

Nataskja-Elena Kersting Lie, MSc
May Aasebø Hauken, PhD
Per Koren Solvang, PhD

Providing Coordinated Cancer Care—A Qualitative Study of Norwegian Cancer Coordinators' Experiences of Their Role

KEY WORDS

Cancer care coordinators
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Salutogenesis
Treatment trajectory

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:** The aim of this study was 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 semistructured in-depth interviews of 26 Norwegian CCs. The data were analyzed using thematic analysis and discussed in the light of the salutogenic theory. **Results:** Cancer coordinators 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 3 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:** Cancer coordinators evolved diversely, in adaption to the local context and patients' needs. The functions' diversity challenged the implementation and external role recognition. Cancer coordinators seemed to apply a salutogenic, resource-focused orientation in order to support a positive development at both the patient and the system levels. **Implications for Practice:** The findings reinforce the call for holistic, patient-centered services in cancer care. Cancer coordinators need appropriate support from the local management to establish the role and local collaborations.

Author Affiliations: Department of Physiotherapy, Faculty of Health Sciences, Oslo and Akershus University College of Applied Sciences (Ms Lie and Dr Solvang); and Center for Crisis Psychology, Bergen (Dr Hauken), Norway.
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Correspondence: Nataskja-Elena Kersting Lie, MSc, Oslo and Akershus University College of Applied Sciences, Faculty of Health Sciences, PO Box 4, St Olavs plass, 0130 Oslo, Norway (nataskja.lie@hioa.no).
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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 the healthcare sector over a prolonged period.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 healthcare 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 healthcare services. They did so by providing up to 75% of the CCs' wages for the first 4 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 in the primary services 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.^{4-8,16} While the position of CC is new to Norway, similar roles have been established overseas that 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.^{5,6,17-19} 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.¹⁷⁻²⁰ Other studies have found that they have positive effects on cooperation and communication between care providers, as well as better service integration.²⁰⁻²² However, in the literature, these roles are described using interchangeable terms; cancer navigators, cancer nurse coordinators, and other similar labels are in use.^{5,6,16-20} Hence, professionals in these positions report that their role lacks recognition and that they have difficulties with professional cooperation.^{6,16,17} Findings from a literature review²³ 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 healthcare 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 navigators' functions as established, for example, in the United States. These functions are described in terms of a service that provides assistance and implements a tailored action plan for patients.¹⁹ 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. Accordingly, the role of CC has evolved diversely in line with the heterogeneous Norwegian municipalities.^{13,14} At present, 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 an individual level, which may include both clinical and nonclinical 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.^{5,6,23}

■ Theoretical Framework

As the intended function of CCs is to facilitate and improve the well-being and health of patients at both an individual and systemic level, this study builds on the salutogenic theory, which was coined by Aaron Antonovsky.^{24,25} 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.^{26,27} These "general resistance resources" describe any biopsychosocial or environmental factor that has the potential to increase a person's capacity to navigate demanding life events, such as undergoing cancer treatment.^{28,29} Such factors can be, for example, assistive devices and medical supplies, information, knowledge, or social support.^{26,28,29} 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."^{25,27} This notion is seen as the driving

 **Table 1 • The Cancer Society's Guidelines and Examples of Work Tasks for Norwegian Cancer Coordinators (CCs)**

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, eg, procedures, checklists, or patient transfer between primary and specialized care
Competence building in the municipalities, such as information, education, and supervision of healthcare 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

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?"

■ Methods

This study applies a hermeneutic approach, inspired by Gadamer.³⁰ Understanding is created through the interactive

relationship between the participant's expressed life world and the researcher's interpretation of this, referred to as a hermeneutic circle.^{30,31} The interpretation occurs when the researcher's preunderstandings and data fuse and are placed in context.^{30,32} To properly enter the hermeneutic circle, we are required to use our own experiences while understanding how these interact with the data.³² 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.^{31,32}

■ 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 municipalities^{11–15} in which they work, we conducted purposive maximum variation sampling,³³ 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 Web sites of the Norwegian Cancer Society, Statistics Norway, and Norwegian municipalities.^{34,35} 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 adequately covered by the 26 CCs who 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.

