, lead to high levels of adjustment and prevent adverse health outcomes and unnecessary use of services.

CCs encouraged patients who experienced limitations from the treatment to establish a 'new normality' by adjusting their routines and goals to their reduced energy levels. This resonates with Salutogenesis and health promotion, as it refrains from the traditional health concept that assumes that 'normality' is analog to the absence of disease.²⁴⁶ Supported by the literature^{114,115,119}, the CCs appeared to advocate for health as a process, influenced by resources, strengths, illness and limitations. In offering cancer patients an alternative perspective on health and normality, CCs seem to resolve the well-known challenge of cancer patients striving to return to normality as experienced prior to the disease, which can exceed their capacity.²⁴⁷

CCs placed importance on providing resources and support based on patients' perceived needs. The literature emphasizes the relevance of this approach, showing that resources *per se* do not necessarily produce better health outcomes.^{2,119,241} Salutogenesis elaborates that health improvements are influenced by a perceptual mechanism. People's perception will thus determine whether resources are discarded or regarded as useful and applied to improve health and well-being.²⁴¹ This line of thought may be relevant for ongoing challenges in assessing the impact of CCs' support on patients.^{99,248} For instance, research²⁴⁸ finding no impact of CCs on patient satisfaction did not examine the "how" or "why" patient satisfaction was not improved. The present study's findings, considering Salutogenesis, suggest that focusing on whether the support appeals to patients' perceived comprehensibility, manageability and meaningfulness could provide a more nuanced understanding and might better explain patients' overall experience of the CCs' support.

8.5.2 A salutogenic perspective on CC' system-level work

It may also be argued that the CCs displayed a salutogenic approach to their system-level work, as they focused on facilitating resources to manage the challenges they encountered. CCs outlined several themes important to system-level work, for instance, external role recognition, skilled professionals, professional collaborations, common systems, routines, procedures and resources for cancer care, acknowledging and trusting work-relations, and more. The themes were described in terms of a facilitator (GRR) if given, or a barrier (GRD) when missing in their municipalities. This is consistent with salutogenic theory, indicating that the absence of a GRR can become a stressor itself.¹¹⁹ Further, the identified themes seem to pertain to comprehensibility (e.g. role understanding), manageability (e.g. local resources) and meaningfulness (e.g. acknowledging working relationships) of CCs system work. Together, the components may account for a collective SOC; the ability of a system or team to facilitate a positive direction and gather more GRRs.¹³²

In line with salutogenic theory, the findings emphasize that the ability of CCs to achieve outcomes at a system level depends on a complex set of contextual influences and social dynamics. However, program evaluations often seem to pay more attention to CC performance alone, rather than considering the manifold factors impacting the role. Accordingly, this study, echoed by the literature¹⁰⁷, suggests a need for paying more attention to the context which can impact the performance of the CC role.

The contextual factors identified in this study appeared to play a vital role, whereby several CCs were able to modify the circumstances to a certain degree. For instance, the CCs encountered notable initial challenges from poorly developed systems, missing teams and resources for cancer care and rehabilitation. Other CCs suggested 'pathogenic conditions' in referring to professionals' lack of focus, skills, time and a skepticism towards collaboration. However, CCs were able to establish collaboration and improve cancer care over time. These findings, supported by the literature^{96,133,180,217,249} suggest that using a minimum level of resources, e.g. social support and recognition, shared interests, communication and involvement in decision-making can significantly strengthen the performance of a system (SOC). In this way, the findings indicate that CCs themselves may be regarded as an important GRR which can strengthen local cancer care systems.

The resource-focused approach of CCs can be seen to contrast traditional approaches to health system improvements that often take a pathogenic orientation^{86,250,251}, focusing on problems and limitations of current practice.²⁵⁰⁻²⁵³ The literature even suggests ‘homeostasis’ as a key feature of health care systems, pointing out a pathogenic-oriented approach to eliminate stressors, learn from mistakes, reduce errors and prevent negative outcomes.^{86,250-252} However, in cancer care, some pathogenic factors, such as an overburdening of professionals, shortages in financial and human resources and care, appear to be enduring stressors which are unlikely to be eliminated at once.^{52,64,65,81,86} Hence, Antonovsky’s¹¹⁹ suggestion of a ‘heterostatic disequilibrium’, focusing on the need to adapt to constant influences and changes, may better describes the key feature of a health care system. Accordingly, the CCs seemed to pursue a salutogenic focus on effective tension management, rather than a pathogenic focus on eliminating barriers. The aforementioned problems of ‘missing electronic systems’ and ‘lack of resources’ in cancer care were perceived as barriers that could not be eliminated. However, the CCs outlined ways to adapt to them, for instance by establishing systems for communication and making better use of existing resources in upskilling local professionals and facilitating patients’ access to offers for other patient groups. Such a salutogenic orientation may be of relevance as the health care systems are facing an increasing number of patients. Moving the focus towards optimizing and using existing resources as displayed by the CCs may facilitate a movement towards patient-centered, coordinated care *despite* existing challenges and resource shortages. This is supported by recent research which increasingly considers salutary factors for strengthening health care systems and communities.

A salutogenic orientation is also reflected in CC programs in the US, where an asset mapping of the health system and the community was outlined as a particular part of the training program for the role.¹⁸⁵ This may be useful for Norwegian CCs as well, who asked for support in implementing and operating their role adequately. Building upon prior research^{111,132,254}, it may be suggested to provide a salutogenic toolkit for implementing the CCs’ position. This could help raise awareness of existing yet underused resources and support CCs in the planning of comprehensible, manageable and meaningful interventions in the local cancer care systems. Mapping the challenges and possible solutions in cancer care in collaboration with superiors and other collaborating partners may enhance the collective SOC and thus the likelihood of salutary outcomes.¹¹³⁻¹¹⁵ This way, the CCs might receive the necessary

guidance, support and collaboration to implement and sustain the role whilst preserving the flexibility to operate their duties according to local circumstances.

8.6 Methodological considerations

In the following, a discussion of the study's methods and the role of the researcher will be provided. While indicators for the strengths and weaknesses are well-established in quantitative research, there is no consensus on how rigor can be established in qualitative research.^{143,145,155} Accounting for the conditions under which understanding takes place is in the center of hermeneutic investigations.¹⁵¹ Thus, trustworthiness of the study can be established in providing the reader with a detailed account of the events, influences and actions of the researcher. Issues of rigor can be assessed in terms of the accuracy and credibility of the data, as well as the degree to which the method will generate similar results when applied at a different point of time.^{137,145,160} In the present study, trustworthiness and rigor has been assured by following recommendations by Koch¹⁵⁵ and Creswell¹⁴⁵. This involves providing an account of reflexivity (the role of the researcher), reflections on the study design and data collection and a discussion of strategies for ensuring rigor and reflections of the theory.

8.6.1 Reflexivity

Reflexivity is a validation strategy through which the researcher's position and any research biases which could potentially impact inquiry are explored and clarified.¹⁴⁵ In hermeneutic studies, the researcher's role is of particular importance, as the researcher becomes their own research instrument.^{141,156} In this study, the candidate's baseline understanding of the topic at hand consisted of prior knowledge of cancer care, the health system and patients' support needs during and after cancer treatment, obtained from undergraduate and postgraduate degrees in public health, health promotion and health psychology. The candidate's Master's project had explored how young adult cancer patients coped with their disease, showing that fragmented health care systems was one of the patients' many challenges. During the PhD research process, comprising literature review, recruitment, data collection and analysis, the candidate successively gained new insights which extended her understanding and clarified the preliminary impressions she had of the cancer coordinator role. In addition, the candidate was, during a research exchange, invited to

present this PhD project to CCs in Australia and as part of a CC gathering in Oslo. Both encounters with the groups of CCs facilitated discussions, additional insights and further investigation into the role.

Based on her education, the candidate had gained knowledge and experience in conducting qualitative research and enhanced her skills in the framework of the PhD courses undertaken. Based on her education, the candidate had prior knowledge of salutogenic theory, which she further developed during the PhD period by attending an international summer school and subsequently at a salutogenic conference abroad. This sparked her interest in applying Salutogenesis as a theoretical framework in the context of the present study.

Further, the candidate had a degree of pre-understanding related to rehabilitation, influencing her awareness of the issue during the research course. The candidate was part of the research group “(Re)habilitation – Individuals, Services and Society” at Oslo Metropolitan University, and a member of the “Professional network group for cancer rehabilitation” at Regional Competence Service for Rehabilitation (RKR) during the PhD period. She also attended conferences on cancer rehabilitation in Norway, all of which highlighting that models for the delivery of cancer rehabilitation need to be better understood. The candidate’s primary supervisor is a Professor of sociology, with extensive research expertise in the field of rehabilitation. The co-supervisor holds a PhD in psychology and rehabilitation of young adult cancer survivors, as well as broad clinical and research expertise in cancer nursing and cancer rehabilitation. Drawing upon their experiences, the supervisors guided the candidate in undertaking research into the topic at hand.

During the PhD period, new national strategies in cancer care and cancer rehabilitation were proposed, which influenced the candidate’s understanding of the political context for Norwegian CCs and cancer care in primary health care. Overall, the candidate experienced entering the hermeneutic circle in the frameworks of each study, and, as outlined above, in the overarching frame of the thesis. Thus, the understanding was both shaped by the candidate’s interaction with the data as well as by literature, conferences and meetings in the network groups, courses, research exchanges and the political context regarding Norwegian cancer care.

However, the candidate has a theoretical-oriented background in health promotion and health psychology and lacks clinical experiences, which e.g. a nursing background could have provided. Hence, it is likely that this impacted the way she approached and understood the topic. Likewise, the candidate had little prior research experience, which is likely to have influenced the research process. On the other hand, the candidate engaged meticulously with the literature, invested much time and energy in order to familiarize thoroughly with the research topic and the process. Moreover, the candidate consulted her supervisors and other candidates during the research process, all of which helped to ensure rigor. Further, the candidate has some prior working experience in the media sector, which enhanced her confidence in interview situations and supported the productive interaction with participants.

8.6.2 The sample

Qualitative studies typically embrace an in-depth investigation with small samples, providing rich and nuanced information on individual's accounts of their experiences.^{137,145,160} This study's sample for the individual interviews embraced 26 participants, depicting a comparably big sample compared to the average size (10-25)¹³⁸ and to the total population (n=130) at the point of data collection. A notable strength of the study is that the sample was carefully selected and mirrored the diverse geographic, organizational and other contextual features that may influence the ways in which the role has evolved and is experienced by the CCs^{137,255}. Such a variation increases likelihood of that the findings will provide different and nuanced perspectives, which is ideal in qualitative research.^{137,138} Further, nuanced perspectives might enhance the likelihood of that the accounts of the study sample are representative for the overall population.

The study sample for the two focus groups consisted of 12 participants, in line with most usual sizes for focus groups.¹⁵⁹ Kitzinger¹⁶⁵ suggests a four to eight people as an ideal group size. This increases the likelihood of having enough participants to generate fruitful, extensive discussions, while limiting the group size in a way that gives each participants sufficient opportunities to speak.¹⁶⁸ However, two focus groups is a low number, which is a weakness of the study. That was due to difficulties in recruiting CCs, who faced constraints in participating as their busy schedules would not provide the time to take a day off to travel to the focus group locations. It might have been that more participants could have been recruited over a longer time, however the time-frames of the present study set limits to how long the

recruitment could be undertaken. However, the literature shows that there exist no standard recommendation for the number of focus groups.^{159,168} Rather than quantity, the emphasis lies on the generation of the rich and nuanced data¹⁶⁸, which both focus group generated.

Although the participants were relatively homogenous in terms of their geographic location, they still represented a diverse sample in terms of other contextual variables. However, CCs from Southern and Northern Norway were underrepresented (with one CC from the Northern part of Norway and one from the Southern part), so that perspectives from CCs in those regions might not have been caught.

Moreover, it must be considered that the Norwegian health care systems differs from many others, in that the most health care is publicly funded. Thereby, data generated by the study sample for individual interviews and the focus groups, did not cover insurance issues, which is underscored as an important aspect of CCs work in other countries.^{32,100,256}

8.6.3 Data collection

The choice of interviews with CCs brings along some limitations to be considered. This thesis investigated CCs' perspectives, and provides thus insights in only one of many sides of the story. Including the perspectives of CCs' collaborating partners, their managers, the patients and their families could have strengthened the study. However, such a wide-ranging approach would have exceeded the frames of this thesis, and practical considerations had to be made with regard to the timeframes and the scope of the PhD project, as described in chapter 6. Rightfully, individual or focus group interviews with the abovementioned actors could have been undertaken in one geographical area, to comply with the timeframes provided for data collection. However, this would have contrasted the aspirations of this study to embrace the diversities in the geographical and municipal contexts in which CCs operate. Other considerations were given to that the recruitment of patients might have forwarded a selection bias, as patients with high satisfaction would have been most likely to participate, respectively, to be referred to such a study, e.g. by the CCs. It would thus have been a risk for that patients' with potentially more negative experiences would not have been included to an adequate extent. In a similar way, participant observation might have contributed to enriched the overall picture and to validating, discarding or generating new perspectives on the findings. However, the focus of the thesis was to generate knowledge of CCs experiences, and not on evaluating their activities or comparing the account of different actors. Further

consideration was given to that patients are a vulnerable group, and that the researcher's presence in patient consultations could have exposed participants to unnecessary burden in a difficult situation. Furthermore, CCs have contact with many professionals in the course of a day. It was considered as highly time-consuming and difficult to gather informed consent, particularly as it seemed difficult to predict whom the CCs would collaborate with in the course of a day. Hence, interviews were judged to be the best suitable methods for giving voice to the CCs. The choice of interviews allowed for in-depth investigation of CCs situated in diverse settings across the whole country. Thereby, rich data were generated that provided nuanced knowledge of the experiences of CCs in primary experiences of enacting their role to deliver patient-centered and coordinated cancer care.

The individual interviews was undertaken at the CCs' workplace, which facilitated in-depth understanding and contextualization of the CCs' narratives, in line with the hermeneutic tenets.^{141,156} However, some of the interviews were undertaken via phone, which may have obstructed in-depth insights. A strength of the interviews is the unique interest the CCs had in participating in the study. This was explained by most of them in terms of their role being new and their resulting interest in contributing to a better understanding of how it was developed, as they hoped to benefit from such insights themselves. This was also reflected in the recruitment procedure, as only one participant declined and another one did not respond. Consequently, the participants were open about their experiences and seemed to be unafraid of revealing challenging issues. The interviews yielded rich data; data saturation was achieved after 22-24 interviews, i.e. no new themes became apparent.¹⁴⁵ Nevertheless, all 26 interviews were conducted and confirmed the findings from the previous interviews. One challenge was that the PhD candidate was a novice researcher and found it initially difficult to interrupt and to risk appearing 'rude' when participants digressed from the initial question, as well as being concerned about missing potentially important information by doing so. This yielded very comprehensive interviews (up to two hours) and some excess information. It is likely that with more experience, the candidate would have been able to appropriately intervene to reduce the length and the level of detail given without missing valuable information. However, this should be seen as a natural learning process which enabled the researcher to develop strategies to better guide interviews over time. This was reflected in the second half of the interviews, which were shorter than previous ones while still providing rich data. Similarly, the candidate was concerned with avoiding interviewer bias and might not have

given sufficient feedback to participants during the first set of interviews. After a while, this was modified as the candidate developed an understanding of when feedback was required and necessary and when it should be avoided to ensure an unbiased interview course.

In the focus groups, a flow in discussions could be facilitated and both focus groups provided rich data. However, in the first focus group this was preceded by some initial difficulties in starting the conversation. This can be explained by the researcher's need to be acquainted with the role of leading a group discussion and potentially adopting an overly restrained approach as a moderator at first. Secondly, some participants gave subsequent feedback on holding back initially, as they were concerned of exposing to others that they might lack knowledge and focus on rehabilitation in their work. Although the researcher had clarified that CCs' experiences were the topic of interest and no expectations concerning their performance was given, this should have been stressed once again at the beginning of the interview. However, this again facilitated a learning process, through which the candidate could moderate the second focus group with these experiences in mind. In the second focus group, participants contributed relatively equally to the conversation, while in the first focus group one participant tended to dominate the conversation. The participant representing a municipality with a strong infrastructure and a structured approach to the CC role. This seemed to reinforce some other participants' hesitance to speak and potentially reveal 'failure' in operating accordingly. However, the candidate was able to involve the other participants by directing questions towards them or encouraging them to provide their experiences. This facilitated a fruitful discussion and brought to light contrasts as other participants responded mentioning different experiences.

