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**The role of cancer coordinators in
improving collaboration in cancer care at
local levels following the Coordination
Reform**

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Abstract

The present study is devoted to one area of change in the Norwegian cancer care associated with the Coordination Reform implemented in 2012. More specifically, my aim has been to shed light on the role cancer coordinators play in cancer care provision at local levels. This underlies both the theoretical presentation and the empirical study undertaken. Cancer coordinator positions were initiated in many municipalities following the Coordination Reform, as part of a trial project implemented by the Norwegian Cancer Society. The main objectives of these positions were to facilitate an increased coordination of cancer care at local levels, to optimize the level and timeliness of care for patients, their next-of-kin and health personnel serving this population in municipalities. As such, implementing cancer coordinator positions was a means to improve the provision of care and assistance for cancer patients and their families in municipalities and to enhance the development and maintenance of adequate collaboration between various municipal and non-municipal health care professionals, organizations, services and institutions to ensure the best possible practice in the area of cancer care (Kreftforeningen 2013). This thesis investigates the theoretical backgrounds for the cancer coordinator initiative and describes the impact of cancer coordinators' activity on the provision of patient-centered care and cancer care coordination, as viewed by the cancer coordinators themselves.

Utilizing a post-New Public Management framework in the theoretical examination allows me to shed light on the explicit and more implicit backgrounds for the implementation of cancer coordinators in municipalities, and to analyze various outcomes as expressed by cancer coordinators in light of this theoretical approach. As the implementation of cancer coordinator positions is inherently interconnected with the Coordination Reform, I have included a brief discussion of this reform from the same theoretical perspective.

Post-New Public Management ideas are characterized by processes aimed to enhance both horizontal and vertical coordination, resulting in greater cross-sectoral collaboration and integration and focuses on value-based management and pro-active leadership (Ling 2002; Alford 2002; Pollitt 2003; Stoker 2006; O'Flynn 2007; Christensen and Lægreid 2007).

The quantitative study has demonstrated that the implementation of the cancer coordinator trial project in several Norwegian municipalities has had a positive impact on the provision of patient-centered care and cancer care coordination, as viewed by the cancer coordinators

themselves. In particular, the majority of cancer coordinators reported that they had good or very good communication with cancer patients and were capable of meeting cancer patients' needs, ensuring a positive impact of their activities on the patients' life situation. Furthermore, cancer coordinators commonly used home-visits as a means of communication with cancer patients and their next-of-kin. Cancer coordinators participated in supervision and education of cancer patients and their families in the municipality at least monthly. The majority of cancer coordinators denoted very good or good collaboration with palliative care and cancer care nurses, oncological outpatient departments, palliative care departments, nursing homes and cancer coordinators of other municipalities and/or representatives of the Norwegian Cancer Society. Moreover, cancer coordinators initiated and maintained collaborative actions with several concerned parties in the municipalities by means of attending or arranging joint meetings at least monthly. On the other hand, this study also revealed organizational and communication difficulties within the area of cancer care, which need to be considered and resolved to further improve the level of care and cancer care coordination. In particular, cancer coordinators denoted that it was sometimes quite difficult or even not possible to communicate and collaborate on cancer patients with general practitioners, NAV, schools and/or kindergartens. In addition, the majority of cancer coordinators reported that better collaboration with general practitioners about new and existing cancer patients, as well as better interaction with hospitals and municipal services, could make their work more effective.

Comparisons of the results from this empirical analysis with the results of studies conducted in similar areas in national and international contexts indicate the presence of common features, particularly with regard to the difficulties in maintaining an appropriate level of coordination. A comparison of the obtained results with the results of the evaluation report of the Norwegian Cancer Society shows that the results of the present study are in line with those reported by the Norwegian Cancer Society.

Cancer coordinators have been shown to provide enhanced patient-centered care for cancer patients and maintain cancer care coordination at local levels. However, the process of cancer care coordination among services, institutions and organizations is considered complicated and has been shown to exceed the resources available to cancer coordinators. As a consequence, cancer coordinators' interaction and collaboration with several health care and municipal services need to be improved.

Key words: cancer care, cancer care coordination, cancer coordinators, municipalities, patient-centered care, post-New Public Management, the Coordination Reform, the Norwegian Cancer Society.

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Preface

My academic background has been formed at the Medical Academy in Russia and my medical practice has subsequently been in radiation oncology and palliative therapy for cancer patients. From this I have realized the importance of a well-functioning public health care system to facilitate lengthy and healthy lives in general, and to improve life for cancer patients in particular. The Norwegian health care system is quite a demonstrative example to explore from this perspective, since this area of health care is granted or “guaranteed” by the welfare state. As a clinician who has worked with cancer patients in vastly different settings, I wanted to explore oncological services and cancer care provided by the Norwegian health care system. More specifically, I decided to devote this thesis to the examination of the project about the implementation of cancer coordinators in several Norwegian municipalities.

Undertaking the work to complete this master’s thesis involved several challenges connected to both the theoretical framework and the empirical analysis. I have examined a fair amount of publications in the area of public administration. I traveled to the Southern and Eastern parts of Norway in order to get insight into cancer coordinators’ work roles in various municipalities. I am very grateful to all those people who helped me overcome the difficulties that arose on my research path.

I am grateful for the input I have received from my supervisor, Astri Syse, Senior Researcher at Statistics Norway. She has been an ideal intellectual mentor and supported me at tough moments, encouraging my research activity.

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List of abbreviations

COCOPS - Coordinating for Cohesion in the Public Sector of the Future

DRG - Diagnosis Related Group

HiOA - Oslo and Akershus University College of Applied Sciences

IP – Internet Protocol

JUG - Joined-up Government

NAV - Norwegian Labor and Welfare Organization

NCS - the Norwegian Cancer Society

NPG - New Public Governance

NPM - New Public Management

NSD - Norwegian Social Science Data Services

NSW - New South Wales

OECD - the Organization for Economic Cooperation and Development

Post-NPM - Post-New Public Management

PVM - Public Value Management

UK - the United Kingdom

US - the United States of America

WOG - the Whole-of-Government

1. Introduction

1.1. Background

With increases in life expectancy and thus aging populations throughout the developed world, the incidence and prevalence of cancer is rising since cancer is a disease strongly associated with aging (Ferlay et al. 2008). According to the Cancer Registry of Norway (2013), more and more people get cancer, but at the same time more people are cured or may live with cancer for years. The annual report for 2011 has shown that about 30 000 people were diagnosed with cancer in 2011 while around 216 000 people in the municipalities are alive after a diagnosis of cancer (Cancer Registry of Norway 2013).¹ The necessity to provide appropriate treatment and care in a cost-efficient manner is thus becoming a pertinent public health issue in Norway, as in most developed countries.

In a broad sense, oncological services include all types of medical treatment and care services, as well as spiritual, psychological and practical support, which are provided to those suffering from oncological diseases by health care personnel, relatives or any other people responsible for care procedures. Publicly provided oncological services in Norway include institutions and organizations such as regional oncological centers, oncological inpatient departments at hospitals, oncological outpatient departments, nursing homes for cancer patients in need of cancer treatment and/or palliative care, hospices for palliative care, home health cancer care and many other cancer-related arrangements which are responsible not only for medical treatment, but for care in general which may or may not be a direct consequence of cancer and/or cancer treatment. Cancer care involves counseling, field education, spiritual support and practical assistance for cancer patients and their next-of-kin. The area of cancer care provision in Norway is nowadays passing through relatively broad changes as the Norwegian health care system is currently undergoing major adjustments due to recently implemented reforms at national and local levels. The Norwegian Ministry of Health has begun the implementation of the Coordination Reform since the start of 2012 in order to manage three distinctive challenges of the Norwegian health care: lack of coordinated services for patients, suboptimal levels of services toward disease prevention, and changing disease patterns due to the aging of

¹ This is termed “prevalence” by the Cancer Registry of Norway, but as some individuals may be cured and no longer be affected by their cancer, it is not a “true” measure of cancer prevalence, but an approximation (Cancer in Norway 2013).

population (Report No. 47 (2008–2009)). This reform has had a major impact in many areas of cancer care as more obligations have been given to municipalities, and positions of cancer coordinators within several municipalities have been established.