■ Interview Procedure

The first author conducted qualitative, audiotaped one-on-one interviews with the informants using a semistructured interview guide, presented in 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 that they deemed relevant to their work. The first author conducted 3 CC pilot interviews, which confirmed the suitability of the interview guide for exploring the phenomenon. As a result, these participants were

 **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)		
Healthcare (eg, elderly center)	14 (54%)	
Administration (eg, service office)	8 (31%)	
Specialized services (eg, local hospital)	3 (12%)	
Intermunicipal (eg, commuting between municipalities)	1 (4%)	
Municipalities covered		
In total	45	
Single municipality/ district	21 (81%)	
≥2	5 (19%)	
Inhabitants covered	1 190 129	45 774 (6163–267 960)

included in the final study sample. In total, the first author held 18 interviews at the workplaces of the CCs and 8 interviews via the telephone because of long traveling 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.³⁶ 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.³⁷ Thematic analysis is a 6-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.^{32,37} Following the 6 steps of thematic analysis,³⁷ we familiarized ourselves with the data (step 1). Then, the first author reread and coded each interview (step 2) using the software HyperRESEARCH,³⁸ 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 coauthors, who coded several interviews for joint analysis. Moving forth and back in the hermeneutic circle of preunderstanding and understanding, the authors continuously reimmersed 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, 1 overarching topic and 3 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, 3 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 subthemes, 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 healthcare system, all of the CCs underwent the experience of encountering a new and unknown function, which most of them had to create

 **Table 3 • The Semistructured Interview Guide**

Main Questions

1. Can you please tell me about your background and your position as cancer coordinator (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 (eg, 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 extent 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?

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, Web sites, 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 toward 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 3 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 in the following sections.

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 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. Cancer coordinators 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 CC's 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 patients 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 2 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)

In addition, 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, for example, 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 healthcare 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 toward 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 3 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 al⁵ 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 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 al³⁹ 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,^{6,13,21} suggest that the municipal management needs to facilitate local working conditions that will help CCs to carry out their tasks effectively, for example, 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 that takes the patients' wider life context into consideration, so as to facilitate adequate support for the patients.^{40–43}

Mirroring national and international evaluations,^{14,16,17} 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 roles,²² 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 accordance to a salutogenic perspective. The literature suggests that a salutogenic orientation in professionals' dialogues with patients can contribute toward enhancing the patients' quality of life and decreasing their psychological distress.^{29,44}

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. Our findings, supported by the literature,^{18,45} 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 research,¹⁷ 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, for example, cancer nurses.^{13,17}

In line with existing knowledge,^{17,20} 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,^{20,40} our 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 they provided the patients with the cognitive, emotional, physical, or material resources that may help them to cope.^{27,44} Resources and positive coping experiences in turn can enhance patients' motivation and confidence in handling demands they are faced with (a high sense of coherence). This can help them to proactively address the upcoming challenges of their care pathways.^{24,29} 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.^{20,22,29}

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,^{16,23} 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^{22,47} suggests that having a resource-oriented focus can increase the opportunities of professionals to facilitate local services and support for the improvement of patient health.

In correspondence with the literature,^{6,17,39} our findings showed that the CCs were overloaded with work as they attempted to work both 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. Cancer coordinators working in larger municipalities or across multiple municipalities seemed to have a strong system focus, whereas 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.^{14,16,17} 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.^{6,16} Our findings, supported by the literature,^{6,16,22} suggest that municipalities should provide more support for CCs and involve them in larger-scale work within the system, while preserving their flexibility to adapt to local needs.

Underpinning previous research,⁴³ 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.^{43,48} Thus, the CCs engaged in educating professionals, supporting them to collaborate with one another and manage complex palliative care cases. Cancer coordinators 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.^{23,46}

Limitations and Trustworthiness of the Study

All qualitative research is impacted by a certain degree of subjectivity.³² 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.^{32,33} A characteristic of in-depth exploration of individual experiences is that the external validity of the

findings is difficult to assess.³³ 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 fulfill their full potential.

Conclusion

Cancer coordinators in Norway offer holistic local support to patients both by addressing 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. Cancer coordinators 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.

References

1. Stewart BW, Wild CP, International Agency for Research on Cancer (IARC). *World Cancer Report 2014*. Lyon, France: IARC; 2015.