Interview bias was accounted for by considering ethical aspects before starting the interview (see 6.5) and following recommendations for interviewing (see 6.3). Further, the researcher avoided providing direct opinions or non-verbal cues, posing leading questions or dismissing topics introduced by the participants.¹⁶³ In the focus groups, the researcher emphasized guiding the discussion rather than joining in with it.¹⁷² This practice ensures that participants are free to speak and avoids introducing bias by participants responding to cues or opinions of the moderator.²⁵⁷

8.6.4 Prolonged engagement and persistent observation

Prolonged engagement and persistent observation is one way to validate qualitative research data, as this can aid in building trust, facilitating in-depth understanding, testing for misinformation and achieving data saturation.¹⁴⁵ In this study, none of those strategies were undertaken, as CCs were interviewed once and observation was not part of the research strategy. This can be regarded as a weakness as those strategies may have enriched the findings. On the other hand, a high number of interviews were undertaken and participants' work experience ranged from months to several years - which can be regarded as a form of prolonged engagement with the data. In addition, alternative strategies were applied to enhance trustworthiness of the data. These included undertaking a thorough mapping of available information on CCs in Norway to get an overview of the field, in the course of the data collection and in visiting the CCs at their workplace. Testing for misinformation was undertaken by posing probing, open-ended questions during the interviews, by continuous discussions with the supervisors and the analytic course, where interpretations were confirmed by a high number of interviews. Further, the relatively large sample size and the rich data facilitated data saturation. The researcher established rapport¹⁶³, the creation of a relationship or climate of trust and understanding, with the participants on the phone and face-to-face before commencement of the interviews. Further, the researcher focused on non-judgmental, active listening, showing courtesy and respect of participants' personal space and boundaries.^{145,162} This included, for instance, support and recognition responses where indicated.¹³⁷ For instance, when asked: "I am not sure if this is important...", the candidate confirmed that all aspects of the CCs' experiences in regard to the topic were of interest and valuable for the interview.

8.6.5 Member checking

Member checking is another strategy for validating qualitative research, by which that participants can provide a feedback on the stages of the research process, the interpretation and understandings of the researcher.^{138,145} In this study, the interview guides for paper I and II were pilot-tested in order to assess the comprehensibility of questions and their usefulness for gaining insights into the research topic.¹³⁷ At the same time, this process helped the candidate to become familiar with the interview situation and to assess how the interview could be undertaken in a real-life situation. This enhanced the candidate's confidence, enabled

asking broader questions and letting the participants' narratives unfold authentically, rather than artificially adhering to the structure of the interview guide.¹⁶⁰ Member checking was also undertaken in terms of probing and follow-up questions in order to clarify that statements were understood correctly.¹³⁷ In the subsequent interviews, the researcher asked the participants for feedback on the interview process and any suggestions for improvement, as ongoing validation of the interview procedure.¹⁴⁵ In addition, the conduction of thematic analysis facilitated member checking through repeatedly re-contextualizing the data extracts, codes and themes into the context of the overall interview and the total data set.^{145,173} Furthermore, the project and its findings were presented in different settings to CCs, during which feedback indicated high validity of the findings.¹⁴⁵

8.6.6 Transparency

Transparency is a benchmark for writing up research and presenting findings. This involves making each step of the research process explicit.^{258,259} In this study, this was undertaken by providing detailed descriptions of the research aim, the context of the research, previous research, theory, methods (including the participants and the study setting), ethical considerations and the discussion of results, theory and methods.²⁵⁹ Transparency was further ensured through rich, detailed description of the findings, by giving participants voice through using direct quotes.¹⁴⁵ This was also ensured by including several appendices which facilitate further insight into the three research papers, approval forms, information letters and the interview guides.²⁵⁹

8.6.7 Accuracy and credibility of the data

Accuracy and credibility of the data in the present study was ensured by employing a high-quality tape for recording of the interviews and focus groups as well as transcribing the tape records. NVivo¹⁷⁵ software was used to assist the analysis, which aided in systemizing and organizing the comprehensive data set. In qualitative health research, reliability often refers to the stability of findings to multiple coders.²⁵⁵ This was ensured by the independent coding of a selection of the interviews by the PhD candidate and the supervisors, with subsequent discussion and comparison of the derived codes and themes to confirm consistency. This involved an inter-coder agreement on the labels and the meanings of the codes and themes, and whether the data excerpts were coded in the same fashion. In this

study, all papers were submitted for blinded peer review, ensuring that individuals who have no connection to the study examine the accuracy of the research process and of the reported data.¹⁴⁵

8.6.8 Choice of theory

Traditionally, Salutogenesis investigates individuals' health, stress and coping mechanisms.^{118,119} This approach is frequently used in quantitative research, with a standardized questionnaire being used to investigate the SOC.²⁶⁰ Using a well-known theory in a different way carries the risk that the choice and use of theory may be difficult to understand. This can represent a weakness of the study, as difficulties in understanding the choice and employment of a particular theory may decrease rigor. However, a salutogenic approach has previously been used both in the framework of qualitative research and to investigate initiatives at a system level, and has been asked for in the literature.^{244,261-263} The strength of this framework is that it responds to the current calls for incorporating a stronger focus on health promotion into research and clinical practice.⁸⁶ It provides nuanced insights into the bio-psycho-social aspects of health, as required to facilitate patient-centered cancer care in primary health care. Its orientation towards resources can aid understanding of how CCs contribute to improving patient-centered, coordinated care. In addition, Salutogenesis employs a focus on complex contextual factors and social dynamics, and could therefore shed light on the processes affecting CCs' actions at a system level. This approach provides new perspectives on the role which might help to facilitate the further establishment, enactment and maintenance of the CC role. Evidently, other theoretical perspectives could have been chosen, e.g. profession theory or organizational theory, but these theories belong to other fields. Theories of health behavior or coping might have been some of many alternative theories within health sciences. Nevertheless, salutogenic theory was considered to provide a more comprehensive picture as it focuses both on internal and external influences that affect a given situation. However, in line with hermeneutic principles, the candidate acknowledges that no one theory can illustrate all aspects of the data, but rather represent one of the many ways to understand a phenomenon.^{150,156}

Using salutogenic theory to explore CCs' experiences gave rise to some challenges during the research process. First, although research using salutogenic theory in other than quantitative approaches research has been demanded in recent literature⁸⁶, it was difficult to assess the best

way to undertake this. As the candidate's immediate scientific environment had not previously conducted such research, she reviewed the literature, attended courses and conferences, and discussed with experienced researchers in order to address the wider application of Salutogenesis to different settings. Whilst this was helpful and facilitated the research process, this also led to a main focus on the theory and its application for a period of time. This poses a risk for introducing a potential research bias, as this study employed a data-driven analytical approach, where theory aids the understanding but does not guide the analytical course.¹³⁷ Here, the candidate was encouraged and supported by her supervisors to distance herself from the primary concern with theoretical aspects and re-orient the focus back to the data at hand. This was regarded as an important learning process, as it enhanced the candidate's reflexivity and facilitated an increased awareness and alertness towards potential research biases.

9. CONCLUSION

In the following, main conclusions from the study will be drawn, followed by the study's implications for clinical practice and further research.

9.1 Main conclusions

The present study has shown that Norwegian CCs are highly knowledgeable professionals, who carry out a broad range of patient- and system-focused tasks as part of their role. CCs encountered initial challenges in enacting the role, as they had to develop and implement the role in a time-consuming process and with very little guidance or support. Over time, most CCs seemed to engage to a high degree in patient-level work. They displayed a focus on patient involvement and on delivering tailored, holistic support based on patients' perceived needs. Although CCs were available to patients in each phase of the continuum, most of them seemed to adopt a focus on palliative cancer patients. Accordingly, one major area for further work and development was shown to be that of cancer rehabilitation. Although the CCs suggested a holistic approach to cancer rehabilitation, they perceived current practices to contrast these conceptualizations. Rehabilitation appeared to be of lesser prominence in the CCs' work, being sidetracked in municipalities or provided in terms of one-dimensional interventions.

The CCs' system-level work was described as more difficult to achieve as their patient-level work was a time-consuming task. Most CCs engaged in a case-based approach to bridge current system gaps for individual patients, rather than adopting a long-term oriented approach to system work. Thereby, some patients may have received high quality care while CCs could not systematically reach out to many other patients. The findings suggested that CCs encountered important topics, such as role recognition, common procedures and acknowledging working relations that could impact the comprehensibility, manageability and meaningfulness, and thereby their ability to enact their system-level tasks. However, over time the CCs seemed to acquire the resources they needed, thereby being able to turn initial challenges into resources for their system-level work. The findings presented here indicate that the CCs adopted a salutogenic view in their work and may represent an important asset for both patients and professionals, as they focus on facilitate comprehensibility, manageability, meaningfulness solutions for current challenges. Salutogenic theory, with a

focus on cognitive, instrumental and motivational resources is suggested as a useful frame for guiding the implementation and research into the CC role.

9.2 Implications for practice

The findings highlight that CCs are not able to undertake all of the intended tasks by themselves and require a better support system to utilize the full potential of their role. This study suggests the need to provide CCs with the appropriate resources and support to establish and maintain the role. This could involve, for instance, guidelines or toolkits as well as management support for implementing and promoting the role in local cancer care. In this regard, a mapping of the municipal context, including needs, barriers and assets for CCs' work are recommended as useful approaches to facilitate successful role implementation. Superiors are suggested to facilitate working conditions allowing CCs to carry out their tasks efficiently, for example by assisting CCs in the role implementation and its promotion, as well as linking CCs with other local professionals. Moreover, the findings suggest a need for incorporating the role into multidisciplinary teams, to further aid CCs in executing the broad range of their tasks. It may be suggested to narrow the scope of the role by assigning CCs a more overarching function. CCs may, for example, pass on their knowledge to other professionals, who in turn could carry out the delivery of quality care at a patient level. Thereby, CCs would have more capacity to achieve system-level improvements. This may also improve role recognition and professional collaboration with, for instance, professionals in specialize care, as the role might be more aligned and differentiated from other health professionals roles.

Further, the findings indicate a need for strengthening the focus on local cancer rehabilitation and to provide patients with holistic and multidisciplinary rehabilitation interventions in each phase of the care continuum. This may be provided in supporting CCs in raising local professionals' awareness of complex cancer rehabilitation, allocating responsibilities and establishing systems for its delivery. Local and national policies could support this process in giving cancer rehabilitation a higher priority and to clarify its concept, content, system and clear responsibilities for its successful delivery.

The findings suggest that a salutogenic, resource-oriented approach could benefit health professionals' work in cancer care. It is recommended to undertake an assessment of patients'

perceived needs, goals and resource to empower them to take charge of their treatment course, their daily life and improve their health. Making better use of available resources and liaise with other professionals, volunteers or agents of distinct patient groups is suggested as a way to improve cancer care in municipalities facing resource shortages.

9.3 Implications for research

This study provides an insight into the current state of CCs' experiences of their work. However, the generated knowledge should be further built upon in future research, for instance by conducting longitudinal studies which can provide insights into the development of the role over time. In addition, there is a need for research to better understand and manage challenges in the implementation and systematic operationalization of the CC role. This may be achieved by implementing and evaluating the use of toolkits and/or guidelines. Furthermore, there is a need for more qualitative research to gain more understanding of the experiences of patients and their families, municipal management and collaborating partners in order to provide a nuanced understanding of CCs' contribution to the delivery of patient-centered, coordinated care. Further, the results and outcomes of the role need to be better explored. As patients' experiences of cancer is an important factor in their treatment process, research capturing the impact of cancer coordinators' support on patients is needed. This could be undertaken in the framework of salutogenic studies, focusing on the impact of CCs' support on patients' comprehensibility, manageability and meaningfulness, and, thus, their SOC. Likewise, investigations into group SOC of professionals in cancer care is suggested to better understand how the role can best be adapted to the individual settings CCs are embedded into.

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APPENDICES:

Appendix I: Paper I

“Providing Coordinated Cancer Care” – A Qualitative Study of Norwegian Cancer Coordinators’ Experiences of Their Role

Abstract

Background: There is a growing need for strategies to improve coordinated, tailored services in cancer care to meet the comprehensive needs of cancer patients. In Norway, cancer coordinators (CCs) have been established to improve coordination and patient-centeredness of services. Little is known about how CCs engage to provide patients with the needed services and support throughout the treatment.

Objective: To explore how Norwegian CCs experience their role and how they enact it in order to enhance coordinated cancer care.

Methods: The study encompasses a qualitative, hermeneutic approach, conducting semi-structured in-depth interviews of 26 Norwegian CCs. The data were analyzed using thematic analysis and discussed in the light of the salutogenic theory.

Results: CCs take a holistic approach to patient care, including both patient- and system-level activities. ‘Providing coordinated cancer care’ emerged as an overarching topic for their role. This topic was elaborated by three main themes: (1) finding their place and creating their function; (2) meeting the needs of cancer patients and helping them cope; (3) promoting well-functioning cancer care systems.

Conclusions: CCs evolved diversely, in adaption to the local context and patients’ needs. The functions’ diversity challenged the implementation and external role recognition. CCs seemed to apply a salutogenic, resource-focused orientation in order to support a positive development at both patient- and the system level.

Implications for practice: The findings reinforce the call for holistic, patient-centered services in cancer care. CCs need appropriate support from the local management to establish the role and local collaborations.

Introduction

Although cancer is one of the leading causes of morbidity worldwide, advances in research and treatment have led to more cancer patients surviving or living longer.¹⁻³ Cancer can be complex, and treating it may require several professionals both inside and outside of the health care sector over a prolonged period of time.⁴⁻⁶ However, patients are experiencing fragmented care trajectories and are reporting that their physical and psychosocial needs are not being met.^{5,7} The provision of coordinated and comprehensive cancer care trajectories has thus become a priority policy objective, both nationally and internationally.^{4,5,8} In Norway, legislation was passed in 2012 to specifically address the improvement of care coordination. The legislation gives greater responsibility to the primary health care services in terms of patient follow-up.⁹ Based on this, the Norwegian Cancer Society initiated the implementation of cancer coordinators (CCs) in the primary health care services. They did so by providing 75% of the CCs' wages for the first four years.^{10,11} As a result, 130 CCs have been implemented to date across almost two thirds of the 428 Norwegian municipalities since 2012.¹¹⁻¹⁵ The overall goal for CCs is to improve the coordination of local services and to ensure that the support needs of patients and their families are met.¹⁰⁻¹² However, in Norway, the position of CC is new and has not been previously tried out. As each municipality was placed in charge of developing a specific job description and operationalizing the role of CC, the position has evolved in diverse ways across the country.¹¹⁻¹⁵ In order to generate a better understanding of how CCs work to improve coordinated cancer care on a local level, this study investigates the CCs' own experiences of the enactment of their role.

Previous research

The need for strategies to improve the coordination of cancer care has been highlighted both nationally and internationally.^{4,8,17} While the position of CC is new to Norway, similar roles have been established overseas which provide support to patients as they navigate their treatment. These professionals are often part of multidisciplinary teams, located in hospitals or in cancer care centers. Others, including Norwegian CCs, are community-based.^{5,6,18-20} It has been shown that professionals occupying these roles provide patients with high levels of support in terms of treatment coordination, financial matters, information and the satisfaction of their psychosocial needs.¹⁸⁻²¹ Other studies have found that they have positive effects on

cooperation and communication between care providers, as well as better service integration.^{21,22,24} However, in the literature, these roles are described using interchangeable terms; cancer navigators, cancer nurse coordinators and other similar labels are in use.^{5,6,17-21} Hence, professionals in these positions report that their role lacks recognition and that they have difficulties with professional cooperation.^{6,17,18} Findings from a literature review¹⁶ show that patient navigation lacks a standardized definition, making it difficult to distinguish navigation from other cancer support services, such as case management and social work. The authors suggest that a definition should emphasize the navigators' focus on perceived barriers to care and strategies to reduce them.

The Norwegian Cancer Society's vision for CCs in primary health care services was that they would provide a point of contact and offer free local support to patients and their families. It is the duty of the CC to provide psychosocial support and to help patients navigate their treatment, both by coordinating the required health services in the municipality and by promoting interdisciplinary collaboration and system improvements.¹⁰⁻¹² This vision seems to align with the primary traits of a navigator's functions as established, e.g., in the US. These functions are described in terms of a service that provides assistance and implements a tailored action plan for patients.²⁰ However, in assigning the ownership of this function to each municipality, the Norwegian Cancer Society provided no further description of what a CC's primary role should be, nor did they specify any particular conditions in terms of their working tasks, evaluation or outcome measurements.¹³

Hence, municipalities have been free to create a CC role adapted to their distinct local needs and in accordance with some broad guidelines, presented in Table 1. [Table 1]. Accordingly, the role of CC has evolved diversely in line with the heterogeneous Norwegian municipalities.^{13,14} At the present time, existing knowledge of how Norwegian CCs carry out their role consists mainly of annual surveys conducted by the Cancer Society.¹¹⁻¹⁵ These surveys indicate that CCs are working as system-level coordinators as well as providing cancer care on individual level, which may include both clinical and non-clinical aspects of care. User surveys show high patient and family satisfaction.^{11,14} However, CCs are facing challenges such as the limited external understanding of their role and, as a result, difficulties in cooperating with local professionals.¹⁵ Therefore, more research is needed to better understand how Norwegian CCs are carrying out their role to improve local cancer care. This

could provide important cues in terms of guiding future cancer care in primary health services.^{5,6,16}

Theoretical framework

As the intended function of CCs is to facilitate and improve the wellbeing and health of patients at both an individual and systemic level, this study builds on the salutogenic theory^{25,26}, which was coined by Aaron Antonovsky. The basis for this theory is the idea that health evolves when individuals are provided with the resources needed to comprehend, manage and make sense of the situation they are faced with.^{27,28} These ‘general resistance resources’ describe any bio-psycho-social or environmental factor that has the potential to increase a person’s capacity to navigate demanding life events, such as undergoing cancer treatment.^{29,30} Such factors can be, e.g., assistive devices and medical supplies, information, knowledge or social support.^{27,29,30} If sufficient resources are provided to facilitate comprehensibility, manageability and meaningfulness, people are more likely to perceive their challenges as consistent with the opportunities they are given to handle them – a notion termed ‘sense of coherence’.^{26,28} This notion is seen as the driving force for people to improve their health. Thus, the salutogenic theory provides a sound framework for understanding how CCs carry out their role to facilitate local cancer care and the necessary resources and support for patients and their families.