From the first of January 2012, most municipalities have been strongly encouraged to have a person who is responsible for providing information, support, certain instructions on diagnosis and treatment procedures, rehabilitation and end of life care for cancer patients and health care personnel. Any new policy implementation in a social sector or in a sphere of health care is an interesting field for investigation, and the present thesis is devoted to the role of cancer coordinators following the Coordination Reform in Norway.

1.2. Intentions of the investigation

1.2.1. Aim

The main aim of this thesis is to investigate selected short-term outcomes of the Coordination Reform in Norway in the area of cancer care provision. More specifically, I have assessed the role of the cancer coordinators' both theoretically and empirically. I have examined the extent to which cancer coordinators have contributed to the provision of patient-centered care and to increased coordination of cancer care. Moreover, I have tried to highlight areas where the provision of well-coordinated cancer care remains complicated despite the role of cancer coordinators as mediators and/or moderators both within municipalities and between municipalities and local and/or regional health care institutions.

1.2.2. Research question

A suboptimal level of coordination of health care services in Norway was a significant reason for the recently implemented Coordination Reform. The reform aimed to help alleviate parts of the problems experienced by patients, their next-of-kin, as well as health care providers. A successful collaboration in the area of cancer care provision between both municipalities and local and/or regional health care institutions and within municipalities may help increase cancer survival and also help improve the quality of life for cancer patients. The position of a cancer coordinator in one or collaborating municipalities was established in order to provide more comprehensive and individual cancer care coordination for patients and caregivers, as well as facilitate more effective

collaboration among a great number of involved parties within and beyond municipalities in the diverse Norwegian setting.

The research provided here primarily concerns the activity of cancer coordinators and their role in the area of cancer care provision in their respective municipalities, and the empirical investigation is limited to the views of cancer coordinators themselves. As such, my main research question reads: *how has the implementation of cancer coordinators in Norwegian municipalities influenced cancer care provision at local levels?*

Admitting that the answers to this question may be complex and entail several dimensions, it appears conducive to examine the possible answers corresponding to two overarching assumptions: *(1) the implementation of cancer coordinators in municipalities has contributed positively to the provision of patient-centered care and improved coordination in the area of cancer care; or (2) for some reasons, the implementation of cancer coordinators in municipalities has failed to contribute fully to patient-centered care and enhanced coordination.*

2. Definitions of operational concepts

2.1. The Norwegian Cancer Society

The Norwegian Cancer Society is a large private organization that provides measures for cancer prevention, advocacy, information, research, care and international cooperation (Kreftforeningen 2012).

The main objectives of the Norwegian Cancer Society are:

- to reduce the prevalence and incidence of cancer in the Norwegian population;
- to improve survival of people with cancer;
- to maintain the best quality of life for people affected by cancer, i.e. cancer patients and their relatives.

Among the main priorities of the Norwegian Cancer Society are research funding, cancer prevention and international collaboration, cancer care, communication and fundraising. The area of cancer care is covered with such arrangements as “Vardesenters” (meeting places for cancer patients and their families with activities that promote quality of life, well-being and coping), Cancer Help Line (direct support to patients and their families), rehabilitation programs, palliative care and cancer coordinators (Kreftforeningen 2012).

From the standpoint of objectives, priorities, funding and practical assistance, the Norwegian Cancer Society may be considered an important driver in the “war on cancer” in Norway (National Cancer Strategy 2013-2017).

2.2. Cancer care

Patients who live with oncological diseases are often in need cancer care, but it is difficult to estimate the exact number of patients belonging to this group at a given point in time, as the group is comprised of both newly diagnosed patients, as well as patients diagnosed several years previously. As the incidence of oncological diseases is rising and the population is aging, there is a rapid increase in the number of cancer patients and cancer survivors in Norway. Moreover, modern cancer treatment has improved survival, and more patients live longer with or after cancer. Taken together, these factors result in an increase in the number of persons requiring cancer treatment and care. The term cancer care may include cancer-related counseling, education, spiritual support and/or practical assistance.

Cancer care delivery systems are fairly well organized in Norway. Particularly close attention is paid to palliative care, i.e. end of life care. Palliative care is per definition not curative, but aims to improve the quality of life of patients who have a serious or life-threatening disease, such as cancer. The goal of palliative care is to prevent or treat, as early as possible, the symptoms and side effects of the disease and its treatment, in addition to the related psychological, social and spiritual problems. Palliative care is also called comfort care, supportive care and symptom management (National Cancer Institute 2010).

The Norwegian Ministry of Health and Care Services regularly publishes guidelines for palliative care. The main manual for palliation in Norway is the National action plan with guidelines for palliative care in cancer care (own translation). The last action plan was released in 2013, and includes information about types of palliative care provision in Norway, various clinical symptoms and their treatment or alleviation, ethical and spiritual aspects, different challenges that appear in the process of treatment, care and communication, specifics of interaction with patients’ next-of-kin and many of the benefits that the state (in this case the municipality) may provide for cancer patients (Helsedirektoratet 2012). The plan also contains data about the organization of palliative care on different levels, starting with specialized palliative centers and hospitals and ending with home-based services in municipalities (ibid).

In parallel with palliative care, also non-palliative cancer care in Norway may be provided by either the state or private institutions, organizations and societies: from the before mentioned “Vardesenters”, Cancer Help Line, rehabilitation programs of the Norwegian Cancer Society up to cancer patients’ communities, home-based services and cancer coordinators in municipalities.

2.3. The Coordination Reform of the Norwegian health care

The Coordination Reform is a governmental project that has been implemented in Norway since January 1, 2012. The underlying motivation was put forward in the following manner by the Norwegian Health Care Minister Bjarne Håkon Hanssen:

In public health spending per capita, Norway ranks among the highest of all OECD nations – but we have not achieved a correspondingly high level of health in return. More people are falling ill, our population is aging, more people need help for longer periods, more diseases are treatable with new technology, and the queues are lengthening for specialist health care services. These developments are simply not sustainable... There is a great deal that is going very well, but many people still do not receive the help they need, when they need it. Insufficient coordination is the main reason that our ill elderly as well as people with chronic diseases, substance abuse problems and mental health disorders too easily lose out in Norway’s current health care system (Report No. 47 (2008–2009)).

The Coordination Reform points to three main challenges in the Norwegian health services:

1. Patients’ needs for coordinated services are not being sufficiently met.
2. There is insufficient initiative aimed to limit and prevent disease.
3. Changes in the demographic and epidemiological patterns in Norway are undergoing great change, resulting in an increasing number of people with chronic and complex illnesses, such as chronic obstructive pulmonary disease, diabetes, dementia, cancer and mental disorders, in need of coordinated services.

These challenges call for more efficient management of services (ibid).

Norwegian municipalities have been given more duties and responsibilities due to the changes following from the reform. At the same time, they have been provided with additional funding to ensure that they will be able to handle the additional tasks. These measures have been taken to ensure that patients will receive “the proper treatment at the right place and at the right time” (ibid). Some of the means that have been offered by the policymakers of the Coordination Reform include clearer guidelines for patients, a new

municipal role emphasizing prevention, focus on early intervention efforts and interdisciplinary measures. More specifically, the Norwegian Government has suggested that patients with needs for coordinated services (such as for instance cancer patients) should be assigned one person as a contact point in the municipality for all health care services (ibid). As a consequence, a project to establish cancer coordinator positions in municipalities was initiated.