2. Ferlay J, Soerjomataram I, Ervik M, et al. *GLOBOCAN 2012 v1.1, Cancer Incidence and Mortality Worldwide: IARC CancerBase No. 11*. Lyon, France: International Agency for Research on Cancer; 2014 <http://globocon.iarc.fr>. Accessed May 26, 2016.
3. Cancer Registry of Norway. *Cancer in Norway 2014. Cancer Incidence, Mortality, Survival and Prevalence in Norway*. https://www.kreftregisteret.no/globalassets/cancer-in-norway/2014/cin2014-special_issue.pdf. Published December 8, 2015. Accessed May 26, 2016.
4. Norwegian Ministry of Health and Care Services. *Together—Against Cancer. National Cancer Strategy 2013–2017*. https://www.regjeringen.no/contentassets/07cd14ff763444a3997de1570b85fad1/i-1158_together-against_cancer_web.pdf. Published June 4, 2013. Accessed March 14, 2016.
5. Walsh J, Harrison JD, Young JM, Butow PN, Solomon MJ, Masya L. What are the current barriers to effective cancer care coordination? A qualitative study. *BMC Health Serv Res*. 2010;10:132.
6. Freijser L, Naccarella L, McKenzie R, Krishnasamy M. Cancer care coordination: building a platform for the development of care coordinator roles and ongoing evaluation. *Aust J Prim Health*. 2015;21(2):157–163.
7. Aubin M, Giguère A, Martin M, et al. Interventions to improve continuity of care in the follow-up of patients with cancer. *Cochrane Database Syst Rev*. 2012;(7):CD007672.
8. The National Board of Health. *National Cancer Plan II—Denmark. National Board of Health Recommendations for Improving Cancer Healthcare Services*. <http://www.sst.dk/-/media/A7052DCF93A641508A48A5B60A933A7D.ashx2005>. Published June 1, 2005. Accessed May 20, 2016.
9. Report No. 47 (2008–2009) to the Storting. *The Coordination Reform. Proper Treatment—At the Right Place and right time* [summary in English]. Oslo, Norway: Norwegian Ministry of Health and Care Services. https://www.regjeringen.no/contentassets/d4f0e16ad32e4bbd8d8ab5c21445a5dc/en-gb/pdfs/stm200820090047000en_pdfs.pdf. Published June 19, 2009. Accessed January 10, 2016.
10. The Norwegian Cancer Society. Cancer Coordinator. https://kreftforeningen.no/Global/Engelsk/A4_kreftkoordinator%20flyer%20UICC2012-rev%20mars13.pdf. Published March 20, 2013. Accessed September 15, 2016.
11. Hernes FH, Lindseth P. *Kreftkoordinatorsatsingen. Første resultatrapportering fra kreftkoordinatorer og ledelse i kommune* [The Cancer Coordinator Initiative. First Report on Results by Cancer Coordinators and the Management in the Municipality.]. Oslo, Norway: Kreftforeningen [The Norwegian Cancer Society]; 2013.
12. Hernes FH, Lindseth P. *Kreftkoordinatorsatsingen. Andre resultatrapportering fra kreftkoordinatorer og ledelse i kommunene - høsten 2013*. [The Cancer Coordinator Initiative. Second Report on Results by Cancer Coordinators and the Management in the Municipality—Autumn 2013.] Oslo, Norway: Kreftforeningen [The Norwegian Cancer Society]; 2014.
13. Vattekar E. *Kreftkoordinatorsatsingen. Hovedrapport 2014*. [The Cancer Coordinator Initiative. Main Report 2014.]. Oslo, Norway: Kreftforeningen [The Norwegian Cancer Society]; March 3, 2015.
14. TNS Gallup. *Brukerundersøkelse Kreftkoordinatorer*. [User Survey for Cancer Coordinators.] Oslo, Norway: Kreftforeningen [The Norwegian Cancer Society]; September, 2014.
15. TNS Gallup. *Pasientforløp* [Patient Care] Oslo, Norway: Kreftforeningen [The Norwegian Cancer Society]; May 2015.
16. Yates P. *Survey of Cancer Care Coordinators Within the COSA Membership*. Clinical Oncological Society of Australia (COSA). https://www.cosa.org.au/media/1059/cosa_report_survey-of-cancer-care-coordinators_2009.pdf. Published April, 2005. Accessed March 21, 2016.
17. Litmus. *Evaluation of the Cancer Nurse Coordinator Initiative. Second Annual Report*. New Zealand Ministry of Health. <http://www.health.govt.nz/system/files/documents/publications/evaluation-of-cancer-nurse-coordinator-initiative-second-annual-report-nov15.pdf>. Published October 21, 2015. Accessed March 21, 2016.
18. Pedersen AE, Hack TF. The British Columbia patient navigation model: a critical analysis. *Oncol Nurs Forum*. 2011;38(2):200–206.
19. American Cancer Society. Navigators Help Cancer Patients Manage Their Care [Web page]. <http://www.cancer.org/myacs/midwest/program/sandservices/american-cancer-society-navigator>. Published February 24, 2017. Accessed March 8, 2017.