Study aim

This study aims to explore and better understand how CCs experience the many facets of their role by posing the research question: ‘How do CCs experience their role and how do they undertake it in order to enhance coordinated cancer care?’

Method

This study applies a hermeneutic approach, inspired by Gadamer.³¹ Understanding is created through the interactive relationship between the participant’s expressed lifeworld and the researcher’s interpretation of this, referred to as a hermeneutic circle.^{31,32} The interpretation occurs when the researcher’s pre-understandings and data fuse and are placed in context.^{31,33} To properly enter the hermeneutic circle, we are required to use our own experiences while

understanding how these interact with the data.³³ To ensure rigor, we aim to give credible account of the research process through a careful description of each step, including the design, data collection, the analytical process and the findings.^{32,33}

Sampling procedure and informants

The recruitment and data collection took place in 2014, based on the eligibility criterion of ‘being a CC funded by the Norwegian Cancer Society’. Considering the diverse evolution of the CC role and the heterogeneous municipalities¹¹⁻¹⁵ in which they work, we conducted purposive maximum variation sampling³⁴, aiming to facilitate nuanced perspectives of the CC role. To inform our selection procedure, we collected data on all existing CCs in terms of their age, gender and background, the terms of their employment and the demographic variables of their municipalities. The data sources were the websites of the Norwegian Cancer Society, Statistics Norway and Norwegian municipalities.^{35,36} From a total of 130 CCs, we extracted a sample which aimed to include CCs who represented a) Norway’s existing 19 counties, b) heterogeneous municipalities, c) full- and part-time employees, d) experienced and newly recruited CCs, e) a broad age span, f) different professional backgrounds and g) both genders. These variables were covered by the 26 CCs that were selected. The first author contacted these CCs via an e-mail containing information about the study and an invitation to participate in a personal interview. Each of the 26 approached CCs gave their consent, and was thereafter contacted via telephone to clarify details and to make an appointment for an interview. No participant was turned away. The final sample consisted of 26 CCs, outlined in Table 2.

[Table 2]

Interview procedure

The first author conducted qualitative, audiotaped one-on-one interviews with the informants using a semi-structured interview guide, presented in Table 3 [Table 3]. The interview guide was developed by the first author and discussed with the third author. The questions were developed based on a literature review and an interview with a Cancer Society consultant for the CC initiative. The main questions targeted the CCs' experiences of how they have carried out their role in order to enhance coordinated cancer care, and were further elaborated upon by follow-up questions. Furthermore, the CCs were encouraged to raise additional topics which they deemed relevant to their work. The first author conducted three CC pilot

interviews, which confirmed the suitability of the interview guide for exploring the phenomenon. As a result, these participants were included in the final study sample. In total, the first author held 18 interviews at the workplaces of the CCs and eight interviews via the telephone due to long travelling distances. Each interview lasted 60 to 120 minutes and was transcribed verbatim.

Ethical considerations

The study was approved by the Oslo and Akershus University College of Applied Sciences and the Norwegian Centre for Research Data and conducted in compliance with the Helsinki Declaration and requirements for data processing.³⁷ Participation in the study was voluntary and all participants gave written and informed consent. Recognizable information regarding the identities of the CCs or their municipality was anonymized in the transcripts and in this article.

Data analysis

The data were analyzed using thematic analysis (TA).³⁸ TA is a six-step qualitative analysis that is widely used in health research. It aligns well with the philosophical hermeneutic approach, as the data are interpreted via a dialectic process between the researcher and the data.^{33,38} Following the six steps of TA³⁸, we familiarized ourselves with the data (step 1). Then, the first author re-read and coded each interview (step 2) using the software Hyper Research³⁹, which facilitated the subsequent organization and grouping of the codes and the respective data extracts into themes (step 3). The first author discussed the work with the co-authors, who coded several interviews for joint analysis. Moving forth and back in the hermeneutic circle of pre-understanding and understanding, the authors continuously re-immersed themselves in the data material, placing the data in context and reviewing and refining the themes (step 4), so that they could capture the meaning of the experiences. The process continued until a consensus was reached for all of the findings. Finally, one overarching topic and three major themes were defined and named, all of which were considered to capture the experience of being a CC in Norway (step 5). These findings are presented in the following (step 6).

Findings

The analysis showed that all CCs shared a common vision for their role and its intention, from which ‘providing coordinated cancer care’ emerged as an overarching topic. The CCs highlighted that their role had a dual focus: while the facilitation of coordinated services was deemed vital for patient support, the CCs perceived the provision of individual cancer care as being of equal importance. This is captured in the following quote:

Making the system run smoothly. (...) Being a link (...) between general practitioners, specialized services and the municipality... [Coordinating and facilitating] the day-to-day lives of cancer patients and their next-of-kin in the best possible way. (CC23)

As the quote indicates, CCs perceived this overarching topic as being multifaceted and saw there to be multiple tasks associated with their role. Rather than embracing all of them, generally, CCs engaged in those tasks that were most relevant for their particular municipalities. We therefore found great contrasts in the performance of the CC role. However, three core themes emerged from the analysis: (1) finding their place and creating their function; (2) meeting the needs of patients and helping them to cope and (3) promoting well-functioning cancer care systems. Some themes were developed using sub-themes, both of which are presented in the following.

Theme 1: Finding their place and creating their function

As the role of CC is new to the Norwegian primary health care system, all of the CCs underwent the experience of encountering a new and unknown function, which most of them had to create themselves. The analysis showed that the process of implementing these roles had been impacted by the municipalities’ contextual frameworks. Important factors included the local infrastructure and cancer care expertise, alongside the degree of support and guidance provided to CCs by the municipal management to carry out this role. However, only a few CCs were part of a network or followed a specific practice. Most CCs described establishing their position to be a surprisingly lonely, self-sufficient and demanding task, particularly in the first year.

This is pioneering work. No one [in the management] had given much thought about what this was supposed to be. (...) It was starting from scratch. (CC3)

Hence, CCs spent a lot of time identifying the ways in which their role might best serve their municipality, and, subsequently, campaigning to promote it using leaflets, websites or other media. All of the CCs emphasized that promoting their function was highly important for connecting with cooperative partners and for ensuring that their role was implemented effectively. Overall, CCs perceived the implementation of their role to be an unexpected and time-consuming task, reducing their capacity to work towards other cancer care related tasks.

Theme 2: Meeting the needs of cancer patients and helping them to cope

A substantial finding was that work focusing on the patient was a major part of the CCs' role. Here, the CCs commonly agreed that their role aimed to 'meet the needs of patients and help them to cope'. In this regard, the CCs described a wide range of distinct issues and tasks to engage in.

It is a very, very comprehensive area. (...) We are supposed to cover all cancer patients at all stages of the disease [and] their next-of-kin... [This includes] rehabilitation, end-of-life care [and] children as next-of-kin. (CC5)

Despite the differences that resulted from operationalizing this patient-focused work, the analysis showed that 'meeting the needs of patients and helping them to cope' embraced three common subthemes: (1) mapping the entire situation; (2) providing psychosocial support and (3) providing practical support and access to the appropriate services. These subthemes are presented below.

Subtheme 1: Mapping the entire situation

In order to meet the needs of patients, all of the CCs assigned importance to engaging in an initial conversation, through which they mapped each patient's entire situation to get an overview of their circumstances. Many CCs stated that the patients were relieved and grateful to be spoken and listened to in their often overwhelming situation. All of the CCs took a holistic approach to supporting their patients, with consideration given to both their physical and psychosocial needs. Many CCs visited the patients at home to observe them in their daily lives.

Visiting the patient at home [...] is time [worth] investing, because it is easier, in a way, to coordinate [local services] when I have [...] seen what [their needs are]. (CC4)

Having a holistic nursing focus. [That means] you cannot just focus on the physical [issues], you have to consider the psychological and the social [issues]. (CC18)

Mapping the entire situation also included the patients' next-of-kin. Most of the CCs were surprised by the high number of next-of-kin who also needed support. Often, the next-of-kin were the patients' primary caregivers, and themselves needed someone to turn to for a range of unmet support needs and with whom to share their perceived burden. Hence, next-of-kin support was an unexpectedly important task for the CCs.

I did not expect [there] to be so much interaction with next-of-kin. I [have] many conversations (...) with next-of-kin. (...) So ... a lot of work with [them]. (CC5)

In any case, most of the CCs found it difficult to estimate the specific number of patients they supported, as the numbers could vary greatly over time. Furthermore, the lack of instructions for assessment meant that it was a challenge for CCs to decide if they should register their patients on a weekly, monthly or annual basis, or whether or not to include phone-calls and next-of-kin support. However, it seemed like those CCs working in smaller municipalities allocated most of their time to personal interaction with a limited number of patients and their next-of-kin. CCs in bigger municipalities, however, were in charge of more patients and focused on connecting them with local professionals and services in order to provide them with the necessary support.

Subtheme 2: Providing psychosocial support

The CCs expressed the view that the patients' psychosocial needs were distinct and complex, and included fears related to death or the future, issues of identity loss or problems related to family, partners and peers. Thus, the CCs provided psychosocial support, helping their patients to process difficult emotional states and come to terms with their situation.

I see that what we talk about creates reflection (...) and they move forward. (CC2)

The regularity and quantity of follow-up varied depending on each CCs' capacity and the needs of the patients. All of the CCs aimed to promote self-management and autonomy in

their patients by helping them to focus on goals and opportunities that were within their grasp, as well as to utilize their coping resources.

One of my main tasks is to teach the patient and their family to help themselves to cope with their everyday [lives) (...) I do this by helping them to access their [own] coping strategies (...) I am a supporter, but not necessarily the performer. (CC2)

Subtheme 3: Providing practical support and access to appropriate services

The third subtheme was ‘providing practical support and access to the appropriate services’. Particularly in the early stages of treatment, the provision of information and the coordination of health services seemed to have a noteworthy influence on patients’ self-reliance. While some patients mostly needed support early in their treatment, other patients had complex, continuous support needs throughout their cancer pathways. The tasks of individual CCs in terms of practical support were thus multifaceted and varied broadly.

It is extremely individual, what a single person needs help with. (...) There are many factors [involved in making their lives proceed] smoothly again. (CC9)

The practical support needs of patients included providing access to assistive and medical supplies as well as guidance on nutrition, physical activity, rehabilitation and legal and financial matters. Some CCs carried out nursing tasks such as wound care or inserting central venous catheters, but most CCs clearly excluded such tasks from their role. Depending on the contextual frameworks of their municipality, each CC’s provision of practical support differed in terms of whether they undertook these particular tasks themselves or acted as mediators by linking up patients with professionals and revealing shortcomings in care pathways.

Theme 3: Promoting well-functioning cancer care systems

The analysis revealed ‘promoting well-functioning cancer care systems’ to be the third main theme, embracing system-level work to provide patients with coordinated cancer care. This was perceived to be a complex task involving numerous actors, sectors and services, all of which need to be aligned to ensure the high quality of cancer care throughout the treatment process.

The goal is [to provide the] best possible cancer care. (...) Good systems in municipalities (...) where tasks are [performed] equally [and not according to] who is at work. (CC21)

In line with their accounts of working with patients, CCs described their engagement with system-level work as being influenced by the frameworks provided by the municipalities. Accordingly, only those CCs working in larger or in multiple, rural municipalities functioned on a primarily administrative level, coordinating services and actors across sectors. Most of the CCs, however, described carrying out service coordination duties in terms of individual case management. In any case, the analysis showed that most CCs focused on two subtopics when working on a systemic level: (1) filling system gaps and (2) fostering collaboration.

Subtheme 1: Filling system gaps

All of the CCs described the filling of system gaps in care pathways as being a main priority of their system-level work. This task was extensive and left little room for larger-scale system work.

[It was] a lot of firefighting. (...) I could get a call and then I was expected to march out and fix it. (...) There was not enough time for system work and coordination and contact with cooperating partners! (CC25)

Additionally, the CCs forwarded their patients' needs to the system level to promote local system improvements or services that facilitated their patients' ability to cope. Challenged by limited local budgets, the CCs took a proactive approach to mobilizing or optimizing existing resources in order to fill service gaps. Several CCs cooperated with grassroots organizations to expand the local service offer, e.g., by establishing cafés for cancer patients. They further advocated for the local offer provided to other groups of patients, such as meeting points, walking groups or other common activities, to include cancer patients as well.

We could benefit from (...) existing resources (...), have them include cancer patients, too. [Like] the health center [or daytime] rehabilitation. (CC17)

In terms of filling system gaps, the CCs particularly focused on reaching out to patients who did not receive any follow-up in their municipality after being treated in the hospital. These were patients who might not require any particular health service, such as physiotherapy or

support from the home care team. However, because they were not linked to the system in any way, CCs were less likely to reach out to these patients.

My greatest challenge as a CC is to detect those outside the health care system. This is difficult. (...) It is easy to contact those who use home care services. (CC5)

Many of the CCs highlighted gaps in the system in areas such as rehabilitation, transferring patients between locations and palliative care. Most of the CCs targeted their activities towards improving palliative care in their municipalities. These CCs perceived that local professionals were lacking in sufficient resources or skills to meet these patients' comprehensive needs. Accordingly, several of the CCs engaged in promoting routines, competency building, education and supervision to support professionals in palliative caregiving.

I tutor health professionals (...) [who] feel insecure about (...) complicated cases (...) [We] discuss the situation and [I] supervise [them] in [the patient's] home. (CC13)

Subtheme 2: Fostering collaboration

All of the CCs viewed the fostering of existing collaborations to be an essential part of their system-level work. However, in all of the CCs' experiences, coordinating services across sectors was a complex task that often involved a range of disconnected actors. As many municipalities lacked strong, professional cancer care networks, most of the CCs were involved with the creation or strengthening of networks, as well as establishing common goals and procedures. This served to enhance the expertise of professionals and to create common quality standards, in order to provide secure local settings for the patients.

I work (...) with routines between the hospital and municipal services. (...) [Patients may] feel very insecure, (...) because they have no [professional] network at home. (CC13)

Thus, the CCs acted as mediators, creating a dialogue between actors in order to prevent partitioned or duplicate examinations. The CCs' common goal in the promotion of well-functioning systems was to ensure seamless services for patients throughout their pathways.

The most important thing is (...) to mobilize and align the necessary services, so that [cancer patients'] pathways become as smooth (...) as possible. (CC4)

Discussion

To our knowledge, this is the first study to explore how Norwegian CCs experience their role and how they act to facilitate coordinated cancer care in their municipalities. The findings illuminate that the role of a CC appears complex and multifaceted, and has evolved in accordance with the Cancer Society's broad vision for the CCs. In any case, all of the CCs emphasized that their total workload would not allow them to carry out all of the features that the role had the potential to embody. Hence, the evolution of the CC role has been diverse, adjusting to the distinct contextual frameworks of their municipalities. However, the analysis shows that all of the CCs regarded 'providing coordinated cancer care' as an overarching topic describing their role, elaborating on this via three core themes: (1) finding their place and creating their function; (2) meeting the needs of patients and helping them to cope and (3) promoting well-functioning cancer care systems. In the following, these findings are discussed in the light of previous studies and of the salutogenic theory.

Finding their place and creating their function

The findings show that most of the CCs had to establish their role themselves, as no job description or designated practice existed for the establishment of CCs. This was depicted as unexpected and time-consuming work in itself, as most of the CCs lacked guidance from the municipal management. Many of the CCs felt alone in a pioneering position and the need for better cooperation with professionals, who frequently did not understand the role of a CC. In a similar way, Walsh et al.⁵ found that coordinators struggled with a lack of recognition of their role from other professionals. As a result, the CCs in the present study engaged heavily in the promoting their work and in professional networking. However, these tasks limited the time they would otherwise have dedicated to patient-focused or system-level work. Likewise, Kelly et al.⁴⁰ found that the organization of multidisciplinary teams placed additional strain on nurse specialists, impeding their capacity to engage in service provision. The present findings, supported by the literature^{6,13,22}, suggest that the municipal management needs to facilitate

local working conditions that will help CCs to carry out their tasks effectively, e.g., through training and supporting CCs to implement their functions and to establish collaborations.