The Coordination Reform has affected many additional areas of the Norwegian health care services. The focus of interest in this thesis is, however, limited to the project of establishing cancer coordinator positions in municipalities to strengthen the coordination of cancer services. As such, the further arguments and data will address solely the question of the role and functioning of cancer coordinators.

2.4. Cancer coordinators

As a subproject of the much larger and more broadly encompassing Coordination Reform, a three to four year trial project with cancer coordinators in Norwegian municipalities was launched in the beginning of 2012. This project was designed by the Norwegian Cancer Society, which agreed to cover 75% of the costs of the newly created positions, whereas 25% of the costs were left for the municipalities to be responsible for. According to the annual report for 2012, the Norwegian Cancer Society planned to invest 120-150 millions NOK in the overall project. About 30 millions NOK were invested in the project in 2012 (Kreftforeningen 2013). The cancer coordinator positions were to be owned and administrated by the respective municipalities. This meant that the authorities of municipalities had to work out a range of responsibilities and action plans for this new position. As a consequence, there is great heterogeneity in the definition and operationalization of these newly established positions across municipalities.

A total of 97 cancer coordinators began their work in 148 municipalities across the country during 2012. Recruitment continued into 2013, and as of November 2013, a total of 112 cancer coordinator positions covering a total 223 municipalities have been established (Kreftforeningen 2014). Thus, around 52% of the 428 Norwegian municipalities have cancer coordinators in place as of today. According to a recent report of the Norwegian Cancer Society (2014), cancer coordinators had been in contact with 4971 patients and 3834 next-of-kin of cancer patients by the end of November 2013. Some of the cancer

coordinator positions are full time, whereas others are part-time. Some positions are established within only one municipality, whereas others are designed to cover two or more municipalities, thus entailing intermunicipal collaboration (ibid).

The overall aim of the Norwegian Cancer Society has been to ensure a permanent establishment of cancer coordinators in municipalities with municipalities covering the full cost, in case of successful trial period (Kreftforeningen 2012).

The cancer coordinator in the municipality should be a person who is responsible for ensuring coordination of assistance and services for cancer patients and their families, for providing good living conditions and the best possible quality of life for the individual cancer patient, for creating consistency and predictability in the area of health care provision and for using interdisciplinary approaches at work (Kreftforeningen 2012). The cancer coordinator of the municipality is supposed to be a health care worker, for instance, a registered nurse, who has obtained an extended experience in working with cancer patients (Telemark kommune 2012). It should be mentioned that although most cancer coordinators are nurses, this was not a requirement from the Norwegian Cancer Society (Kreftforeningen 2012).

As more and more people get cancer, and at the same time more people are cured or live with cancer for years, the need for available, personalized and coordinated arrangements directly at the location of cancer patient's residency is essential to optimize care and to maintain costs. In such conditions, the cancer coordinator position could foster a visible and accessible area of expertise for people dealing with cancer, as well as individuals and institutions aiming to provide help and support. Cancer coordinators may present an overview of relevant programs and services, information, support, instructions about diagnosis, treatment, rehabilitation, as well as relief and care at life's end. The cancer coordinator is also obliged to work intersectorally, providing advice and guidance to relevant agencies and partners in the municipality and cooperating with patient associations, volunteers and peers, as well as other non-public service providers (Kreftforeningen 2012).

Norway possesses a great amount of human resources and services that could be used in the area of cancer care: specialized nursing homes, home-based services (both municipal and private), hospices, palliative teams and quite a few private alternatives like for instance

Fransiskushjelpen and other initiatives. However, cancer care may be enhanced if there is increased knowledge of one another, as well as communication between the different service providers. Cancer coordinators could play an important role in providing such knowledge and coordination. The lack of information among the cancer patients and their next-of-kin about such treatment and care options may result in practical, medical and psychological problems that could be minimized by appropriate coordination. Insufficient knowledge about the home-based services that may be given to a cancer patient by for instance public home health care providers at any point in time could increase the adverse consequences of cancer and its side effects. Positions of cancer coordinators were thus called for to increase the accessibility of cancer care and improve efficiency in handling cancer patients' problems through improved relations with all the services responsible for providing cancer care.

The establishment of cancer coordinator positions is not a novel idea, although it is new in Norway. Several other developed countries have cancer coordinators in place. A broad example of a country that has implemented cancer coordinator positions is the United States (US). Almost all large private or state-supported hospitals with cancer departments have employed cancer coordinators.

The Praxair Cancer Center in Connecticut, for example, proposes the service called "cancer care coordinator" within the variety of other offerings for cancer patients and their families (Western Connecticut Health Network 2014). The cancer care coordinator in the Praxair Cancer Center is a specially trained oncology nurse who may start working with cancer patients from diagnosis onward in order to help find or clarify information, suggest questions to ask, send/refer these patients to the right place to manage cancer symptoms and provide support, hope and encouragement (ibid).

The Banner Desert Cancer Center also offers cancer patients the opportunity to work with a cancer care coordinator (Banner Desert Medical Center 2014). The cancer care coordinator is a certified nurse practitioner with prolonged experience in cancer care who is supposed to assist with any part of a patient's cancer journey, from scheduling tests and treatments to answering questions about hospital programs and services, providing support and serving as a personal liaison for cancer patients undergoing treatment and seeking

guidance (ibid). However, since the health care system of the US is vastly different from that of Norway, direct comparisons are challenging to undertake.

Another example of a relatively efficient implementation of cancer coordinator positions can be found in Australia in the state of New South Wales (NSW), where the cancer care coordinators' project was initially launched in 2004 and has become very successful (Cancer Institute NSW 2011). The Australian case is more similar to that of Norway because the organization of health and care services in New South Wales is quite similar to the organization of health and care services in Norway. However, some structural differences should be noted. Positions of cancer coordinators in NSW were completely financed by the Cancer Institute of New South Wales. Around 50 cancer coordinators worked in the Australian state on several grounds: metropolitan cancer coordinators were primarily based at a single institution and coordinated the care of patients of one tumor type or treatment modality, whereas rural cancer coordinators were community based and generally functioned across multiple tumor types or treatment modalities (Cancer Institute NSW 2011, 3).

According to the Cancer Institute of New South Wales, the position of cancer coordinator was implemented to increase access to care coordination for cancer patients in the regions, and to develop a form of care coordination that could operate throughout all cancer services (ibid). The evaluation of the Australian project made in 2009-2010 has demonstrated that cancer coordinators contributed to more direct service delivery, enhanced the patient-centered care, improved care coordination and supported multidisciplinary care (Cancer Institute NSW 2011, 9). The positive results of the Australian project allow for hope for positive effects from the introduction of cancer coordinators also in Norway.

3. Theoretical concepts

3.1. New Public Management

3.1.1. Main ideas of New Public Management

A broad look at the situation in Norway shows that public policies in welfare and health care areas have been associated with a group of reforms that can be merged under the principles of the concept known as New Public Management (NPM). According to Christensen and Lægveid (2011), the key ideas of NPM come from new economic

institutional theory and management theory which have in common some principles concerning actors' motivation, focus on efficiency and contain elements of both centralization and decentralization. Taken together, both new economic theory and management theory stress that the public sector should learn from the private sector (Christensen and Lægreid 2011). Initial ideas underlying the development of NPM arose in US and the United Kingdom (UK), but diffused relatively rapidly and were present in the majority of capitalistic countries during the period 1970 to 1980 (McTavish 2003; Fusarelli and Johnson 2004).

Hood (1991, 4-5) describes the NPM paradigm by the weight placed on the following components:

- disaggregation of elements in the area of public sector;
- private sector rules in practical management;
- explicit standards and performance measuring;
- high emphasis on output controls;
- practical professional management;
- higher level of competition in the public sector;
- greater discipline and parsimony in the use of resources.