20. Carroll JK, Humiston SG, Meldrum SC, et al. Patients' experiences with navigation for cancer care. *Patient Educ Couns*. 2010;80(2):241–247.
21. Steinberg ML, Fremont A, Khan DC, et al. Lay patient navigator program implementation for equal access to cancer care and clinical trials: essential steps and initial challenges. *Cancer*. 2006;107(11):2669–2677.
22. McMurray A, Cooper H. The nurse navigator: an evolving model of care. *Collegian*. 2016;24(2):205–212.
23. Dohan D, Schrag D. Using navigators to improve care of underserved patients: current practices and approaches. *Cancer*. 2005;104(4):848–855.
24. Antonovsky A. *Health, Stress, and Coping*. San Francisco, CA: Jossey-Bass; 1979.
25. Antonovsky A. *Unraveling the Mystery of Health—How People Manage Stress and Stay Well*. San Francisco, CA: Jossey-Bass; 1987.
26. Antonovsky A. The salutogenic model as a theory to guide health promotion. *Health Promot Int*. 1996;11(1):11–18.
27. Lindström B, Eriksson M. Contextualizing salutogenesis and Antonovsky in public health development. *Health Promot Int*. 2006;21(3):238–244.
28. Milberg A, Strang P. What to do when 'there is nothing more to do'? A study within a salutogenic framework of family members' experience of palliative home care staff. *Psychooncology*. 2007;16(8):741–751.
29. Delbar V, Benor DE. Impact of a nursing intervention on cancer patients' ability to cope. *J Psychosoc Oncol*. 2001;19(2):57–75.
30. Gadamer HG. *Philosophical Hermeneutics*. Linge D, trans-ed. Berkeley, CA: University of California Press; 1976.
31. Lavery SM. Hermeneutic phenomenology and phenomenology: a comparison of historical and methodological considerations. *Int J Qual Methods*. 2003;2(3):21–35.
32. Koch T. Implementation of a hermeneutic inquiry in nursing: philosophy, rigour and representation. *J Adv Nurs*. 1996;24(1):174–184.
33. Creswell JW. *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*. Los Angeles, CA: Sage; 2009.
34. Kreftforeningen. Kreftkoordinator i kommunen [The Norwegian Cancer Society. Cancer Coordinators in municipalities] [Web page]. <https://kreftforeningen.no/rad-og-rettigheter/praktisk-hjelp/kreftkoordinator-i-kommunen/>. Accessed September 15, 2016.
35. Statistisk sentralbyrå. Folkemengde og befolkningsendring [Statistics Norway. Population and population changes] [database]. <http://www.ssb.no/befolkning/statistikker/folkendrkv/kvartal/2013-08-16?fane=tabell#content>. Accessed January 30, 2017.
36. World Medical Association Declaration of Helsinki. Ethical Principles for Medical Research Involving Human Subjects. 18th WMA General Assembly. Adopted June, 1964. <http://www.wma.net/en/30publications/10policies/b3/index.html>. Accessed February 10, 2015.
37. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77–101.
38. Hesse-Biber S, Dupuis P, Kinder TS. HyperRESEARCH: a computer program for the analysis of qualitative data with an emphasis on hypothesis testing and multimedia analysis. *Qual Sociol*. 1991;14(4):289–306.
39. Kelly MJ, Lloyd TD, Marshall D, Garcea G, Sutton CD, Beach M. A snapshot of MDT working and patient mapping in the UK colorectal cancer centres in 2002. *Colorectal Dis*. 2003;5(6):577–581.
40. Jiwa M, Longman G, Sriram D, Sherriff J, Briffa K, Musiello T. Cancer care coordinator: promoting multidisciplinary care—a pilot study in Australian general practice. *Collegian*. 2013;20(1):67–73.
41. Sanson-Fisher R, Girgis A, Boyes A, Bonevski B, Burton L, Cook P. The unmet supportive care needs of patients with cancer. Supportive Care Review Group. *Cancer*. 2000;88(1):226–237.
42. Adler NE, Page AEK. *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*. Washington, DC: National Academies Press (US); 2008.
43. Harrison JD, Young JM, Price MA, Butow PN, Solomon MJ. What are the unmet supportive care needs of people with cancer? A systematic review. *Support Care Cancer*. 2009;17(8):1117–1128.
44. Langeland E, Wahl AK, Kristoffersen K, Hanestad BR. Promoting coping: salutogenesis among people with mental health problems. *Issues Ment Health Nurs*. 2007;28(3):275–295.
45. Aiello Bowles EJ, Tuzzio L, Wiese CJ, et al. Understanding high-quality cancer care: a summary of expert perspectives. *Cancer*. 2008;112(4):934–942.
46. Fleissig A, Jenkins V, Catt S, Fallowfield L. Multidisciplinary teams in cancer care: are they effective in the UK? *Lancet Oncol*. 2006;7(11):935–943.
47. Sullivan GC. Evaluating Antonovsky's salutogenic model for its adaptability to nursing. *J Adv Nurs*. 1989;14(4):336–342.
48. Abelsen B, Ringholm T, Emaus P-A. *Hva har Samhandlingsreformen kostet kommunene så langt?* [What are the costs of the Norwegian Coordination Reform for the municipalities so far?] Norut Alta Rapport. [Report from the Northern research Institute in Alta.] 2012:9. http://norut.no/sites/norut.no/files/static_files/content/download/4571726/9305257/Norut%20Alta%20Rapport%202012_9%20hva%20har%20samhandlingsreformen%20kostet%20kommunene.pdf. Published August, 2012. Accessed June 10, 2016.