Meeting the needs of cancer patients and helping them to cope

Most of the CCs stated that direct patient work was a major part of their role. All of them emphasized the importance of conducting holistic initial assessments, considering their patients' physical and psychosocial support needs to subsequently provide them with the necessary support. This research underlines the fact that the support needs of patients exceed treatment-related aspects, and suggests an initial assessment which takes the patients' wider life context into consideration, so as to facilitate adequate support for the patients.⁴¹⁻⁴⁴

Mirroring national and international evaluations^{14,17,18}, the findings show that many of the CCs spent a great deal of time providing psychosocial support, information and expert advice, as well engaging as consultants, in order to support both the patients and their next of kin in coping with their situation. Like other professionals in coordinating roles²⁴, our participants placed an emphasis on encouraging patients to focus on decision-making, goals, opportunities and coping resources. This emphasis on resources demonstrates how CCs have been working in according to a salutogenic perspective. The literature suggests that a salutogenic orientation in professionals' dialogues with patients can contribute towards enhancing the patients' quality of life and decreasing their psychological distress.^{30,45}

According to our participants, the holistic support they provided included a surprisingly high amount of work with next-of-kin, who often struggled with their own unmet support needs. The findings, supported by the literature^{19,23}, underline that focusing on the family is essential for health services and professionals working in cancer care.

However, this comprehensive approach to working directly with patients also presented a challenge to the CCs in terms of the scope of their role. When undertaking home visits to observe and support patients and their families, some of the CCs felt obliged to carry out nursing tasks when required, something that reflects the findings of a recent national report.¹⁵ Supported by previous research¹⁸, the CCs in this study stated that performing such care tasks could reinforce the poor external understanding of their role, lead to diversion from their

intended tasks and duplicate other nursing roles in the municipality. Thus, there seems to be a need for a clear demarcation between the role of CC and, e.g., cancer nurses.^{13,18}

In line with existing knowledge^{18,21}, the CCs experienced that meeting the practical support needs of patients was another vital aspect of their role. This was particularly important in the early stages of treatment, as information, access to medical and assistive devices and support concerning financial and work-related matters are all vital in helping patients to comprehend and adapt to their situation. Supported by other studies^{21,41}, the findings suggest that the CCs play an important role in facilitating patient contact with the health system, by acting as an expert consultant to support patients to orient themselves and navigate their cancer pathways. The findings indicate that the CCs acted according to a salutogenic perspective, as their support with the cognitive, emotional, physical or material aspects of cancer care may help patients to cope.^{28,45} Resources and positive coping experiences can, in turn, enhance patients' know-how and confidence in handling demands they are faced with (a high sense of coherence). This can help them to pro-actively address the upcoming challenges of their care pathways.^{25,30} Research shows that navigators can enhance their patients' sense of coherence and coping abilities, which in turn may prevent the risk of adverse effects and unnecessary hospitalization.^{21,24,30}

Promoting well-functioning cancer care systems

The CCs specified that working on a systemic level was another major aspect of their role. In line with the literature^{16,17}, the CCs particularly worked to promote local multidisciplinary networks, procedures and competence building. Similarly, previous research shows that multidisciplinary teams are important to improve the coordination of services, referral processes and treatment planning.⁴⁶ Despite limited local budgets, the CCs worked to enhance services for patients by using local resources and networks. These findings indicate that the CCs took a salutogenic approach to system-level tasks, as they shifted their focus from resource limitations to the discovery of local solutions for improving cancer care. Evidence^{24,48} suggests that having a resource-orientated focus can increase the opportunities of professionals to facilitate local services and support for the improvement of patient health.

In correspondence with the literature^{6,18,40}, the findings showed that the CCs' were overloaded with work as they attempted to both work with patients and with the system, indicating a need

to narrow their work scope. Here, the size of the municipality seemed to play a vital role in shaping the CCs' function. CCs working in larger municipalities or across multiple municipalities seemed to have a strong system focus, while CCs in medium-sized or small municipalities described system work in relation to individual case management. Coordinators elsewhere⁶ had a similar approach to system-level assignments, focusing predominantly on managing individual cases, forwarding information in the system and raising the awareness of other professionals to the needs of their patients. The flexibility of the CC role seems to benefit CCs in adjusting to local conditions.^{14,17,18} However, this can also limit them from realizing the full potential of their role, if municipalities do not facilitate and support their integration into the system.^{6,17} The findings, supported by the literature^{6,17,24}, suggest that municipalities should more provide support for CCs and involve them in larger-scale work within the system, while preserving their flexibility to adapt to local needs.

Underpinning previous research⁴⁴, the CCs saw the improvement of palliative cancer care as a high priority, as this group of patients was regarded as having the most complex and unmet needs. Often, these needs exceed the scope of what municipalities can provide in terms of competency or resources.^{44,47} Thus, the CCs engaged in educating professionals, supporting them to collaborate with one another and manage complex palliative care cases. CCs underscored local curative care and rehabilitation as areas that remain inadequately covered, most likely due to a lack of local knowledge or resources to target each stage of the cancer pathway equally.^{16,46}

Limitations and trustworthiness of the study

All qualitative research is impacted by a certain degree of subjectivity.³³ To enhance the credibility of the study, we thoroughly engaged with the literature and conducted an interview with an expert to prepare the interview questions. Furthermore, we reflected on our presumptions, both separately and jointly, and critically discussed each step in the research process. Our distinct backgrounds enhanced our awareness of our preconceptions.^{33,34} A characteristic of in-depth exploration of individual experiences is that the external validity of the findings is difficult to assess.³⁴ However, our heterogeneous study sample may be to our advantage, as the findings provide a detailed account of the role of a CC, reflecting the variations in the evolution of the Norwegian CC role.

Clinical implications and recommendations for future research

The findings suggest that CCs seem to have an important role in providing patients with coordinated cancer care. The findings reinforce the call for health professionals to take a holistic approach to addressing the needs of patients and to support patients and their families to cope with their situation. In so doing, individual assessments and supportive dialogues are proposed as important tools. The findings also indicate a stronger emphasis on the inclusion of next-of-kin in cancer care, as they seem to have distinct and unmet support needs. The findings indicate that a salutogenic approach to resources and opportunities may provide an important framework to improve patient-centered services. Appropriate support for establishing the CC role and a specific job description both seem to be vital. Local training, tutoring and follow-up for CCs, as well as better integrating them into local multidisciplinary teams, appear to be important factors for the establishment and enactment of the CC role. However, there is a need for more research into the factors facilitating and hindering the implementation of the CC role, as well as on opportunities to fulfil their full potential.

Conclusion

CCs in Norway offer holistic local support to patients by addressing both the patients' individual needs and coordinating their care on a systemic level. The Norwegian CC role seems to be characterized by its diversity and includes multifaceted work tasks, influenced by the contextual frameworks of the distinct municipalities they work under. The uniqueness of the role lies in the CCs' autonomy in determining the ways in which they can best support patients and next-of-kin in their municipalities. The flexibility to adapt to local frameworks can further benefit cross-sectoral collaboration and strengthen local cancer care systems. However, this also challenges CCs as their role lacks external understanding and their role is accompanied by a high workload. CCs experience the need to narrow the broad range of potential tasks and to define priority areas in which to engage. Most CCs seem to perceive individual case management to be a main priority, partly due to limited opportunities for them to engage in larger scale work within the system. This indicates the need for the municipal management to provide stronger support to safeguard the required frameworks for implementing and promoting the CC role, including embedding it in local systems and networks.

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Tables

Table 1: The Cancer Society's Guidelines and Examples of Work Tasks for Norwegian Cancer Coordinators

Guidelines and examples of work tasks for Norwegian Cancer Coordinators

CC shall have an overview over:

- all cancer patients in the municipality
- relevant offers and services in the municipality
- patient associations and volunteers and collaborate with them

CC shall disseminate and promote their function through:

- leaflets and information on the municipality's home page.
- visibility and accessibility to persons affected by cancer and their next-of-kin
- visibility and accessibility to the specialized health services
- collaboration with the local general practitioners, cancer nurses and the patient coordinator in hospitals

CC shall have a patient-directed function, including:

- advice and guidance for patients and relatives on matters related to the diagnosis, treatment, rehabilitation, palliative and terminal care
- individual case management
- follow-up of children and young next-of-kin
- establishing good routines for contact with and follow-up of bereaved

CC shall have a system-level function, including

- implementing routines for cooperation and interaction within the municipality and across sectors, e.g. procedures, check lists or patient transfer between primary and specialized care
- competence building in the municipalities, such as information, education and supervision of health care professionals and other relevant agencies in the municipality
- periodic collaboration meetings with resource nurses and general practitioners and with health professionals in the hospitals
- implementing routines for interdisciplinary and cross-sectoral work.
- provide feedback on what works and does not work in the health system

Table 2: Overview of the Study Sample

| Variables | Study sample (% of study sample) | Average (range) |
|--|---|----------------------------|
| Age | - | 48 (27-62) |
| Gender | | |
| Female | 25 (96%) | |
| Male | 1 (4%) | |
| Profession | | |
| Nurse | 25 (96%) | |
| Additional specialization as a cancer nurse | 21 (81%) | |
| Additional specialization in palliative care | 2 (8%) | |
| Other than nurse | 1 (4%) | |
| Full-time equivalent | | |
| Full time (100%) | 15 (58%) | |
| Part-time (50%) | 11 (42%) | |
| Year of employment | | |
| 2012 | 15 (58%) | |
| 2013 | 5 (19%) | |
| 2014 | 6 (23%) | |
| Administrative organization in the municipality (placement) | | |
| Health care (e.g. elderly center) | 14 (54%) | |
| Administration (e.g. service office) | 8 (31%) | |
| Specialized services (e.g. local hospital) | 3 (12%) | |
| Inter-municipal (e.g. commuting between municipalities) | 1 (4%) | |
| Municipalities covered | | |
| In total | 45 - | |
| Single municipality / district | 21 (81%) | |
| Two or more | 5 (19%) | |
| Inhabitants covered | 1.190.129 | 45774 (6163 – 267960) |

Table 3: The Semi-Structured Interview Guide

Semi-structured interview guide

Main questions:

1. Can you please tell me about your background and your position as CC in your municipality?

Follow-up questions: What is your profession, and what is your prior work experience?
How large is your municipality, and how many patients do you work with?
What is your full-time equivalent?
When was the CC position established in your municipality, and what was the goal?
Where has your position been organized and where is your workspace located in your municipality?

2. Can you please tell me about the process of becoming established as a CC?

Follow-up questions: Could you please elaborate on your experiences with difficulties and supportive factors in becoming established?

3. How does a typical workweek look like for you? What tasks do you engage in?

Follow-up questions: Would you please elaborate on patient-directed work and system-work?

4. Can you please tell me about your experiences of cooperating with other professionals?

Follow-up questions: Could you please elaborate on your experiences with difficulties and supportive factors in cooperating with other professionals?
Could you please tell me about the ways in which cooperation takes place? (e.g. routines, procedures, agreements, meetings)

5. Based on you experience, what do you think is the primary role of CC in local cancer care?

Follow-up questions: To what extend and in what way have you been able to improve coordination and tailoring of services for patients in your municipality?
What tasks do *not* belong to working as a CC?
What are your visions and future goals regarding your work as CC?

6. Is there anything you think of as important regarding the CC position that you would like to add?

Appendix II: Paper II

“From challenges to resources”. A qualitative study of cancer coordinators’ experiences with barriers and facilitators for enacting their system-focused tasks

Abstract

Background: Cancer coordinators (CCs) operate at both patient- and system level in order to provide patients with tailored and coordinated services. In common with international CCs, Norwegian CCs denote notable progress in their patient-focused work, while reporting ongoing challenges in carrying out system-focused tasks. However, little is known about the barriers and facilitators for CCs' system-level work.

Objective: To explore Norwegian CCs' experiences of barriers and facilitators for enacting system-focused tasks.

Methods: The study applies a qualitative method, conducting an interpretative data inquiry of semi-structured in-depth interviews with 26 Norwegian CCs. The data were analyzed using thematic analysis, and discussed in light of previous research and salutogenic theory.

Results: The analyses revealed three main themes: (1) 'Understanding the role and local cancer care', (2) 'Systems for care delivery in primary health care', and (3) 'Commitment to collaboration'. Where present, the themes could represent important facilitators, while their absence could depict notable challenges to CCs system-focused work. Over time, as CCs were able to mobilize resources, they were able to gradually turn initial challenges into facilitators in the context of system-level work.

Conclusions: CCs encounter cognitive, practical and relational topics that impact their system-focused activities. Adopting a salutogenic focus can help CCs mobilized resources needed to turn challenges into facilitators for system-level work.

Implications for practice: Cancer care coordination cannot be undertaken by CCs alone. CCs' embedding in multidisciplinary teams, common systems for care provision, meaningful work relations and professionals' commitment to cancer care represent important facilitators for CCs' system-focused tasks.

Introduction

Cancer can be a complex disease and its treatment can require a broad range of multidisciplinary actors and services.¹⁻³ To meet the growing need for patient-centered, coordinated cancer care, professionals in a navigating function have been introduced in several countries.⁴⁻⁹ In Norway, the role, which is a novel part of primary health care services, is referred to as cancer coordinator (CC).¹⁰⁻¹⁴ In line with existing functions elsewhere, Norwegian CCs adopt a dual work focus, including both patient- and system-oriented tasks to help cancer patients overcome barriers to coordinated care.^{2,3,6,12} To date, CCs in Norway and other countries denote notable progress in terms of their patient-focused work, while reporting ongoing challenges in carrying out system-level aspects of their role.^{4,5,13} In response to calls for more research into the CC role, this study explores CCs' experiences of barriers and facilitators for their system-focused tasks. Such insights can provide valuable information for achieving coordinated care with the help of CCs.^{2,3}

Previous research

Professionals in navigating functions have been established on an international basis, interchangeably referred to as coordinators, navigators or similar terms.^{4,6-9,15} To facilitate adequate actions in the different settings, most CC positions are context-bound and characterized by a flexibility to adapt the role and its tasks to the needs of the local setting.^{3,12} In Norway, the establishment of CCs has been initiated by the Cancer Society, providing municipalities with funding for up to 75% of the wages of CCs in primary health care over a period of one to four years.^{10,12} The underlying idea for Norwegian CCs aligns with the vision for existing functions elsewhere and aims to provide patients and municipalities with a resource to support a better tailoring and coordination of cancer care trajectories across sectors and disciplines.^{4,6,7,12} However, nationally and internationally, no standard definition exists for the role. Hence, CCs have to find their place among various actors in cancer care and determine adequate ways to operate in their particular context.^{3,13} This has given rise to great differences in how CCs enact their role, and a widespread request for research into the CC role in order to enhance understanding of the role.^{5,7,12}

This paper is the second study of a larger research project investigating the CC role in the context of Norwegian primary health care. The findings from the first study¹⁶ brought to light

that, while CCs reported notable progress in their patient-focused work, most of them outlined system-focused tasks to be sidetracked and challenging to carry out. International literature identifies similar challenges in the achievement of CCs system-focused tasks, indicating, among others, difficulties concerning external role comprehension and collaboration with professionals.^{5,7,12} CCs may be contested in achieving coordinated care across sectors, especially when actors are not used to collaborating.^{2,17} In turn, CCs who succeed in operating at the system level are acknowledged as a vital resource in cancer care among other professionals.^{4,14} However, current knowledge of contextual factors that impact CCs in achieving the full potential of their function remains scant.^{2,3,18} To fill this research gap, this study explores CCs' perceived barriers and facilitators for their system-focused tasks.

Theoretical background

This study applies Salutogenesis as a theoretical framework to discuss the findings. The salutogenic theory, coined by Aaron Antonovsky^{19,20}, is best known as a framework for investigating resources that individuals apply in order to constructively cope and stay healthy under challenging circumstances. However, researchers have emphasized the transferability of the framework to the system level in order to explore factors that affect e.g. community-based or organizational health.²¹⁻²⁴ In this context, health is viewed in terms of the productivity or output of a setting and the well-being of its actors.²⁵ Salutogenesis supplies a problem-oriented approach to organizational health with a focus on resources in interventions or systems.^{22,25} The resources are termed general resistant resources (GRRs), which can be any internal or external factors that enable a constructive approach to managing stress-causing events.^{19,20} Knowledge, experience, money, support and traditions are examples of GRRs.²² GRRs can enhance comprehensibility, manageability and meaningfulness of a situation. Comprehensibility is “the extent to which one perceives the stimuli that confront one (...) as making cognitive sense, as information that is ordered, consistent, structured, and clear”.^{20, pp.16-17} Manageability describes a perception of that “resources are at one’s disposal that are adequate to meet the demands posed by stimuli that bombard one”.^{20, p.17} Meaningfulness is a notion of that demands are “worth investing energy in, are worthy of commitment and engagement”.^{20, p.17} These three components deploy a sense of coherence (SOC), a perceived consistency of demands and resources that can enable coping.^{19,20} The SOC is the personal or collective driving force to utilize the given resources to achieve positive outcomes.^{26,27} In

turn, general resource deficits (GRDs) can result in adverse reactions to stress and negative health outcomes, and hinder a positive development.²⁸ In this study, the framework is used to explore CCs' experiences of barriers and facilitators in their system-focused tasks.