On the other hand, Tolofari (2005), Yamomoto (2003), Ferlie et al. (1996) and Boston et al. (1996) note the following distinctive features of NPM:

- commercialization and privatization that imply extracting government from the trading aspects;
- managerialism and marketization that are characterized by such tools as mission statements, development plans, labor contracts and performance agreements;
- cutting costs and applying only the least necessary amount of resources with the aim of achieving the maximum utility possible;
- allocation of the resources on the basis of evaluation of sufficient results;
- making the provision and quality of services dependent on competition;
- centralization/decentralization, including delegation or spreading of management authority;
- disaggregation that implies separation of policy formulation from policy execution;
- strict performance obligations concerning employees and employers, and high rates of contract employment.

Kelly (1998) and Lynn (1998) argue that the NPM concept gives priority to performance management, specific institutional mechanisms and structural modalities on the grounds of some particular features of human behavior, focused basically on individualism and individual rationality. According to Kaboolian (1998), the main principles of NPM imply that:

- economic market is a correct pattern for all the interactions in public sector;
- functions of policy realization and delivery are supposed to be separated and created as a chain of contracts;
- a group of new managerial technique is to be implemented, including performance-based contracting, competition, market incentives and deregulation.

Over time, outcomes from NPM measures across the world, including for instance Australia, New Zealand and the UK, have been far from successful (Entwistle and Martin 2005; O’Flynn and Alford 2005; OECD 2003). According to Entwistle and Martin (2005), competitive regimes, which were introduced and applied in many countries, have been costly to implement and rarely delivered real competition. O’Flynn and Alford (2005) point out that competitive administrative models cause a fragmentation of interactions that may result in destructive behavior of concerned parties. The report of the Organization for Economic Cooperation and Development (OECD) draws some conclusions on NPM, emphasizing that “reforms produced some unexpected negative results” (OECD 2003, 2). In the framework of NPM, policymakers were primarily concerned with the economic substance of management processes and missed essential features of human and social nature, which were in fact important for more effectual governance (Moore 1995).

The lack of positive outcomes from the implementation of the NPM principles has become a boost for significant changes in the area of public services administration. Thus, in the late 1990s, many countries, which had previously relied on NPM reforms, shifted to rely on quite a different set of ideas later entitled a post-NPM approach (Christensen and Lægheid 2011).

3.1.2. NPM in the Norwegian health care

The Norwegian Hospital Reform in 2002 may be considered an example of a NPM reform in the Norwegian public sector. The implementation of the reform started in 2002, when the administration of Norwegian hospitals was relocated from the counties to the central

government. According to Christensen and Læg Reid (2009), the reform centralized the ownership rights, so that the Ministry of Health supported by two subordinate institutions was given the main responsibility in the area of administration. The reform was characterized by an innovative management system, which was regarded as an enterprise model (Christensen, Læg Reid and Stigen 2006). Five regional health enterprises with separate management were established under the Ministry of Health, and resulted in an organization of approximately 250 institutions into 34 local health enterprises under regional departments (Læg Reid, Opedal and Stigen 2005).

According to Christensen and Læg Reid (2009), the official purpose of the reform was to amplify effective interactions thus providing more efficient utilization of resources through better control over the hospitals' finances. This purpose corresponds highly to the basic principles of NPM on aspects of performance management.

Some characteristics of NPM inherent in the hospital reform were quite pronounced. The reform introduced the key concepts of commercialization and managerial autonomy, since the hospitals were withdrawn from the ordinary public administration and changed into enterprises, which were supposed to be autonomous from the perspective of management (Christensen and Læg Reid 2009). Moreover, the establishment of a Diagnosis Related Groups (DRG) system for cost reimbursements, that may be characterized as an incentive system for the treatment of patients or 'money-follows-the patient' system, transformed both administrative actors and doctors in hospitals into strategic actors (Christensen, Læg Reid and Stigen 2006). The main intention behind the use of DRG in Norway was to enhance the activity levels of hospitals. According to Christensen, Læg Reid and Stigen (2006), performance-based funding was one of the major sources of governance in the framework of the Hospital Reform. In particular, the DRG system was a constituent of the activity-based funding system. Furthermore, it was a management mechanism in contracts between regional health enterprises and hospitals used both as a way to increase the performance in hospitals and to boost improved efficiency (ibid). All these aspects provide evidence for the NPM concepts in the implementation of the Hospital Reform in Norway in 2002.

It should be noted, however, that it would not be possible to fully implement NPM reforms in their purest sense in the area of Norwegian health care, because Norway is a welfare

state with a very strong government component and a relatively low level of privatization and market-based competition in public sector in general and in health care in particular (Christensen and Lægreid 2011). These presuppositions in the Norwegian case facilitated a fairly rapid spread of ideas, which were called post-New Public Management concepts (ibid).

3.2. Post-New Public Management

3.2.1. Main post-New Public Management concepts

The ideas of post-NPM have gradually been replacing the ideas of NPM within the public service sphere due to the inability of the latter to deliver expected positive results (Entwistle and Martin 2005; O’Flynn and Alford 2005; OECD 2003). For Norway, changes began as a consequence of the shift in the government after the election in September 2005 and are currently continuing.

Post-NPM is often used as a collective term, encompassing the new concepts that substitute NPM ideas with alternatives in the area of public sector administration. The term is used extensively in the latest works of the Norwegian authors Tom Christensen and Per Lægreid, who conduct investigations within the public sector field in Norway and publish extensively on public sector reform and institutional change in a comparative perspective. Christensen is a professor of public administration and organization theory at the University of Oslo, Norway, whereas Lægreid is a professor of administration and organization theory at the University of Bergen, Norway. The post-NPM theories on health care organization provided by Christensen and Lægreid comprise the main background for the theoretical part of this thesis and will thus be described and discussed in more detail in the following paragraphs.

The term post-NPM is not universally used or commonly accepted. Some other short definitions or names, such as for instance Public Value Management, New Public Governance, or Whole-of-Government Approach, have been given to the range of policies that have come to replace NPM (Stoker 2006; Osborn 2006; Christensen and Lægreid 2007). Nonetheless, I will use the term post-NPM here, but briefly discuss the background for the other terms for completeness purposes.

The term Public Value Management (PVM) has been extensively used in works of British and American authors such as Mark H. Moore (1995), Gavin Kelly, Geoff Mulgan and Stephen Muers (2002), R.F.I. Smith (2004), Janine O’Flynn (2005) and Gerry Stoker (2006). According to Stoker (2006), PVM presupposes that the service delivery can generate public value provided that the collaboration between the concerned parties and the official management is strong and connected with the idea of legitimacy of the government’s decisions for the concerned parties. O’Flynn (2005) states that one of the necessary concepts of the public value paradigm “is the concept of collective preferences which distinguishes it from the individualist focus of the NPM”. The first ideas about the importance of public value may be found in the book of Moore (1995) “Creating public Value: Strategic management in Government”. According to Moore (1995), the situation in the private sector, where private sector managers must form the private value, corresponds to the situation in public sector, where the formation of public value is the main practice of public managers. Public value, in accordance with O’Flynn (2005), is “a multi-dimensional construct” that is built not only on the basis of obtained results, but also thanks to processes “which may generate trust or fairness”. The essence of the concept of PVM is thus fairly identical to the concept of post-NPM.

The term New Public Governance (NPG) has been applied most extensively by Stephen P. Osborne in his works from 2006 onwards. In addition, Bob Hudson (2004) and Tony Bovaird (2006) mention this approach. Osborne (2006) argues that the period of NPM ideas was a transient period where conventional public administration ideas were transformed into a new set of ideas named New Public Governance (NPG). According to Osborne (2006, 384), a state that relies on New Public Governance is

both a plural state, where multiple inter-dependent actors contribute to the delivery of public services, and a pluralist state, where multiple processes inform the policy making system. As a consequence of these two forms of plurality, its focus is very much upon inter-organizational relationships and the governance of processes, and it stresses service effectiveness and outcomes.