Study aim

This study aims to identify which factors Norwegian CCs perceive as affecting them in carrying out system-level work to deliver coordinated care. It addresses the research question: “What do CCs experience as barriers and facilitators for operationalizing system-focused tasks?”

Method

The present study applies a qualitative method, by carrying out an interpretative data inquiry inspired by the work of Gadamer.^{29,30} Taking the ontological stance that no single independent truth about a phenomenon exists, understanding is generated by a dialectical process, which is also referred to as a hermeneutic circle. The hermeneutic circle is entered via a dialogue, in which the informants' accounts and the investigators' interpretations constantly interact and compare, until the different horizons merge into a shared, co-constructed understanding of reality.^{30,31} Such a constructivist epistemology anticipates that interpretations are affected by historical and cultural context, subjective experiences and prior knowledge.²⁹ However, methodological rigor can be ensured when accounting for how pre-understandings have influenced the analytical process.³² All of the present authors have prior experience with qualitative health research. The first author is educated in health promotion and psychology, the second author has a background in sociology, and the third author has a background in cancer nursing. This has yielded diverse perspectives and discussion, and helped us pursue a reflexive process regarding our pre-understandings in order to approach the phenomenon faithfully.^{32,33}

Sampling procedure and informants

Based on the inclusion criterion ‘being a Cancer Society-funded CC in Norway’, we conducted purposeful maximum variation sampling³², aiming to recruit a diverse sample with regard to CCs professional background, terms of employment, age and gender, as well as

demographic variables of their municipalities. The sampling procedure was informed by a prior mapping of the whole population (n=130 CCs), through which relevant information was systematically collected from the websites of the Norwegian Cancer Society, the websites of the Norwegian municipalities and Statistics Norway.^{15,34} The first author contacted the selected CCs via email with study information and an invitation to participate. All approached CCs gave their consent and were subsequently contacted by telephone to discuss further details and set an interview date. The sampling procedure was finalized when the range of the aforementioned variables was covered by the CCs in the study sample, and has also been described in the first study of this research project.³⁵ The final sample included 26 Norwegian CCs. [Table 1]

Interview procedure

The first author conducted qualitative interviews with the informants. Eighteen face-to-face interviews were undertaken at the CCs' workplaces, while a further eight interviews were conducted by telephone due to long distances. The interviews were semi-structured and based on an interview guide with open-ended questions. [Table 2] The questions were informed by prior research, addressing CCs' experiences in executing system-level aspects of their role. Follow-up questions aimed at encouraging the CCs to elaborate on hindering and facilitating factors as well as raise additional topics, if needed. We conducted three pilot interviews that confirmed the suitability of the interview guide. These were included into the sample. The interviews lasted 60 to 120 minutes, and were recorded and transcribed verbatim.

Ethical considerations

The Oslo and Akershus University College of Applied Sciences and the Norwegian Centre for Research Data approved the conduct of our study. The study was carried out in compliance with the Helsinki Declaration and data processing requirements.³⁶ Study participation was voluntary and based on informed and written consent from all participants. Recognizable data on the identity of CCs or municipalities were anonymized in the transcripts and remain so in this article.

Data analysis

The study applied a thematic analysis of the data as proposed by Braun and Clarke³⁷, using the NVIVO³⁹ software to aid the organization of the rich data material. The steps involved the researchers' familiarization with the data and a subsequent open coding and labelling of relevant data extracts. In an iterative process, codes were refined and organized as themes and subthemes to capture important aspects of the phenomenon. The codes and themes were reorganized and relabeled several times. This procedure continued until all researchers considered the themes and subthemes as providing a rich, consistent picture of CCs' accounts.³⁷

Findings

The analyses revealed three main themes and several subthemes that the CCs encountered in the system-focused aspects of their role. The first theme was: 'Understanding the role and local cancer care', elaborated by two subthemes: 'Clarity of the CC role' and 'Cancer-related knowledgeability of collaborating partners'. The second theme was: 'Systems for care delivery', comprising four subthemes: 'Integration of the CC role', 'Common procedures, 'Communication across sectors and disciplines' and 'Local resources'. The third theme was: 'Commitment to collaboration', including two subthemes: 'Acknowledging work relations', 'Shared ownership and responsibilities'. Instead of depicting distinct sets of challenges or facilitators, the themes could represent both. Where present, the themes could represent important facilitators for CCs' system-work. Their absence, in turn, could depict a barrier to the system-focused tasks. The analysis indicated a positive trend over time, as CCs were able to mobilize resources, which helped to gradually turn initial challenges into facilitators in the context of system-level work. The findings are presented in the following.

Theme 1: Understanding the role and local cancer care

CCs experienced the extent to which other professionals understood the CC role and patients' needs and services in local cancer care as affecting their opportunities for system-focused work. The subthemes are elaborated on in the following.

Subtheme 1a: Clarity of the CC role

The CCs delineated that a clear positioning of the CC role in cancer care was a vital prerequisite for them to carry out system-focused work. This included a clear position description and initial role orientation, so that other professionals in primary health care would understand and differentiate the role from other actors in cancer care, such as cancer nurses, home care teams or coordinators in specialist care. In a comparable way, many CCs themselves seemed to initially lack clarity concerning their intended tasks, as most municipalities had not provided them with a role description or orientation. Consequently, the CCs described that the role often was inadequately promoted in primary and specialized services, reinforcing challenges concerning role recognition.

There was a confusion (...) [among the professionals. In terms of] what she was doing, what I was doing, what the contact nurse was doing (...) we actually didn't know. CC2

To enhance clarity concerning the CC role, the CCs had to resolve which work tasks would best suit their municipality and how they could promote the role locally. However, most CCs received little management support and supervision, as well as investing much time and effort in determining and communicating their tasks to collaborating partners and the patients.

I used a lot of time (...) to develop a system of what I would do and how I would promote [the CC role]. I have a lot of knowledge now (...) that makes it easier. CC5

To orient themselves towards their work, many CCs described consulting with local professionals or other CCs as helpful. Some CCs were part of a project group or had created their own project plan with goals and tasks for their role. These CCs perceived their role to be more clearly defined, promoted and understood, and reported fewer difficulties in professional collaboration.

Subtheme 1b: Cancer-related knowledgeability of collaborating partners

The analysis revealed that local professionals' cancer-related expertise and skills affected CCs' system-focused activities. CCs perceived several actors to lack knowledge of cancer care and patients' physical, psychosocial, occupational or financial needs. This yielded

separate service provision, rather than a holistic approach to patients' bio-psycho-social needs.

I think there is little holistic thinking and too much focus on, 'You need cortisone, I'll write a prescription' (...) There is nothing more, such as: 'How are you? (...) Do you need support at home?' They leave that to others or might not even think about it. CC1

Further, many CCs regarded services across sectors to be disconnected and lacking transparency, such that professionals had little overview of patients' entire treatment course or knowledge of existing services and relevant actors involved in cancer care. Thus, CCs emphasized their efforts to train local actors via education, competence building, tutoring or guidance in procedures. Other CCs used informal arenas, e.g., lunch meetings, to facilitate knowledge exchanges.

We have [multidisciplinary] lunches (...) every second week (...) To learn what is going on in the field, what services there are. Very smart, because (...) you hear about services you didn't even know existed in the municipality and I can forward it to my patients. CC3

Theme 2: Systems for care delivery

The analysis illuminated that CCs experienced the prevailing systems for care delivery in primary health care as another major topic. This was elaborated in terms of four subthemes, presented below.

Subtheme 2a: Integration of the CC role

The analysis revealed that proper integration and visibility of the CCs' role in existing systems had a major impact on their ability to execute their system-focused tasks. Many CCs explained that the management had no planned approach to the implementation of the role. Hence, CCs described a seemingly random or unfavorable organization of the role and localization of CCs' offices, in terms of inadequate access to professional work arenas and databases. This could deter CCs from cooperating with other professionals, resulting in many CCs working in isolation. The visibility of the role in health care systems and settings was of concern regarding hospitals, as several interchanging actors needed to be informed and reminded of involving CCs in their work.

The bigger the hospital, the more difficult it gets. Because so many are involved (...) [They don't] always contact us when releasing patients who may need to see us. CC13

As CCs perceived themselves to have little influence on IT systems, many of them focused on other ways to improve the integration of their role, e.g., by adding their details to contact lists for staff in specialized and primary services. Several CCs had their office relocated to facilitate better access to and availability for e.g. home care teams, administration staff, general practitioners, or nurses. This helped to enhance their visibility and interaction with other professionals.

Subtheme 2b: Common procedures in cancer care

The CCs highlighted that routines for cooperation as well as common standards and procedures in cancer care across sectors had notable impact on their ability to carry out system-focused tasks. Several CCs explained that professionals could struggle with adopting and sustaining new routines in their often hectic workdays. In addition, many professionals were used to working via case-to-case approaches, rather than standardized care procedures.

Everyone has distinct approaches (...) and the information provided often differs. CC4

However, several CCs were aware that more systematic professional collaboration and common care procedures across sectors could be facilitated via standardized tools, e.g., checklists, written procedures or training, which supported establishing, conducting and maintaining new routines.

We developed a standard trajectory, with checklists, to provide comprehensive care to the patients (...) [such as] routines for collaboration (...) and knowledge dissemination. CC21

Subtheme 2c: Communication across sectors and disciplines

While communication systems across sectors and disciplines were outlined as an important feature of system-focused work, most CCs pointed out a lack of meeting points and shared electronic systems. This hampered information exchanges within primary health care and across sectors, mostly regarding patient transfers from hospital to the municipalities.

Various epicrisis signed by different doctors (...) Verbal transferals (...) The hospital thinks the general practitioner follows up (...) but he has not received an update (...) They don't communicate, as they don't have a shared electronic journal system. CC4

To improve cross-sectoral communication, most CCs are engaged in regular contact and information exchanges with relevant actors, e.g., via emails or by telephone, visiting them at work, joining existing network groups or establishing multidisciplinary teams. However, narrow time frames or significant distances could impact CCs' ability to gather all professionals together.

We don't have a common workplace (...) so we have fixed weekly meetings (...) But, it is a hassle (...) It would be so much easier if we had a shared workspace. CC20

Subtheme 2d: Local resources in cancer care

Most CCs outlined local political commitment as well as sufficient resources and service offers in cancer care, which affected their opportunities for system-level action. Only a few CCs worked in municipalities that had established, e.g., a local or regional cancer care plan or mobilized external funding for developing local cancer care. Most CCs, however, described limited political prioritization and little available resources for cancer care. As a result, some CCs worked to increase local budgets via external funding. However, many CCs sought to better utilize the given resources, e.g., by including their patients in local offers for other patient groups. Other CCs allied with neighboring municipalities, patient associations or volunteers to enhance services.

Collaborating with others... various organizations (...) is what is needed to manage to establish [local service] offers [in cancer care] (...) Otherwise, we couldn't do it.

CC21

All CCs emphasized the embedding of their role in local structures as a crucial factor in the manageability of system-level tasks in cancer care. Most CCs had no mandate for decision-making or budgeting, while reporting very limited management support for system-level action, such as implementing routines or enhancing local services. While several CCs noted that such circumstances impeded their system-focused work, some CCs found solutions in allying themselves with local professionals, stating common action could facilitate a bottom-up implementation of routines.

We allied ourselves with general practitioners to design a common procedure, which got approved by a steering group, then got disseminated to all the departments. CC22

A few CCs pointed to increased cooperation with their management over time, which resulted in considerable support in terms of forwarding CCs' inputs at a system level.

Theme 3: Commitment to collaboration

The analysis illuminated commitment to collaboration as a third major topic. This was elaborated on by two sub-themes, presented in the following.

Subtheme 3a: Acknowledging work relations

All CCs stated that acknowledging work relations was a key factor associated with other professionals' commitment to collaborations with CCs and CCs' system-focused activities. To begin with, some CCs experienced skepticism or reluctance to accept their role among local professionals, who appeared to be protective of their fields and unwilling to change familiar routines. Other actors, in turn, seemed hesitant towards collaborating with CCs as they expected an additional workload. To overcome initial barriers, CCs worked to build up trusting interpersonal relations via an ongoing dialogue and mutual support in their interaction with professionals, in which they clarified the intention of the role as being supplementary to, rather than competing with, existing roles.

It could have been a problem if I had joined in with a new role, walking all over their work (...) So, we [discussed and] reached an agreement, and it works well. CC1

CCs also emphasized the value of multidisciplinary team meetings, giving members the opportunity to discuss cases and share competences, information and skills in a common space.

Subtheme 3b: Shared ownership and responsibilities

The CCs outlined that a perception of shared ownership and responsibilities appeared to impact professionals' formal and informal commitment to collaboration with CCs and to their activities undertaken at a system level. CCs noted a lower adherence to changes when other actors, e.g., general practitioners or health care staff in hospitals, were encouraged to adopt new routines without having taken part in their development. Therefore, CCs engaged in

collaboration with respected professionals or authority figures, e.g., head nurses or team leaders, who could propose and promote routines and a sense of commitment among health care staff in their department. Similarly, the active involvement and participation of collaborating partners, e.g., in formal networks or project groups, had a noteworthy influence on their commitment and enhanced a notion of shared ownership and responsibility, e.g., about implementing new procedures.

When things come from the bottom up, from those who enact the services (...) are they much easier [to implement] than having me imposing procedures from outside.

CC22

However, some CCs found that professionals signaled discomfort when taking on responsibilities in cancer care, as they lacked adequate expertise. Here, CCs' engagement in education, tutoring or common procedures could help to motivate and secure professionals in providing cancer care.

I have the competence, maybe, that is needed to secure (...) health personnel. Providing [them with] information and skills, so that they feel more secure in a situation with cancer patients. Because, when you feel insecure about something, you avoid it.

Discussion

The analysis revealed three main themes and several sub-themes affecting CCs in undertaking system-focused work. The subthemes could both present facilitators, and, if missing, barriers to CCs' system-focused activities. The main findings will be discussed considering Salutogenesis and prior research.

Understanding the role and local cancer care

The CCs in the current study emphasized that the clarity of their role was a vital factor that impacted their system-focused tasks. However, most CCs stated that they had received inadequate role orientation and management support, and had struggled with defining and communicating the scope of their role. Similarly, the literature^{4,5,12} indicates that an inadequate description and promotion of the CC role can pose ongoing challenges to the external role recognition. To enhance clarity of the role, our participants engaged in regular

contact with other CCs or local actors to clarify and promote their role within the professional field. This was identified as the most common form of role orientation overseas⁷ and suggested as a means by which to raise external awareness of the CC role.⁵ However, our participants indicated the need for a systematic approach and management support to define and promote their role.

This study also identified health professionals' specialized expertise, familiarity with services in cancer care, and patients' complex needs as other vital comprehensibility aspects that affected CCs system-focused work. Thus, CCs concentrated on training local professionals, which has helped to educate and raise awareness of services in cancer teams overseas^{5,8} and can enhance health professionals' cancer-care related knowledgeability.²⁶ However, competence building is time-consuming and may limit CCs' capacity to engage in other aspects of their role.⁵ From a salutogenic perspective, the present theme and its sub-themes can be viewed as cognitive features, thus, the comprehensibility component influencing the ability of CCs and their co-workers to facilitate positive developments within local systems for cancer care. Considering this, the subthemes could depict important resources (GRRs) or resource deficits (GRDs) that impact CCs in their system focused work. Consequently, it may be suggested that providing adequate resources that can enhance the group-level comprehensibility of CCs' role and cancer care may facilitate CCs' system-focused activities. In particular, our study suggests a need for better support for CCs, e.g., from the management, as important GRRs to enhance role clarity and professionals' knowledgeability of cancer care. Overseas, the responsibility for clarifying the CC role and training local professionals has been assigned to a cancer network⁸, a national nurse lead⁴⁰ or a head nurse⁸, who has been shown to enhance personal and collective comprehensibility of professionals' work elsewhere.²⁶ Other support for CCs could include the provision of an implementation toolkit, or placing the state in charge of developing and offering educational programs for professionals in cancer care, as proposed in the US.⁹

Systems for care delivery in primary health care

The analysis showed that established systems for care delivery as a second main topic. This was elaborated in terms of the extent to which integration of the CC role had been undertaken, and the degree of common procedures, communication across sectors and disciplines, and

local resources in cancer care. From a salutogenic perspective, this theme and its subthemes could depict instrumental aspects pertaining to the manageability of executing system-focused aspects of the CC role. Most CCs outlined their role to be organized and located unfavorably to begin with, for example lacking access to professional arenas and electronic databases, forcing them to work in isolation rather than in a team. This aligns with literature on CCs elsewhere^{5,40}, and seemed to inhibit their opportunities to carry out the system-focused tasks of their role. Salutogenic research confirms that poor work frames and missing occasions to interact socially can deter the manageability of health professionals' work.²⁶ Thus, the present study suggests the need to associate CCs with networks or cancer care teams in order to support their system-level tasks.