Bovaird (2006) points out that the key management mechanisms in case of a NPG approach imply trust, relational contracts and capital, whereas Hudson (2004) emphasizes that NPG tends to create and evaluate stable inter-organizational relationships. The ideas,

which formulate the basement of NPG, are close to post-NPM concepts, and in a broad perspective the NPG concept may be viewed as similar to that of post-NPM.

The Whole-of-Government (WOG) approach defined new concepts that substituted NPM in several countries. This term was introduced in working papers and official guidelines from many states in the beginning of the 2000s. In 2006, OECD published a report entitled “The Whole of Government Approaches to Fragile States” about the range of WOG approaches for unstable developing countries. The majority of developed countries, such as the UK, Canada, Australia and many others, had already begun their implementation of WOG approaches according to available governmental web sites and white papers (Pollitt 2003; Treasury Board of Canada Secretariat 2005; Australian Government 2004).

According to Christensen and Lægheid (2007), the Whole-of-Government approach could be considered a “generation of reforms initially labeled ‘joined-up government’ (JUG)” that found its evidence in the Anglo-Saxon countries as a reaction to negative results of NPM. Pollitt (2003), cited in Christensen and Lægheid (2007), argues that some of the aims of the WOG/JUG approaches are to gain better policy functioning by means of horizontal and vertical coordination, to improve the use of limited resources, to generate collaboration between different concerned parties and to offer people unproblematic access to services. It should be mentioned that the WOG approach corresponds fairly well with the concepts of post-NPM, so these two terms could be treated as synonyms for our purposes here.

Taking into account all terms described above, it should be accentuated that the term post-NPM is the most appropriate for this thesis for the following reasons:

- the term post-NPM is more collective than the alternative terms described above, and it may include different approaches, since it does not have specific characteristics in the name of the term;
- the prefix “post” indicates both the period of time and the fact that the ideas of post-NPM took place after an unsuccessful period where NPM prevailed;
- the presence of the name NPM in the term shows that the ideas of post-NPM have been influenced by NPM and after gathering the prefix with the actual name of the policy, it may be designated that the ideas of post-NPM have appeared as a result of insufficiency of NPM.

The term post-NPM is a collective concept. However, it can be characterized and defined quite precisely. According to Christensen and Lægreid (2007, 1060), the first post-NPM ideas as the concepts of joined-up governance appeared during Tony Blair's government in the UK in 1997, and the "main aim was to get a better grip on the 'wicked' issues straddling the boundaries of public sector organizations, administrative levels, and policy areas". The post-NPM ideas have spread promptly in Anglo-Saxon countries where they were substantially tied to NPM's deficiencies and expressed as:

- the measures towards vertical reintegration of some agencies and enterprises, by means of dissolving some of them and integrating their activities in the ministries, or establishing more controls and constraints on agencies and state-owned enterprises;
- the measures towards strengthening central political capacity by employing more political assistants at the ministries and offices of public management organizations and by approaching administrative capacity to the political executive power (Lægreid and Christensen 2011, 395).

Considering the post-NPM characteristics extracted from Ling (2002), Alford (2002), Pollitt (2003), Stoker (2006), O'Flynn (2007) and Christensen and Lægreid (2007), the general definition of post-NPM could include the following items:

- higher level of centralization and greater government control;
- vertical coordination: directing more central resources towards subordinate institutions and using stronger instruments of central control;
- horizontal coordination: greater cross-sectoral collaboration and integration;
- the concept of public value, which indicates collective preferences formed by citizens
- broad pro-active leadership with working for perspective for collective goals and values;
- focus on value-based management and ethical standards (cultivating a unified sense of values, team-building and involvement of participating organizations).

Some authors claim that the post-NPM reforms have not fully replaced the NPM reforms today (Christensen and Lægreid 2011; Bouckaert et al. 2010), but have become adjustments of NPM. One way or another, the influence of post-NPM ideas is sufficiently major to change the basic norms and values in the area of contemporary public sector management in general and health care management especially in the majority of Anglo-Saxon and Nordic countries.

3.2.2. The Coordination Reform in Norway from the perspective of post-New Public Management ideas

Norway could be viewed as a country that over time has been quite reluctant to the implementation of NPM ideas in its purest sense in the area of health care owing to the features of health care delivery (Christensen and Læg Reid 2007). The concepts and main characteristics of post-NPM ideas, on the contrary, correspond well with the Norwegian health care model (ibid). The recently implemented Coordination Reform may be considered an example of the post-NPM concepts implementation, which manifests itself within the framework of cooperation improvement and connection of two major levels of health care provision.

The relevance of post-NPM ideas for Norwegian public sector development is indicated in the last reports of the project Coordinating for Cohesion in the Public Sector of the Future (COCOPS). COCOPS is currently working on the assessment of the impact of consequences of NPM reforms in Europe, providing detailed information about the conditions of the public sector in various European countries through these reports. Norwegian representatives of the project, Per Læg Reid, Åsta Dyrnes Nordø and Lise H. Rykkja, describe and analyze the situation within the Norwegian public sector in general and in the Norwegian health care in particular. The report, released in May 2013, emphasizes the fact that the Norwegian government in the period of 2005-2013 tended to stress such post-NPM characteristics as “the participation of employees”, “collective features and societal solutions, voices support for a large public sector”, and was “skeptical towards competitive tendering, out-sourcing and privatization” (Læg Reid et al. 2013, 11). As such, the Coordination Reform may be viewed as promoting post-NPM ideas in the area of health care. According to Læg Reid et al. (2013, 49),

...the Coordination Reform is focusing on the relationship between the primary health care with a municipal responsibility and the specialist health care with government owned health enterprises responsibility. The goal is for the patients to receive the proper treatment – at the right place and right time. A binding system of agreements between municipalities and health authorities has been launched and financial incentives and municipal co-financing of patient treatment has been introduced.

The Coordination Reform was designed and implemented by the Norwegian Ministry of Health and Care Services. The reform empowers municipalities, which may be considered as lower layers of the state organization. Empowerment mainly concerns co-financing of

the municipal activities in line with the reform. This issue designates the presence of vertical coordination in the form of directing more central resources to lower organizations. The development of vertical coordination is one of the typical signs of post-NPM (Christensen and Lægreid 2007).

According to the Report No. 47 (2008-2009) of Norwegian Ministry of Health and Care Services, the Coordination Reform is supposed to cope with the following challenges of the Norwegian health care sector:

- patients' needs for coordinated services are not being sufficiently met;
- there is too little initiative aimed at limiting and preventing diseases in the services;
- population development and the changing range of illnesses among the population.

The following solutions for the challenges are stressed on page 3 of the report as the key steps in the on-going reform:

- a clearer role for the patient;
- a new municipal role emphasizing prevention, early intervention efforts, low threshold initiatives and interdisciplinary measures;
- changing the funding system so that municipal co-funding of the specialist health care services becomes a vital element;
- developing the specialist health care services to enable them to apply their specialized competence to a greater extent;
- facilitating better-defined priorities;
- improved information and communication technologies;
- competent health care professionals.

Each key step of the reform is explained in detail, and recommended measures are outlined by the policymakers in the aforementioned report.