Our participants referred to common procedures for care and collaboration as relevant factors when managing their system-focused tasks. Our findings indicate that hectic workdays and a high turnover of professionals in clinical settings could pose barriers to implementing and maintaining new routines. However, our study, supported by international surveys^{3,5,8,40}, showed that CCs were able to facilitate and support common routines across sectors by providing health care providers with training and standardized tools, e.g., for referrals, screening or care procedures. This emphasizes that cross-sectoral communication, e.g., via electronic systems, have a noteworthy influence on CCs' opportunities to carry out system-level work. Similar to CCs in New Zealand^{4,40}, Norwegian CCs are often faced with inadequate IT infrastructure and support. As the latter's opportunities to exploit IT systems seemed to be limited, most of them focused on facilitating cross-sectoral communication via multidisciplinary team meetings. Previous research^{2,3,8,41} indicates that multidisciplinary teams can support communication and service alignment among health care providers. On the other hand, it is known that organizing multidisciplinary meetings can challenge CCs in terms of additional workload, a lack of local facilities, and difficulties in ensuring the attendance of all actors.^{2,41-43}

Further, our participants suggested that local commitment and human and financial resources for cancer care affect their system-focused activities. The present study reinforces the findings reported in the literature^{2,3,8,40}, which show that CCs can be challenged by local resource shortages, poor management support and a lack of any mandate for decision-making or budgeting to enforce system-level action. Consequently, our participants were dependent on the support of local professionals to facilitate a bottom-up initiation of system-level action,

which added to their regular workload. However, a systematic literature review⁴⁴ found that resource downsizing, poor management support and demands for increased productivity could negatively affect professionals' healthcare settings. Our findings suggest that a close collaboration between CCs and their superiors can be important resources to enhance the former's (manageability of) system-focused task. From a salutogenic perspective, the practical implications outlined in this section may depict GRRs that can enhance manageability of CCs system-focused tasks. The literature^{4,26} confirms that the manageability of health professionals' working conditions can be enhanced by ongoing communication with the management. Further, municipalities are suggested to allocate or recruit adequate resources and facilities to support collaborative action, which have previously been proposed to improve the manageability of health professionals' work.^{4,7,26}

Commitment to collaboration

The current study found that other professionals' commitment to collaboration regarding CCs' system-focused work as the third major topic. This was elaborated in terms of in how far the CCs and other professionals had engaged in acknowledging work relations and adopted a notion on shared ownership and responsibilities. Through the lens of Salutogenesis, these features describe motivational aspects regarding system-focused action, associating to the meaningfulness concept in Salutogenesis. Our findings show that CCs can experience interpersonal barriers to system-focused action in cancer care, particularly in terms of a lack of buy-in and collaboration with other health professionals, such as general practitioners or long-established nurses, who could be inclined to be protective about their fields. The literature confirms that CCs could be challenged by a lack of buy-in^{2,3}, highlighting that role conflicts or imbalance can be psychosocial risk factors that may affect the outcome of interventions in a community setting.⁴⁴ To overcome these barriers, Norwegian CCs underscored creating trusting and acknowledging professional relations, which have previously benefited the work of coordinators overseas.⁴ Our findings reveal that professional work relations could be improved by facilitating an open dialogue between CCs and local professionals in order to clarify the CC role as a resource and support for local actors, as well as co-create adequate ways for collaboration. Similarly, the American Association of Critical-Care Nurses⁴⁵ emphasizes that soft issues of professional practice, e.g., true collaboration, skilled communication and meaningful recognition, can improve the quality of the work

setting, and health care practice and its outcomes. Regarding the hospital setting and busy working culture, the CCs found that building close working relations with all actors involved was almost impossible, such that alternative strategies were required to ensure commitment to new routines. Our study showed that CCs' collaboration with respected professionals, e.g., head nurses, could facilitate communication and buy-in for new working procedures in the distinct divisions. The literature on the application of Salutogenesis in organisations²¹ confirms that prevailing relationship and power structures can help to transfer planned action into practice.

Our study identified shared ownership and responsibilities as key features impacting CCs' system-level activities. The CCs highlighted that involving professionals in multidisciplinary networks or project groups could foster a sense of shared ownership and enhance professionals' commitment to system-level action. Networks can be a source for knowledge exchange, social support and belonging^{7,25,26}, which are identified as resources (GRRs)^{20,27} to increase meaningfulness and can thus enhance people's motivation to act in order to achieve positive developments (the sense of coherence) with regard to collaborative action. The literature^{7,46} confirms that integration, participation and empowerment can promote a supportive psychosocial environment. However, some of the present CCs experienced ongoing difficulties in collaborating with local actors who lacked specialized skills and appeared to be uncomfortable with becoming involved in cancer care. Thus, CCs put their efforts into competence building and linking-up of professionals for knowledge exchange and learning. Coordinators overseas^{3,5} have reported similar strategies to enhance professionals' engagement in cancer care. The literature^{44,46} suggests that participation in collaborative cultures, mutual exchange and support yield a positive attitude towards change processes and enhance professionals' occupational self-efficacy.

In line with national and international evaluations^{5,11,12,40}, our study observes that CCs experience a positive trend and better facilitation for their system-focused tasks over time. The present CCs displayed a salutogenic approach to overcoming barriers to system-level tasks as they mobilized the required assets to improve cancer care systems. The literature^{47,48} underlines that interventions with a salutogenic focus can enable self-optimization from within. In promoting strengths and resources, CCs seem to depict an example of a salutogenic intervention and may themselves be considered a GRR for achieving viable improvements in local cancer care.

Limitations and trustworthiness of the study

Qualitative research always embraces a certain degree of subjectivity.^{30,31} To ensure rigor in the present study, we have provided a detailed account of the entire research process. The authors analyzed the data independently and discussed the findings subsequently. Regular discussions stimulated ongoing awareness of own presumptions and facilitated ongoing reflexivity in each of the researchers, in order to be as faithful to the data as possible.^{31,33} The external validity of the findings from in-depth interviews is difficult to assess.³² However, our diverse sample mirrored the variety in which the CC role has evolved and facilitated rich data on their experiences.

Implications for practice

The insights gained via the present study indicate that CCs need better support or guidelines to adjust their role and services to the context of their particular setting. Municipalities are advised to take a greater responsibility for facilitating CCs' system-level tasks, including the provision of a role orientation and the adequate integration of CCs into existing systems, e.g., by facilitating their access to relevant professional settings and systems. There is a need to provide measures for increasing cancer care competences among local professionals, e.g., via seminars or courses. The establishment of local cancer care teams and regular team meetings are suggested to provide resources that will ensure professional commitment, collaboration, shared ownership, knowledge exchange and service development. It is suggested that local management considers providing adequate technologies and additional resources to safeguard communication and collaboration between CCs and other professionals across sectors. The study showed that factors influencing CCs' work could be related to comprehensibility, manageability and meaningfulness, which should be paramount when implementing the CC role in local systems.

Conclusion

The present study identified three main themes and several subthemes influencing CCs in executing their system-focused tasks. The main topics encountered by the CCs included 'Understanding the role and local cancer care', 'Systems for care delivery in primary health care' and 'Commitment to collaboration'. Considering salutogenic theory, the topics in this

study depicted central cognitive, practical and relational resources for CCs' work, whose absence, in turn, appeared to impose barriers to CCs' system-focused tasks. The insights gained through this study emphasize that cancer navigation cannot be undertaken by CCs alone. The role must be understood and established as part of a local network. Management support is required to develop a position description and promote the role to collaborating partners. System-focused work task of CCs need to be undertaken in collaboration with multidisciplinary teams, in which common systems for care provision and communication, sufficient resources, acknowledging work relations and shared ownership and responsibilities represent the pillars of local cancer care.

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List of Tables

Table 1. Overview of the study sample

| Variables | Study sample (% of study sample) |
|---|---|
| Gender | |
| Female | 25 (96%) |
| Male | 1 (4%) |
| Profession | |
| Nurse | 25 (96%) |
| Additional specialization as cancer nurse | 21 (81%) |
| Additional specialization in palliative care | 2 (8%) |
| Other than nurse | 1 (4%) |
| Worked as a CC since | |
| 2012 | 15 (58%) |
| 2013 | 5 (19%) |
| 2014 | 6 (23%) |
| Full-time equivalent | |
| Full-time (100%) | 15 (58%) |
| Part-time (50%) | 11 (42%) |
| Organization of the position (placement) | |
| Administration (e.g., service office) | 8 (31%) |
| Specialized services (e.g., local hospital) | 3 (12%) |
| Intermunicipal (commuting between municipalities) | 1 (4%) |
| Number of municipalities covered | |
| One municipality/one capital district | 21 (81%) |
| Two or more municipalities | 5 (19%) |
| | Range |
| Number of inhabitants covered | 6,163-267,960 |

Table 2. The semi-structured interview guide

| The semi-structured interview guide | |
|--|--|
| Main question | <i>Can you please tell me about your experiences of implementing the CC function and establishing collaborations with professionals in your municipality/ies?</i> |
| Follow-up questions | <p>Challenges:</p> <p>Could you please elaborate on challenges you may have perceived concerning:</p> <ul style="list-style-type: none"> - the establishment of a new position - establishing working relationships and collaboration - improving services in the municipality <p>What are challenges ahead?</p> <hr/> <p>Facilitators:</p> <p>Have you been able to solve any of the challenges described above? If so, what factors helped you to overcome the challenges you described?</p> <p>Could you please elaborate on facilitators you have experienced concerning:</p> <ul style="list-style-type: none"> - the establishment of a new position - establishing working relationships and collaboration - improving services in the municipality <p>What is possibly most needed in order to enact the function at a later stage on?</p> |

Appendix III: Paper III

“We need to focus more on cancer rehabilitation” - Experiences from Norwegian Cancer Coordinators in Primary Health Care

Abstract

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 interventions is debated and services are underutilized. Cancer coordinators (CCs) provide patients with coordinated services throughout the trajectory. Yet, little is known about CCs' rehabilitation-focused tasks. This study's objective is to explore Norwegian CCs' experiences with the delivery of rehabilitation interventions in primary health care. Data were retrieved from two focus group interviews with 12 participants, analyzed using thematic analysis and discussed in light of Salutogenesis. The analysis illuminated three themes. 1) 'A missing link to cancer rehabilitation', 2) 'Trying to put cancer rehabilitation in the spotlight, 3) 'The need to build a system for rehabilitation service delivery'. The results indicate that the CCs perceive a lacking focus on and missing systems for cancer rehabilitation in primary health care. CCs may improve local practices by advocating patients' needs and educating professionals. However, CCs must be supported, e.g. via education and training concerning system-level work, an increased local policy focus and adequate resources for cancer rehabilitation. More research is needed into how CCs may facilitate complex 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 (Harrington, Hansen, Moskowitz, Todd, & Feuerstein, 2010), 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). Still, cancer rehabilitation services are often fragmented, one-sided and poorly developed (Gamble, Gerber, Spill, & Paul, 2011; Stout et al., 2016), particularly so in primary health care (Bober et al., 2009; Faithfull, Samuel, Lemanska, Warnock, & Greenfield, 2016). Thus cancer survivors commonly report unmet rehabilitation needs (Veloso et al., 2013).

To provide cancer patients with comprehensive services, including rehabilitation, the Norwegian Cancer Society (NCS) launched 130 cancer coordinators (CCs) in primary health care. CCs cover to date almost two-thirds of the Norwegian municipalities in 2012 (Vattekar, 2015). Resembling international navigator and coordinator functions, CCs operate at both the patient- and the system-level to address barriers to care and to facilitate services and support for people affected by cancer (Monterosso, Platt, Krishnasamy, & Yates, 2011; Reigle, Campbell, & Murphy, 2017; Smith, 2016; Vattekar, 2015). Consequently the CC role has evolved diversely and embraces a very broad specter of potential tasks. However, little is known about CCs' activities regarding cancer rehabilitation in primary health care. Likewise, internationally, 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). To bridge this research gap, this paper focuses on Norwegian CCs' experiences with the delivery of complex cancer rehabilitation interventions in primary health care.

Background

Advances in knowledge of the bio-psycho-social treatment sequelae have brought along an increased demand for providing complex rehabilitation interventions throughout the cancer control continuum. (Hellbom et al., 2011; Miller et al., 2016; Veloso et al., 2013). Complex interventions typically combine elements of physical activity, nutrition, psychoeducation and goal setting, peer support and individual follow-up. Research indicates that complex

rehabilitation interventions, based on survivors' expressed support needs, have a better effect on physical functioning, fatigue, psychological distress and Quality of Life (QoL) than single approaches (Fors et al., 2011; Mewes, Steuten, Ijzerman, & van Harten, 2012; Scott et al., 2013). However, there has only been little focus on cancer rehabilitation throughout the cancer control continuum and how comprehensive rehabilitation interventions may be provided in primary health care (Bober et al., 2009; Faithfull et al., 2016, Ugolini et al., 2012).

In Norway, rehabilitation is incorporated into national policies, giving patients the right to coordinated services and an individual care plan (Helse- og omsorgsdepartementet, 2011; Hellbom et al., 2011). However, in cancer care, the responsibilities for initiation and coordination of complex rehabilitation interventions are often unclear, which can yield fragmented and poorly coordinated services in primary health care (Hellbom et al., 2011; Helsedirektoratet, 2012). Consequently, many cancer patients are at risk of missing out on rehabilitation services, reporting unmet rehabilitation needs, psychological distress and reduced QoL (Miller et al., 2016; Thorsen et al., 2011; Veloso et al., 2013).

Over the recent years, there has been a growing interest in using professionals in navigating roles to facilitate coordinated cancer care. Prior 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, Hauken, & Solvang, 2017; Monterosso et al., 2011; Smith, 2016). Accordingly, CCs may delineate one possible model to ensure the delivery of complex cancer rehabilitation interventions. However, it is poorly understood and under-researched in how far CCs utilize the role to do so. The literature underscores a need for more research into models and systems to ensure complex cancer rehabilitation in primary health care (Alfano et al., 2012; Hewitt, Greenfield, & Stovall, 2006; Miller et al., 2016). Previous research hitherto 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 (Lie, Hauken, & Solvang, 2017) has indicated that although cancer rehabilitation is incorporated into the CCs' position description, its role in CCs work appears to be marginal. Hence, there is a clear need to better understand in how far and how CCs operate to facilitate cancer rehabilitation in the municipalities. Therefore, the

present study seeks to explore Norwegian CCs' experiences with the delivery of complex cancer rehabilitation interventions in primary health care.

Theoretical Rationale

Cancer rehabilitation is commonly defined as a goal-oriented, coordinated and multidisciplinary health promoting process that assists the individual to obtain best possible functioning and participation in the physical, psychological, social and vocational life domains, release symptom burden, enhance independence and QoL (Hellbom et al., 2011; Jensen, Piester, Nissen, & Pedersen, 2004; Reigle et al., 2017). Hence, cancer rehabilitation includes a holistic perspective on health and health-promoting factors and processes. Consequently, Salutogenesis, coined by Aaron Antonovsky (Antonovsky, 1979, 1987), was chosen as an appropriate framework for discussing this study's findings. Salutogenesis focuses on factors creating health and wellbeing. Within this perspective, health care professionals may act as key facilitators to improve health and promote coping. Accordingly, health professionals can promote patients' general resistant resources (GRRs), which are any internal or external factors that enable a constructive approach to managing stress-causing events in different ways^{28,29}, e.g. via support, knowledge, experience, and adequate rehabilitation services. GRRs can enhance a situation's comprehensibility, manageability and meaningfulness, which can yield a sense of coherence (SOC), a perceived consistency between demands and resources (Antonovsky, 1979, 1987).

Study Aim

This study aims to generate knowledge of the delivery of cancer rehabilitation interventions in primary health care from the perspectives of Norwegian CCs. 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 approach built on the work of Gadamer (Creswell, 2013; 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 impacted by the context, prior knowledge and subjective experiences (Gadamer, 1989), the researchers discussed how the context and their own pre-understandings may have impacted the interpretation (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’. We invited 20 CCs who represented heterogeneous municipalities and of different ages, genders, full-time equivalent and work experience. The sampling was informed by Statistics Norway, websites of the Cancer Society and Norwegian municipalities (Kreftforeningen, 2012; Statistisk sentralbyrå, 2014). Due to great traveling distances and limited time, 14 out of 20 CCs declined to participate. Using convenience sampling (Creswell, 2013; Morgan, 1997), we consecutively recruited CCs living close to where the interviews were held. In line with the recommended sizes for focus groups (Morgan, 1997), we finished the recruitment when a total of 14 CC 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, respectively five participants. No participant was turned away. The characteristics of the final study sample are outlined in Table 1 [Table 1].