A more detailed examination of the content of the Coordination Reform reveals a high degree of correspondence with the concepts characterizing post-NPM. Most of the measures included in the reform point to improved horizontal coordination, greater cross-sectoral collaboration and integration. As an example, the increased responsibilities laid on municipalities concerning disease prevention and early intervention require improved coordination between regional and municipal levels of health care provision. The report states on page 7 that a "system of agreements on distribution of tasks and cooperation

between municipalities/cooperating municipalities and health authorities should be legally established”. The issue of cross-sectoral collaboration is underlined also in measures regarding patients’ pathways. It is denoted on page 5 of the report that “the municipalities should be required to ensure that patients with needs for coordinated services are assigned one person as a contact point”. Further, the report underscores the importance of cross-sectoral collaboration among doctors and medical personnel. On page 8, it notes that the municipalities must be sure that “regular general practitioners coordinate with others” and medical staff provides coordinated care for patients discharged from hospitals. Features of post-NPM concepts, such as the focus on value-based management, cultivating a unified sense of values, team building and involvement of participated organizations is also found in the report. As such, it acknowledges the need for a higher rate of involvement from patients and their organizations, implementing teamwork, creating more coordinated services for patients and concentrating on cohesion in the patient pathways, rather than on partial services.

Selected main features of the Coordination Reform, which correspond to central characteristics of post-NPM ideas, are presented in Table 1.

Table 1. The Coordination Reform in the framework of post-New Public Management ideas

Post-NPM features*	Manifestations in the Coordination Reform**
Vertical coordination	Directing more central resources to lower level organizations (municipalities)
Horizontal coordination	Cross-sectoral collaboration and integration: both inside the municipalities and between the municipal and regional levels (contact person for patients, doctors and other medical personnel)
Value-based management	Focus on cohesion in the patient pathways

* According to Ling (2002), Alford (2002), Pollitt (2003), Stoker (2006), O’Flynn (2007) and Christensen and Lægreid (2007).

** According to Report No. 47 (2008–2009).

Owing to the fact that post-NPM features appear to correspond well with the Norwegian Coordination Reform, post-NPM has been chosen as the main theoretical framework for the empirical analysis. These theoretical considerations have been useful in the design and the undertaking of analysis of the study. Furthermore, I have specifically addressed the extent of correspondence between the realization of the cancer coordinator initiative and post-NPM ideas, along with consequences of the implementation of the cancer coordinator positions for the relevant actors within the health care system in Norway.

3.2.3. The role of cancer coordinators in Norway from the perspective of post-New Public Management ideas

According to Christensen and Lægreid (2007, 1062), high-level politics and shifts in central government mechanisms are not the only and definitely not the most important reform tool for promoting “whole-of-government” and “public value management” initiatives. Post-NPM recommends lower-level politics and getting people in municipalities, regions, local governments, civil society companies and market-based organizations to work together (ibid). According to Pollitt (2003, cited in Christensen and Lægreid 2007, 1063), post-NPM initiatives need cooperative efforts and cannot easily be imposed top-down. The role of cancer coordinators, according to the Coordination Reform and in the framework of the trial project of the Norwegian Cancer Society, may be considered as an expression of post-NPM ideas at the local level. A more thorough examination of the official information concerning cancer coordinators’ activity, as well as a review of the municipal requirements for cancer coordinators, reveals several items, which correspond rather well with typical post-NPM features.

First, cancer coordinators are supposed to work to improve horizontal coordination in the municipalities. This may be exemplified by cancer coordinators’ work to implement procedures for cooperation and interaction of health care services and institutions inside the municipality by promoting best practices for interaction with general practitioners, nursing homes, contact nurses, cancer patients and their families, as well as with patient organizations, volunteers and other non-municipal stakeholders (Telemark kommune 2012). According to the information from Nedre-Eiker municipality (Lange 2012), cancer coordinators operate to improve collaboration and integration between the municipal and regional health care organizations by creating best possible interactions with hospitals concerning cancer patients in order to meet patients’ needs after discharge.

Second, cancer coordinators' activities focus on value-based management. According to the Cancer Coordinator presentation paper from the Norwegian Cancer Society, the main aim of the cancer coordinator is to help improve the "quality of life for cancer patients and their next-of-kin" (Kreftforeningen 2012). In line with this, cancer coordinators' principal duties, such as providing advice, guidance and spiritual support for cancer patients and their families, are related more to the value-oriented approach than to pure management (Telemark kommune 2012). Furthermore, the positions of cancer coordinators were established from the basis that each cancer patient is a valuable member of society who should be provided with necessary information and assistance, and thus be empowered and supported with regards to autonomy (Kreftforeningen 2012). Such an approach is here seen as implicative of patient-centered care.²

Third, the feature of pro-active leadership for collective goals appears to be one of the key characteristics of the cancer coordinators' activities, since cancer coordinators are directed to be visible and accessible for people with cancer, to inform, instruct and advise relevant agencies and partners, to have an overview of cancer patients and their needs in the municipality, to ensure the follow-up of children and youths who are dependents, and to have an overview of relevant offers and services in the municipality for cancer patients (ibid). In other words, cancer coordinators aim to implement aims important for the municipality as a whole.

Table 2 capsulates key points of the correspondence between the cancer coordinator initiative and post-NPM features.

Table 2. Cancer coordinators' functioning in the framework of post-New Public Management ideas

Post-NPM features*	Manifestations in the cancer coordinator initiative**
Horizontal coordination	Cooperation and interaction of health care services and institutions within the municipality

² Since the idea of patient-centered care may be considered and described along different dimensions it was decided to place weight on the approach outlined in Christine Bechtel and Debra L. Ness (2010). This approach states that patient-centered care consists of such attributes as "whole-person" care, communication, patient support and empowerment, ready access and autonomy (ibid).

	Better collaboration and integration between the municipal and regional health care organizations
Value-based management	Aims to help reach better quality of life for cancer patients Value-oriented approach of main responsibilities Patient-centered care (bottom-up)
Pro-active leadership	Work from the perspective of the goals of the municipalities

* According to Ling (2002), Alford (2002), Pollitt (2003), Stoker (2006), O’Flynn (2007) and Christensen and Lægheid (2007).

** According to the Norwegian Cancer Society (2012) and Telemark municipality (2012).

The impact of post-NPM concepts for the cancer care provision at the local level, as well as to the Norwegian health and care services more generally, is fairly pronounced. The evaluation process of current reforms and their outcomes is still ongoing (Lægheid et al. 2013). As such, it appeared relevant to consider the results of the empirical investigation conducted from this perspective. Prior to completing the empirical investigation, specified assumptions of possible results were made.

3.3. Hypotheses of the research

The main aim of the empirical investigation conducted as part of this thesis was to find out *how the implementation of cancer coordinators in Norwegian municipalities has influenced cancer care provision at local levels*. The positive, or ideal, results of the study would demonstrate that cancer care has become more patient-centered and coordinated as cancer coordinators in municipalities are able to facilitate collaboration between different municipal and non-municipal health care organizations, institutions and services, offering enough information, assistance and care for cancer patients, so that cancer patients and/or their families are provided with more knowledge on places to seek help, necessary medical, practical and spiritual assistance, as well as choices of actions in various situations related to both the disease itself, its medical consequences, as well as to practical issues. However, there may be pronounced discrepancies between ideal and actual results.

Two overarching assumptions put forward in Chapter 1 imply that: (1) *the implementation of cancer coordinators in municipalities has contributed positively to the provision of patient-centered care and improved coordination in the area of cancer care; or (2) for some reasons, the implementation of cancer coordinators in municipalities has failed to contribute fully to patient-centered care and enhanced coordination.* The theoretical aspects described in this chapter, as well as international and national experiences in the field of cancer coordinators' functioning, allow me to present these assumptions more precisely in four specific hypotheses, as outlined below.

Hypothesis 1

Cancer coordinators work as qualified informants and visible contact persons, who can discuss cancer patients' illnesses and help solve related organizational and spiritual problems with them, thus improving patients' confidence and assurance thereby contributing to an increased level of patient-centered care.

Hypothesis 2

Cancer coordinators operate as moderators for cancer patients, their families and all possible concerned parties both within and beyond the municipality, facilitating intersectoral and interdisciplinary coordination of cancer care.

Hypothesis 3

Cancer coordinators encounter difficulties in their work to improve the implementation of patient-centered care for the patients they meet for different reasons, including the lack of working hours, education, training and/or communication problems.

Hypothesis 4

The process of cancer care coordination between services, institutions and organizations situated both within and beyond the jurisdiction of the municipality is complicated and exceeds the resources available to cancer coordinators in terms of establishing and maintaining collaborations.

4. Methodological framework

4.1. Study design: quantitative method based on a qualitative approach

The design of the study is characterized by quantitative techniques and instruments.

According to Schutt (2008), quantitative methods are supposed to characterize variations in

social life concerning quantities. Data that are regarded as quantitative are numbers or attributes that can be ordered in terms of magnitude (ibid). Using numbers in order to analyze data demands special tools, which can be found in the area of statistics (Chambliss and Schutt 2010). Statistics might be considered a numerical description of a population and this description is typically based on a sample of that population (ibid). In case of this particular research, all cancer coordinators who work (or could have been working) in Norway are considered to comprise the “population”, whereas the group of cancer coordinators who answered the questionnaire constitutes my sample.

Descriptive statistics was one of the main instruments of data presentation applied herein the empirical analysis. According to Chambliss and Schutt (2010), descriptive statistics describe the distribution of variables and relationship among variables. It should be noted that a variable is a measured characteristic or attribute that is different for different subjects, and quantitative variables may be measured at an ordinal, interval, and/or ratio scales (MacDonald and Headlam 2011). The ordinal level of measurement has been applied at the first stages of data analysis. At the ordinal level, the numbers attached to cases indicate only the ordering of the cases, permitting greater-than and less-than distinctions, but the gaps between the various responses do not necessarily have any particular meaning (Engel and Schutt 2009). For several variables, the ordinal level was transformed into an interval level of measurement. This allowed performing inferential mathematical operations, such as calculating summary statistics and creating contingency tables (ibid).

An essential argument in favor of using quantitative techniques was to describe the overall situation and summarize the data obtained from the respondents. However, it is important to mention that an electronic questionnaire, the main tool for gaining the primary data, was designed based on qualitative interviews.

Six face-to-face interviews with cancer coordinators and cancer care nurses were conducted prior to the questionnaire development in order to get a better insight into their particular situation and understand changes in the area of cancer care due to the establishment of cancer coordinator positions. Four cancer coordinators and two cancer care nurses from various municipalities agreed to participate in this initiative. All six interviewees were women, who had previously worked as nurses in the area of cancer care

for more than 10 years. Five interviews were conducted in the Eastern part of Norway in the period from August to October 2013, and one interview was conducted in the Southern part of Norway in December 2013. One municipality had a population of about 20 000 inhabitants, the other one had a population of about 40 000 inhabitants, and the third one was one of the largest cities in the Eastern region. The interviews were conducted in Norwegian, lasted on average around 90 minutes and were recorded with the help of a dictaphone with the permit of the informants. Shortly after each interview, the data were transcribed into written form in Norwegian. Each conversation was about six pages of printed text. The interviews were conducted as conversations where the interviewer tried to let the informants tell about their experiences concerning the overall situation in the area of cancer care and changes related to cancer coordinators' activities. An interview guide with main themes and questions was prepared in advance. Informants were encouraged to speak freely on cancer coordinators' functioning. The interview guide was used as a checklist to ensure that informants also discussed the questions I wanted to highlight specifically (the interview guide is attached in Appendix 3).

4.3. Study design: online electronic survey

The design of the present study is descriptive with the elements of evaluation, because the study itself aims to obtain the overview of the current situation concerning cancer coordinators' functioning and to evaluate their impact on cancer care provision. The main instrument used for gaining the data is an online electronic survey. According to Chambliss and Schutt (2010), survey research is a research in which information is gathered from a sample of individuals by means of their responses to a set of standardized questions. As a method for data gathering, a survey is characterized with some important advantages both for researcher, respondents and people who are interested in the results of the study. Chambliss and Schutt (2010) state that there are at least three positive features of survey research: versatility, efficiency and generalizability. Versatility implies the wide range of uses to which they are put; efficiency is gained as surveys are fast means of collecting data on a wide range of issues at relatively low costs; generalizability corresponds to the point that surveys can be widely distributed to representative samples (ibid).³ However, survey research is also characterized by shortcomings. Electronic surveys for instance imply a low

³ Representative sample is a sample that "looks like" the population from which it was selected in all respects that are potentially relevant to the study (Chambliss and Schutt 2010).

ability to ensure the questionnaire completion and a rather low opportunity to include and use open-ended questions (ibid). It is difficult to obtain a good response rate in case of using survey research in the form of a questionnaire, since motivation to respond among respondents is usually not very high (Kidder and Judd 1986; Burns 2000). Furthermore, questionnaires may be misleading when created incorrectly, and the researcher may attempt to see too much into results (ibid).

One of the reasons for opting to use an electronic survey was the fact that each cancer coordinator in Norway is assigned an official e-mail address. The list of e-mail addresses for the majority of cancer coordinators (n=104, including those who participate in intermunicipal coordination at the time of survey start) is posted on the web site of the Norwegian Cancer Society. An electronic mode has also become the most preferable variant after consultations with cancer coordinators during qualitative interviews because cancer coordinators confirmed that they were all supposed to use e-mail and computerized programs in their everyday work.

The online electronic survey or web-survey was created with the help of the system LimeSurvey. LimeSurvey is the preferred system for surveys and feedback for students and staff of Oslo and Akershus University College of Applied Sciences (Oslo and Akershus University College of Applied Sciences 2013). After reading the text-manual, watching the video-manual of the LimeSurvey application, as well as gaining access to the LimeSurvey scheme-generator from the survey administrator of the university, I started the procedure of generating the questionnaire. The list of questions with the variants of answers can be found in Appendix 4. The system LimeSurvey allows one to check and examine the survey before activation, and there is an option to anonymize the respondents. In case of my questionnaire, the respondents are anonymized and I, as the researcher, do not have access to information for their identification.

A questionnaire is a survey instrument containing the questions in a self-administered survey (Chambliss and Schutt 2010). While one generates questions for the questionnaire it is very important to be precise and consistent so that respondents can understand correctly what they are asked about. The context created by the questionnaire in general has a major impact on how individual questions are interpreted and answered (ibid). The formulation of questions and response categories for the questionnaire has been the most time-

consuming process of the study in general. The task was to be clear and precise in order to achieve two ultimate aims: (1) to make questions which are understood and interpreted correctly and in a similar way by cancer coordinators; (2) to obtain answers which are relevant to the proposed hypotheses. The questionnaire was made in Norwegian. In the process of creation, it was checked by three cancer coordinators, the research supervisor, representatives of the Norwegian Cancer Society and the advisor of the Norwegian Social Sciences Data Service. All the recommended changes were made and the final version of the questions was transferred into the electronic form. The questionnaire was sent out January 26, 2014, and two general reminds were sent within the next month. The ethical considerations that were made, as well as the structure of questions, cover letter and exact features of the questionnaire are described in detail in the paragraph regarding data collection.

4.4. Selection of participants

Participants of the survey were selected by means of purposive sampling. Purposive sampling is a nonprobability sampling method⁴ in which elements are selected for a purpose, commonly because of their unique position, i.e. a purposive sample may be a “key informant survey” that targets individuals who are particularly knowledgeable about the issues under investigation (Schutt 2008, 173). In the present research, the majority of all existing Norwegian cancer coordinators were selected as possible respondents. The main criteria for respondents’ selection were his/her working as a cancer coordinator of the municipality and his/her potential availability by e-mail address. An additional criterion for cancer coordinators was their work within one municipality, without intermunicipal responsibilities. Cancer coordinators without intermunicipal responsibilities were supposed to provide information on issues regarding coordination and patient-centered care at the local level in a pure sense, as this information would not be related to cancer care coordination at the regional level.