Interview Procedure

The focus group interview procedure was planned and conducted in line with the guidelines of Kitzinger and Barbour (1999) and Morgan (1997). Focus groups are particularly useful for examining the different perspectives of participants operating within a network, as the emphasis relies upon participant interaction and discussion of their own concepts and views, e.g., on cancer rehabilitation and its delivery, as required by the present study (Kitzinger & Barbour, 1999). The interviews were held in conference rooms in the two largest towns of

Norway. The interviews were moderated by the first author, supported by a co-moderator who acted as an observer. An independent researcher co-moderated focus group one and the second author co-moderated focus group two. The interviews were conducted using a semi-structured interview guide [Table 2] based on prior research and discussions in the research team. The questions targeted CCs' experiences with the delivery of complex rehabilitation interventions in primary health care, allowing the CCs 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. All participants gave informed and written consent, and the researchers followed established guidelines in preserving anonymity and safely handling the data (World Medical Association, 1964).

Data Analysis

The data were analyzed using the six steps to thematic analysis (TA) (Braun & Clarke, 2006). First, all 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. In the fifth step two main themes were identified and labeled, both of which represented a coherent and rich picture of how the CCs elaborated the concept of cancer rehabilitation and how they contribute to cancer rehabilitation in primary health care in Norway. The sixth step is the presentation of findings, as discussed below.

Results

The analysis revealed three main themes that evolved from the focus group discussions on the CCs' experiences with the delivery of cancer rehabilitation interventions in primary health care: (1) 'A missing link to cancer rehabilitation'; (2) 'Trying 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

Theme 1 reflected the CCs' experiences of the current delivery of cancer rehabilitation services in primary health care. Most CCs outlined a vision of complex cancer rehabilitation interventions that addressed patients' bio-psycho-social needs holistically throughout the cancer care continuum. However, the CCs underscored that this vision contrasted current practices in primary health care, as they experienced a missing connection to rehabilitation interventions during patient's cancer trajectory.

The CCs outlined that existing local services were few and mainly provided in terms of single, post-treatment interventions such as physiotherapy, rather than aligned in terms of complex interventions. The CCs noted that many health professionals seemed to have little knowledge of patients' comprehensive rehabilitation needs and lacked a common conceptualization of cancer rehabilitation. This was explained by that municipalities hitherto had focused on facilitating palliative care, whereas cancer rehabilitation was sidetracked and responsibilities for its delivery were unclear. The CCs underscored the latter as a particular challenge in patients' transitioning between health care sectors.

'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 know little about rehabilitation.' FG1

The CCs elaborated that general practitioners, who are usually the patients' main contact in Norwegian primary health care, did not routinely and pro-actively reach out to patients after their discharge from the hospital, e.g., for the assessment of rehabilitation needs. Furthermore, general practitioners and other health professionals seldom referred their patients to the CCs for support regarding rehabilitation. Hence, the CCs hardly detected and worked with patients

in need of complex rehabilitation interventions. Consequently, the CCs anticipated that patients could receive fragmented or no local rehabilitation services.

‘There are few of them in our system, and there must be many more out there, who are under treatment and should rehabilitate (...). However, we don’t get any referrals.’ FG1

The delivery and content of rehabilitation interventions depended thus on the initiative of patients, families or dedicated professionals. Accordingly, CCs raised concerns regarding social inequality in rehabilitation, as patients with little resources and support could miss out on rehabilitation services.

Theme 2: Trying to put cancer rehabilitation in the spotlight

Theme 2 embraced CCs’ accounts of how they operated to facilitate rehabilitation interventions in primary health care. CCs outlined utilizing their role to advocate patients’ bio-psycho-social rehabilitation needs, aiming to enhance professionals’ awareness of and focus on complex cancer rehabilitation interventions. Some CCs promoted rehabilitation interventions throughout the trajectory, in pleading for early needs assessments and interventions to minimize the need for further treatment.

‘It is important to promote [rehabilitation] (...) and that it is useful to the patients.’

FG2

Furthermore, the CCs encouraged professionals to focus on patient involvement and patients’ expressed, psychosocial needs when planning rehabilitation interventions.

‘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.’ FG1

Likewise, the CCs themselves focused needs assessments on the question: ‘What matters to you right now?’ to address patients’ values, goals and resources, and not only their problems or limitations.

‘It is always positive when you start to talk about rehabilitation with the patients. (...)

Placing emphasis on the resources. (...) What is rehabilitation for YOU?’ FG2

Several CCs worked to facilitate local rehabilitation services, in linking the patients to local offers for mixed patient groups or in collaborating with volunteer organizations to establish low-cost services that promoted physical or mental health, e.g., walking groups, patient cafés and meeting points. Some CCs found that such offers also seemed to alleviate the family caregivers' burden, too, which was outlined as an important aspect of a holistic approach to cancer rehabilitation. Although some CCs noted that local health professionals gradually seemed to increase their knowledge of patients' rehabilitation needs, they perceived that changing mindsets had yet rarely translated into changing practices.

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

Theme 3 related to CCs perspectives concerning the way forward to facilitate complex cancer rehabilitation interventions in primary health care. The CCs underscored the need for collaborative action of local professionals to establish a systemic delivery and equal access to complex cancer rehabilitation interventions in the municipalities. The general practitioner was identified as a key person and collaborating partner for CCs.

‘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 general practitioner who receives all the epicrises and needs to be a hook to catch these patients.’ FG1

CCs noted that municipalities progressively succeeded in establishing systems for palliative care, so that more attention might be focused on the delivery of complex cancer rehabilitation interventions onwards. However, to make that possible, the CCs also underscored the need for adequate resources and facilities in the municipalities. This included the use of electronic systems or individual cancer rehabilitation care plans to facilitate cross-sectoral communication and service coordination. Moreover, the CCs indicated the need for future national and local policies to increase the focus on cancer rehabilitation and promote changing practices in cancer care.

Discussion

To our knowledge, this is the first study to explore CCs' experiences with the delivery of cancer rehabilitation interventions in primary health care. The main findings will be discussed in the following section.

Theme 1: A missing link to cancer rehabilitation

The findings suggest that the CCs' visions of holistic cancer rehabilitation contrasted with their experiences of their own and other health professionals' current practices in primary health care. Rather than delivering complex interventions, rehabilitation offers in municipalities were perceived embrace single interventions, e.g. physiotherapy. Likewise, the literature shows that multidimensional or complex rehabilitation seems to be underutilized (Bober et al., 2009; Helsedirektoratet, 2012; Mewes et al., 2012; Scott et al., 2013). The CCs explained that in Norway, cancer rehabilitation could be side-racked in the municipalities, because the facilitation of palliative care was regarded as priority and most urgent need. Similar was found in previous research, elaborating that palliative patients often have urgent and complex needs that require the specialized skills of local professionals (Monterosso et al., 2011; Silver et al., 2015).

In line with the literature, our findings indicate that professionals in primary health care lacked a clear understanding of cancer rehabilitation, suggesting a need to enhance their skills and knowledge of the late-effects of cancer treatment (Bober et al., 2009; Nekhlyudov, Aziz, Lerro, & Virgo, 2013). Furthermore, the participants described the lack of systems and responsibilities for cancer rehabilitation, particularly in patients' transfer from specialized services to primary health care. Research confirms that unclear responsibilities at the interfaces in health care can put patients at risk of missing out on services in primary health care (Grunfeld & Earle, 2010; Nielsen, 2011; Reigle et al., 2017).

The CCs elaborated that general practitioners did not routinely contact the patients for an assessment of rehabilitation needs after hospital discharge. Similarly, previous research indicates that most primary health care physicians do not regularly provide multidimensional cancer rehabilitation, requiring for their increased, pro-active involvement (Bober et al., 2009)

Theme 2: Trying to put cancer rehabilitation in the spotlight

CCs delineated acting as patient advocates and educating local health professionals on cancer rehabilitation, thus operating in line with international recommendations. (Hewitt et al., 2006; Jensen et al., 2004; Nekhlyudov et al., 2013). Similarly, other CCs have a strong focus on the education and professional development of health care providers (Monterosso et al., 2011). Supported by previous research (Barry & Edgman-Levitan, 2012; Charles et al., 1997), our participants promoted early needs assessments and patients' participation in their health and recovery. Salutogenic theory underscores that meaningful support and resources are important elements in facilitating health improvements (Antonovsky, 1987).

CCs' attempted to facilitate local rehabilitation offers, e.g. walking groups, and to provide their patients with existing local rehabilitation services. However, their narratives seem to resemble case-to-case approaches with a focus on delivering one or more single services, rather than the systemic delivery of holistic, complex interventions with a multidisciplinary team. Previous research confirms that CCs work highly self-sufficiently (Monterosso et al., 2011; Smith, 2016) and that there is a limited degree of multidimensionality in primary health care (Bober et al., 2009). Other research underscores that a holistic approach to patient care might not be the case in clinical practice, even though health professionals strive to do so (Farell, Walshe & Molassiotis 2017).

Consulting the literature, it becomes evident that the present CCs' accounts of their activities for cancer rehabilitation align to a high degree CCs' activities at other stages of the trajectory (Lie et al., 2017; Monterosso et al., 2011; Smith, 2016). In line with previous research, our findings indicate that rehabilitation interventions seem to be poorly integrated into and demarcated from other services in cancer care (Alfano et al., 2012; Gamble et al., 2011; Silver et al., 2015; Stout et al., 2016). Our participants addressed that lacking systems for the delivery of cancer rehabilitation interventions could cause social inequalities, as patients with little resources were put at risk of missing out on services. Prior research has shown that unequal access to care can increase the risk of unmet rehabilitation needs in cancer patients (Veloso et al., 2013)

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

The present CCs outlined a clear need for a more resources and support to enact system-level work towards complex and holistic rehabilitation service delivery. This underscores the fact that CCs have a broad range of other work tasks and limited capacity to engage equally in all of them (Lie et al., 2017; Monterosso et al., 2011; Smith, 2016). On the other hand, it is striking that none of the main themes discussed in the focus groups involved planned or systematic approaches to enhance rehabilitation service delivery, project proposals or the management of multidisciplinary teams. This may testify of that CCs, most of whom are nurses, may require additional training or formal education to facilitate system level changes, e.g with a focus on system work, management skills, or public health initiatives.

However, the present CCs' calls for adequate frames and resources to enact both patient-and system level work is supported by suggestions elsewhere (Freijser et al., 2015; Monterosso et al., 2011). The present study proposes that equipping local professionals with both knowledge and skills regarding cancer rehabilitation is vital in facilitating systemic service delivery further on. In line with the literature, the CCs highlight that assigning general practitioners a central, pro-active role in respect of rehabilitation needs assessment may contribute to patients' equal access to rehabilitation services (Bergholdt et al., 2013; Blanch-Hartigan et al., 2014; Grunfeld & Earle, 2010). Finally, the participants suggested that tools such as electronic systems and individual cancer rehabilitation care plans could help facilitate the coordinated delivery of rehabilitation interventions. Such care plans are established elsewhere to assist CCs and other professionals delivering complex rehabilitation interventions that respond to patients' individual needs (Blanch-Hartigan et al., 2014; Hewitt et al., 2006). Last but not least, political forces strongly impact on health professionals work. Our participants discussed a local focus on palliative care, which is mirrored in national and international political documents. Political calls for a stronger focus on rehabilitation may increase the likelihood for CCs to receive better support to focus their work on cancer rehabilitation onwards.

Limitations and trustworthiness of the study

Trustworthiness in qualitative research can be ensured by providing a detailed account of the research process and reflexivity concerning one's own preconceptions (Koch, 1996). To ensure trustworthiness, each step of the present research has been described and presented in detail. Furthermore, the researchers continuously discussed their presumptions about the topic, a process that enhanced their reflexivity throughout the research process. Focus groups may provide less detailed accounts than individual interviews; however, they have the advantage of stimulating reflections, comparisons and discussions between participants and facilitate nuanced perspectives on the topic (Morgan, 1997). Due to difficulties in recruitment, in the current study sample CCs from northern and southern areas of Norway were underrepresented, so that their potentially distinct perspectives may not be reflected. However, the study sample represents CCs from highly varying municipalities, which may enhance the transferability of the findings to other municipal settings.

Conclusion and implications for research and clinical practice

The findings indicate that Norwegian CCs place importance on the delivery of complex and holistic cancer rehabilitation in primary health care. However, they cited the delivery of current rehabilitation interventions to be sidetracked, characterized by one-sided approaches rather than complex and holistic services. Challenges to complex interventions were outlined in terms of missing systems and local resources for service delivery and limited knowledge of local professionals. There is a need for increased cross-sectoral collaboration and communication, and a systemic involvement of general practitioners in patients' rehabilitation course. Health care providers may place greater emphasis on the early assessment of patients' needs and goals, and on patient involvement in rehabilitation interventions. CCs may benefit from education and training on system-level work and project management as well as collaboration with multidisciplinary teams to better facilitate system-level action for cancer rehabilitation. Political strategies are needed to clarify systems and responsibilities for cancer rehabilitation service delivery, and to increase the local focus on and resources for cancer rehabilitation. More research is required to identify best practices for cancer rehabilitation and how CCs may contribute to facilitate cancer rehabilitation in primary health care.

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Tables

Table 1: Overview of the Study Sample

| Variables | Study sample (% of study sample) | | |
|---|-------------------------------------|----------------------|----------------------|
| | Focus group 1 | Focus group 2 | Total |
| Gender | | | |
| Female | 5 (100%) | 6 (86%) | 11 (92%) |
| Male | - | 1 (14%) | 1 (8%) |
| Age | | | |
| Mean (Range) | 50 (31 – 57) | 52 (38 – 62) | 51 (31 – 62) |
| Profession | | | |
| 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%) |
| Worked as a CC (months) | 24 (11-32) | 24 (13-29) | 24 (11-32) |
| Mean (range) | | | |
| Full-time equivalent | | | |
| Full time (100%) | 3 (60%) | 5 (71%) | 8 (67%) |
| Part- time (50%) | 2 (40%) | 2 (29%) | 4 (33%) |
| Organization of the position (Placement) | | | |
| 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%) |
| Number of municipalities covered | | | |
| One municipality / one capital district | 5 (100%) | 6 (86%) | 11 (92%) |
| Two or more municipalities | | 1 (14%) | 1 (8%) |
| Number of inhabitants covered | | | |
| Mean (Range) | 28097 (10397 – 48062) | 37819 (7806 – 84476) | 33768 (7806 – 84476) |

Table 2: The Semi-Structured Interview Guide

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

Appendix IV: Information letter/consent scheme individual interviews

Informasjonsbrev og forespørsel om deltakelse i individuelt intervju til kreftkoordinatorer:

Forespørsel om deltakelse i forskningsprosjektet

Kreftkoordinatorens rolle i samhandling for helhetlige kreftrehabiliteringstilbud

Bakgrunn og formål

Undersøkelsen er et PhD prosjekt som gjennomføres ved Høyskolen i Oslo og Akershus, Fakultet for helsefag, Institutt for Fysioterapi og i samarbeid med Kreftforeningen, som støtter gjennomføringen av undersøkelsen. Prosjektleder er stipendiat Nataskja-Elena Kersting Lie, med hovedveileder professor Per Koren Solvang.

Undersøkelsen retter fokus mot betydningen av tverrfaglighet og samhandling mellom kommuner, spesialisthelsetjenesten, profesjonelle og brukere for kreftrehabilitering. Hensikten med undersøkelsen er å få kunnskap om konkret praksis, forventninger og dilemmaer som aktører i kreftrehabilitering opplever i tverrfaglig samarbeid, samt metoder og redskaper som kan brukes for å håndtere mulige utfordringer. Undersøkelsen skal blant annet gi innsikt i kreftkoordinatorenes erfaringer med stillingen og de krav som stilles til kreftkoordinatorrollen gjennom ulike aktører i helsesektoren.

Metodene som er valgt for gjennomføring av undersøkelsen er blant annet intervju med kommunalt ansatte kreftkoordinatorer. Intervjuene er tenkt gjennomført som individuelle intervjuer med kreftkoordinatorer. I tillegg gjennomføres det fokusgruppeintervjuer med henholdsvis 6-8 ansatte i kommunene, spesialisthelsetjenesten, kreftkoordinatorer og kreftoverleverer.

Siden du er kreftkoordinator i din kommune, ønsker jeg med dette å forespørre deg om du er villig til å delta i et individuelt intervju i undersøkelsen.

Hva innebærer deltakelse i studien?

Det individuelle intervjuet vil ta utgangspunkt i de ansattes erfaringer med arbeidet innen kreftrehabilitering. Temaene i intervjuene vil kretse omkring hvordan det daglige arbeidet gjennomføres, og hva rammebetingelsene for yrkesutøvelsen er. Intervjupersonene vil bli bedt om å reflektere om aktuelle og mulige fremtidige utfordringer i arbeidet og hvordan disse kan håndteres. Spørsmål vil kretse rundt hvordan kreftkoordinatorer i konkrete situasjoner gjør bruk av fagkunnskap, og hvordan krav fra ulike aktører, lovgivning og regelverk og brukerens erfaring og kunnskap trekkes inn i de faglige overveielser.

Praktiske opplysninger

Intervjuet vil ta omtrent halvannen time (90 min.) og gjennomføres av stipendiat Nataskja-Elena Kersting Lie. Intervjuet vil bli gjennomført i kommunen kreftkoordinatoren er lokalisert i. Det blir gjort lydopptak av intervjuene. Alle opplysninger om deltakere og institusjon vil bli behandlet konfidensielt og forskeren er underlagt taushetsplikt. Ingen andre personer utenom forskeren og tilknyttede veileder vil ha tilgang til personopplysninger og lydbåndopptak. Opptakene transkriberes etter gjennomført intervju. Transkripsjonene vil kun inneholde avidentifisert informasjon, der navn er erstattet med et deltagernummer. Datamaterialet anonymiseres i publikasjoner fra undersøkelsen og innsamlede opplysninger i lydopptak og transkripsjoner vil bli makulert ved prosjektslutt, senest ved utgangen av 2017.

Frivillig deltakelse

Deltagelsen er frivillig og informanten har rett til å trekke seg uten å angi grunner for dette. Studien er meldt til Personvernombudet for forskning, Norsk samfunnsvitenskapelig datatjeneste AS.

Dersom du har spørsmål til studien, eller har spørsmål om deltagelse i undersøkelsen, ta kontakt med undertegnede på telefon 67 23 62 51 eller mobil 92460118.

Dersom du er villig til å delta i denne undersøkelsen, ber vi om at du fyller ut og signerer vedlagte svarslipp og sender den elektronisk tilbake til undertegnende. Dersom du ønsker å sende svarslippen i posten og ønsker en frankert og adressert konvolutt ber vi om tilbakemelding om dette. Deretter vil du snarlig få et forslag om tid og sted for intervjuet.

Vennlig hilsen

Nataskja-Elena Kersting Lie
Stipendiat
Fakultet/institutt: Fakultet for helsefag/ Institutt for fysioterapi
E-post: Nataskja.Lie@hioa.no
Telefon (kontor): +47 67 23 62 51 / mob. 92460118
Besøksadresse: Pilestredet 50, Oslo
Kontornummer: G123

Samtykkeerklæring

Jeg har mottatt informasjon om studien, og er villig til å delta i studien.

- Jeg stiller meg positiv til å delta i et individuelt intervju.
- Jeg ønsker å kontaktes via telefon for nærmere opplysning om tid og sted for intervjuet.
Tlf.nr.: _____
- Jeg ønsker å kontaktes via e-post for nærmere opplysning om tid og sted for intervjuet.
E-post adresse: _____

(Signert av prosjektdeltaker, dato)

Appendix V: Information letter/consent scheme individual interviews

Informasjonsbrev og forespørsel om deltakelse i fokusgruppeintervju til kreftkoordinatorer:

Forespørsel om deltakelse i forskningsprosjektet

Kreftkoordinatorens rolle i samhandling for helhetlige kreftrehabiliteringstilbud

Bakgrunn og formål

Undersøkelsen er et PhD prosjekt som gjennomføres ved Høyskolen i Oslo og Akershus, Fakultet for helsefag, Institutt for Fysioterapi og i samarbeid med Kreftforeningen, som støtter gjennomføringen av undersøkelsen. Prosjektleder er stipendiat Nataskja-Elena Kersting Lie, med hovedveileder professor Per Koren Solvang.

Undersøkelsen retter fokus mot betydningen av tverrfaglighet og samhandling mellom kommuner, spesialisthelsetjenesten, profesjonelle og brukere for kreftrehabilitering. Hensikten med undersøkelsen er å få kunnskap om konkret praksis, forventninger og dilemmaer som aktører i kreftrehabilitering opplever i tverrfaglig samarbeid, samt metoder og redskaper som kan brukes for å håndtere mulige utfordringer. Undersøkelsen skal blant annet gi innsikt i kreftkoordinatorernes erfaringer med stillingen og de krav som stilles til kreftkoordinatorrollen gjennom ulike aktører i helsesektoren.

Metodene som er valgt for gjennomføring av undersøkelsen er blant annet intervju med kommunalt ansatte kreftkoordinatorer. Intervjuene er tenkt gjennomført som fokusgruppeintervju med 6-8 kreftkoordinatorer. Et fokusgruppeintervju kan danne en arena for å utveksle, dele og diskutere egne erfaringer i fellesskap, og kan tydeliggjøre viktige felles problemstillinger eller muligheter som oppleves i sammenheng med bruk av kreftkoordinatorer for rehabilitering. I tillegg gjennomføres det fokusgruppeintervju med ansatte i kommunene, spesialisthelsetjenesten og kreftoverlevende.

Siden du er kreftkoordinator i din kommune, ønsker jeg med dette å forespørre deg om du er villig til å delta i et fokusgruppeintervju i undersøkelsen.

Hva innebærer deltakelse i studien?

Fokusgruppeintervjuet vil ta utgangspunkt i de ansattes erfaringer med arbeidet innen kreftrehabilitering. Temaene i intervjuene vil kretse omkring hvordan det daglige arbeidet gjennomføres, og hva rammebetingelsene for yrkesutøvelsen er. Intervjupersonene vil bli bedt om å reflektere om aktuelle og mulige fremtidige utfordringer i arbeidet og hvordan disse kan håndteres. Fokusgruppen vil videre bli bedt om å reflektere over hvordan tverrfaglighet praktiseres, og hvordan krav fra ulike aktører, lovgivning og regelverk og brukerens erfaring og kunnskap trekkes inn i de faglige overveielser. Videre skal intervjuet belyse hvordan det kan tilrettelegges for samarbeid på tvers av fagfelt og tjenestenivåer og på hvilken måte kreftkoordinatorer kan bidra til forbedret samhandling.

Praktiske opplysninger

Intervjuet vil ta omtrent halvannen time (90 min.) og gjennomføres av stipendiat Nataskja-Elena Kersting Lie. Intervjuet vil bli gjennomført på et sted som gir kortest mulig reisevei for deltakerne. Det blir gjort lydopptak av intervjuene. Alle opplysninger om deltakere og institusjon vil bli behandlet konfidensielt og forskeren er underlagt taushetsplikt. Ingen andre personer utenom forskeren og tilknyttede veileder vil ha tilgang til personopplysninger og lydbåndopptak. Opptakene transkriberes etter gjennomført intervju. Transkripsjonene vil kun inneholde avidentifisert informasjon, der navn er erstattet med et deltagernummer. Datamaterialet anonymiseres i publikasjoner fra undersøkelsen og innsamlende opplysninger i lydopptak og transkripsjoner vil bli makulert ved prosjektslutt, senest ved utgangen av 2017.

Frivillig deltakelse

Deltagelsen i undersøkelsen er frivillig og informanten har rett til å trekke seg uten å angi grunner for dette. Studien er meldt til Personvernombudet for forskning, Norsk samfunnsvitenskapelig datatjeneste AS.

Dersom du har spørsmål til studien, eller har spørsmål om deltagelse i undersøkelsen, ta kontakt med undertegnede på telefon 67 23 62 51 eller mobil 92460118.

Dersom du er villig til å delta i denne undersøkelsen, ber vi om at du fyller ut og signerer vedlagte svarslipp og sender den elektronisk tilbake til undertegnende. Dersom du ønsker å sende svarslippen i posten og ønsker en frankert og adressert konvolutt ber vi om tilbakemelding om dette. Deretter vil du snart få et forslag om tid og sted for intervjuet.

Vennlig hilsen

Nataskja-Elena Kersting Lie

Stipendiat

Fakultet/institutt: Fakultet for helsefag/ Institutt for fysioterapi

E-post: Nataskja.Lie@hioa.no

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Jeg har mottatt informasjon om studien, og er villig til å delta i studien.

- Jeg stiller meg positiv til å delta i et fokusgruppeintervju.
- Jeg ønsker å kontaktes via telefon for nærmere opplysning om tid og sted for intervjuet.
Tlf.nr.: _____
- Jeg ønsker å kontaktes via e-post for nærmere opplysning om tid og sted for intervjuet.
E-post adresse: _____

(Signert av prosjektdeltaker, dato)

Appendix VI: Recommendation letter from the NCS



KREFTFORENINGEN

Oslo, 10. november 2014

Deres ref.:
Vår ref.:
Saksbehandler: Liv Eli Lundeby

Anbefaling - forskning på kreftkoordinator

Høyskolene i Oslo og Akershus gjennomfører en undersøkelse om kreftkoordinatorens rolle for samarbeid i helse- og rehabiliteringstjenester. Undersøkelsen er et PhD prosjekt som gjennomføres av stipendiat Nataskja-Elena Kersting Lie, med hovedveileder professor Per Koren Solvang og medveileder professor Tone Alm Andreassen.

Kreftforeningen har hatt et møte med høyskolene i Oslo og Akershus og er glade for at det frembringes mer forskningsbasert kunnskap om kreftkoordinatorordningens betydning for pasienter, pårørende og samhandlingen mellom leddene i offentlig sektor.

Vi deler gjerne av vår egen kunnskap med prosjektet og mener at det er flott dersom kreftkoordinatorer, deres ledere og berørte samarbeidsorganer gir noe av sin tid til dette formålet.

Med vennlig hilsen
Kreftforeningen

Heidi Brorsson



Semi-structured interview guide

Main questions:

1. Can you please tell me about your background and your position as CC in your municipality?

Follow-up questions: What is your profession, and what is your prior work experience?
How large is your municipality, and how many patients do you work with?
What is your full-time equivalent?
When was the CC position established in your municipality, and what was the goal?
Where has your position been organized and where is your workspace located in your municipality?

2. Can you please tell me about the process of becoming established as a CC?

Follow-up questions: Could you please elaborate on your experiences with difficulties and supportive factors in becoming established?

3. How does a typical workweek look like for you? What tasks do you engage in?

Follow-up questions: Would you please elaborate on patient-directed work and system-work?

4. Can you please tell me about your experiences of cooperating with other professionals?

Follow-up questions: Could you please elaborate on your experiences with difficulties and supportive factors in cooperating with other professionals?
Could you please tell me about the ways in which cooperation takes place? (e.g. routines, procedures, agreements, meetings)

5. Based on you experience, what do you think is the primary role of CC in local cancer care?

Follow-up questions: To what extend and in what way have you been able to improve coordination and tailoring of services for patients in your municipality?
What tasks do *not* belong to working as a CC?
What are your visions and future goals regarding your work as CC?

6. Is there anything you think of as important regarding the CC position that you would like to add?

Appendix VIII: Interview guide, paper II

The semi-structured interview guide

| | |
|----------------------------|--|
| Main question | <i>Can you please tell me about your experiences of implementing the CC function and establishing collaborations with professionals in your municipality/ies?</i> |
| Follow-up questions | <p>Challenges:</p> <p>Could you please elaborate on challenges you may have perceived concerning:</p> <ul style="list-style-type: none"> - the establishment of a new position - establishing working relationships and collaboration - improving services in the municipality <p>What are challenges ahead?</p> <hr/> <p>Facilitators:</p> <p>Have you been able to solve any of the challenges described above? If so, what factors helped you to overcome the challenges you described?</p> <p>Could you please elaborate on facilitators you have experienced concerning:</p> <ul style="list-style-type: none"> - the establishment of a new position - establishing working relationships and collaboration - improving services in the municipality <p>What is possibly most needed in order to enact the function at a later stage on?</p> |

Appendix IX: Interview guide, paper III

Table 2: The Semi-Structured Interview Guide

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

Appendix X: Approval from the ethical committee/NSD

Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES



Harald Hårfages gate 29
N-5007 Bergen
Norway
Tel: +47-55 58 21 17
Fax: +47-55 58 96 50
nsd@nsd.uib.no
www.nsd.uib.no
Org.nr. 985 321 884

Nataskja-Elena Kersting Lie
Institutt for fysioterapi Høgskolen i Oslo og Akershus
Postboks 4 St. Olavs plass
0130 OSLO

Vår dato: 06.06.2014

Vår ref: 38673 / 3 / LB

Deres dato:

Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 02.05.2014. Meldingen gjelder prosjektet:

| | |
|-----------------------------|--|
| 38673 | <i>Kreftkoordinatorernes rolle i samhandlingsnettverk innen rehabilitering</i> |
| <i>Behandlingsansvarlig</i> | <i>Høgskolen i Oslo og Akershus, ved institusjonens øverste leder</i> |
| <i>Daglig ansvarlig</i> | <i>Nataskja-Elena Kersting Lie</i> |

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, <http://www.nsd.uib.no/personvern/meldeplikt/skjema.html>. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, <http://pvo.nsd.no/prosjekt>.

Personvernombudet vil ved prosjektets avslutning, 01.06.2017, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Katrine Utaaker Segadal

Lene Christine M. Brandt

Kontaktperson: Lene Christine M. Brandt tlf: 55 58 89 26

Vedlegg: Prosjektvurdering

Dokumentet er elektronisk produsert og godkjent ved NSDs rutiner for elektronisk godkjenning.

Avdelingskontorer / District Offices:

OSLO: NSD, Universitetet i Oslo, Postboks 1055 Blindern, 0316 Oslo. Tel: +47-22 85 52 11. nsd@uio.no
TRONDHEIM: NSD, Norges teknisk-naturvitenskapelige universitet, 7491 Trondheim. Tel: +47-73 59 19 07. kyrr.svarva@svt.ntnu.no
TROMSØ: NSD, SVF, Universitetet i Tromsø, 9037 Tromsø. Tel: +47-77 64 43 36. nsdmaa@svt.uit.no



Formålet med prosjektet er å studere kreftkoordinatorenes rolle i samhandlingsnettverk innen rehabilitering. Data samles inn gjennom personlig intervju med kreftkoordinatorer. Videre gjennomføres fokusgruppeintervjuer med kreftkoordinatorer, kommunalt ansatte som arbeider med rehabilitering, ansatte i spesialisthelsetjenesten og kreftoverlevende som nå driver med likemennsarbeid. Det vil også gjennomføres en elektronisk spørreundersøkelse som sendes ut til kreftkoordinatorer i kommunene.

Utvalget informeres skriftlig og muntlig om prosjektet og samtykker til deltakelse. Informasjonsskrivene av 03.06.2014 er godt utformet. I setningen om anonymisering og prosjektslutt, kan det imidlertid presiseres enda tydeligere i skrivene at alt innsamlet datamateriale (også navneliste/koblingsnøkkel) anonymiseres, og lydband slettes, ved prosjektslutt.

I lys av prosjektets tematikk tas det høyde for at det vil kunne fremkomme sensitive opplysninger om helseforhold under intervjuene med kreftoverlevende (likemenn), jf. personopplysningsloven § 2 nr. 8 c).

LimeSurvey er databehandler for prosjektet. Personvernombudet forutsetter at det foreligger en databehandleravtale mellom LimeSurvey og Høgskolen i Oslo og Akershus for den behandling av data som finner sted, jf. personopplysningsloven § 15. For råd om hva databehandleravtalen bør inneholde, se Datatilsynets veileder på denne siden: <<http://www.datatilsynet.no/verktoy-skjema/Skjema-maler/Databehandleravtale---mal/>>

Personvernombudet legger til grunn at forsker etterfølger Høgskolen i Oslo og Akershus sine interne rutiner for datasikkerhet.

Prosjektslutt er angitt til våren 2017 i informasjonsskrivene til utvalget, og ombudet har justert dato for prosjektslutt i henhold til dette. Ifølge prosjektmeldingen skal innsamlede opplysninger da anonymiseres. Anonymisering innebærer å bearbeide datamaterialet slik at ingen enkeltpersoner kan gjenkjennes. Det gjøres ved:

- å slette direkte personopplysninger (som navn/koblingsnøkkel)
- og slette/omskrive indirekte personopplysninger (identifiserende sammenstilling av bakgrunnsopplysninger som f.eks. bosted/arbeidssted, alder og kjønn)
- samt slette lydopptak

Vi gjør oppmerksom på at også databehandler (LimeSurvey) må slette personopplysninger tilknyttet prosjektet i sine systemer. Dette inkluderer eventuelle logger og koblinger mellom IP-/epostadresser og besvarelser.

Det forutsettes at intervjuguidene til fokusgruppeintervjuene, samt endelig versjon av spørreskjema, ettersendes ombudet så snart de foreligger.