It was possible to contact most of the potential respondents thanks to an information list about the e-mail addresses of cancer coordinators all over the country, administered by the Norwegian Cancer Society and available online. In addition, the Norwegian Cancer

⁴ Nonprobability sampling is a sampling method in which the probability of selection of population elements is unknown. Nonprobability sampling method is useful in a quantitative study when a research question calls for an intensive investigation of a small population, or when a researcher is performing a preliminary, exploratory study (Schutt 2008).

Society provided information on the exact amount and names of the municipalities that have implemented cancer coordinators. This was essential for checking the e-mail addresses of cancer coordinators on the official web sites of municipalities. Furthermore, the official web sites of municipalities were useful for finding the data about cancer coordinator positions regarding intermunicipal responsibilities. As a result, 91 e-mail addresses of potential respondents were identified and re-checked towards information from the municipalities. The maximum number of respondents would thus be 91.

4.5. Data collection

Information derived from informants' answers to the questions of the questionnaire is the primary data source for the empirical investigation. The questionnaire included 44 questions divided into four groups (see Appendix 4). The first group contained 16 questions and was created basically for obtaining an overall picture of characteristics of respondents and the municipality they work in. The second group consisted of 13 questions related to respondents' interaction with patients and their families. The third group constituted ten questions about interactions between respondents and municipal (internal) concerned parties. The fourth group involved five questions and concerned interactions between respondents and concerned parties functioning outside the jurisdiction of the municipality.

All questions were closed-ended. The reason to choose a closed-ended mode was the intention to obtain numerical data that could be counted and represented in graphs and tables to shed light on the aforementioned hypotheses. The vast majority of the questions required respondents to select only one possible answer out of three to five options. However, there were also multiple-choice questions, which allowed respondents to select more than one option. This is noted explicitly in the results section.

The questions were created in Norwegian in order to minimize potential language barriers. The questions were later transferred to English. Special attention was paid to the general context of the questionnaire and the concrete context of each question. The basic ideas were taken from the evaluation survey made by the Cancer Institute of New South Wales (Cancer Institute NSW 2011). The previous conversations in the form of qualitative interviews with cancer coordinators were also very helpful. From analysis of the words and expressions used by cancer coordinators during interviews, it was possible to write the

content of the questionnaire in a manner that was likely to enhance the understanding and interpretation among cancer coordinators.

A cover letter was sent to all 91 cancer coordinators by e-mail to introduce the survey to the respondents and to ensure their confidentiality and anonymity should they opt to participate. The cover letter, also termed the information letter, contained general information about the research, including its purposes, period of conduct and parties involved; the name of the questionnaire and the probable duration of the process of filling it out; the rules of confidentiality; the request to participate; the inserted link to the survey; and the information about the researcher, including full contact data for any emerging questions, feedback and supplements from the respondents (for more details see Appendix 3 and the paragraph regarding ethical considerations).

Those cancer coordinators who opted to participate (after reading the information letter) could thus easily click on the link and start answering the questions. The questions appeared in front of the respondents in four blocks in accordance with the four groups of questions. The respondents were presented with a process bar, which showed the percentage of fulfillment. Cancer coordinators could skip questions they did not want to answer. After finishing the process of filling out the questionnaire, the respondents pressed the button “finish survey” to submit the data to the LimeSurvey store. Participants did not have an opportunity to answer survey questions more than one time, as it was restricted in the initial settings. However, prior to pressing the “finish survey” button, they could change their answers as many times as they wanted.

The process of data gathering started January 26, 2014 and finished February 14, 2014. The response rate was 52%, as 47 cancer coordinators out of 91 participated in the survey and fully or partly answered the questions of the questionnaire.

4.6. Data analysis

The process of primary data analysis was divided into five main phases. Much of the analysis was performed in Norwegian, whereas the results were translated into English and are presented in the results section and in appendices.

The first phase of the data analysis was devoted to data cleaning and creating a representative data set for further usage. According to Chambliss and Schutt (2010), data

cleaning is the procedure of checking data for errors after the data have been entered in a computer file. The LimeSurvey system allowed me to review all responses from the informants in a single table. During the procedure of data cleaning, those respondents who answered less than 80% of questions were coded as “partly-answered”. These respondents tended to answer only the first 5-7 questions and did not provide any specific information relating to the hypotheses in question. For these respondents, I decided not to impute or substitute missing data, because value imputation may lead to a misclassification, either- or overestimating responses (Parr et. al 2008). As such, only questions, which were answered, were analyzed, and the responses that were left unanswered were not included in the respective analysis to avoid unnecessary uncertainty in the presentation tables. As a consequence, some respondents did not contribute to the study at all.

The second phase consisted of the univariate analysis made by LimeSurvey statistical tools, the procedure of transferring the data to MS Excel files and deleting all identifiable information about the respondents to ensure that the ethical obligations were met. Univariate analysis provided frequency distributions and percentages of measured variables. Each question was considered to be a variable.

Chambliss and Schutt (2010, 161) state that frequency distribution is a numerical display presenting the number of cases and, as a rule, the percentage of cases (i.e. the relative frequencies), corresponding to each value or group of values of a variable. The tables with the frequency distributions were transferred to a MS Excel file, where the data were translated from Norwegian into English. Next, represented tables and figures, such as graphs, pie-charts and bar-charts, were created.

The third phase consisted of two main procedures: primary data-coding and transferring of the coded data to Stata 12, my preferred program for statistical data analysis due to its quite user-friendliness and versatility (MacDonald and Headlam 2011). Coding of the primary data implied the procedure of renaming the values of the majority of variables. As a result, 30 of 44 variables received numerical values corresponding to the interval level of measurement. The table of codes is portrayed in Appendix 6. After coding, the primary data were transferred to the Stata Editor for further analysis.

The fourth phase of the data analysis included statistical summary of all interval level variables. The mean, maximum and minimum values, as well as standard deviation were

computed. The table with these results is presented in Appendix 7. The main part of analysis consisted of the examination of the results of the univariate analysis in relation to hypotheses. The majority of questions of the questionnaire were attached to a certain hypothesis (from 1 to 4). Table 3 portrays the distribution of questions in relation to hypotheses.

Table 3. Matching questions and hypotheses

Hypotheses	Variables (question number in the questionnaire)
1. Cancer coordinators provide patient-centered care	8, 14, 18, 19, 20, 21, 24, 25, 27, 28, 29, 38
3. Cancer coordinators struggle to provide patient-centered care	
2. Cancer coordinators provide coordination both within and beyond municipalities	12, 13, 26, 30, 31, 32, 33, 34, 35, 36, 37, 41, 43, 44
4. Cancer coordinators struggle to provide coordination both within and outside their municipalities	

Hypotheses 1 and 3 concerned patient-centered care and implied interpretation of multiple parameters such as:

- cancer coordinators' assessment of their communication with patients and their families;
- cancer coordinators' availability and visibility in municipalities;
- cancer coordinators' ability to meet patients' needs;
- means of communication used for being in touch with patients;
- receiving training for developing better communication with patients;
- cancer coordinators' view on patients' safety;
- cancer coordinators' participation in supervision and education of patients and their families.

Hypotheses 2 and 4 related to the provision of coordination and considered issues such as:

- cancer coordinators' opinion about the lack of coordination in different areas of health care services;
- cancer coordinators' perceptions regarding their work within the coordinating unit of the municipality;
- frequency of cases when cancer coordinators experience the lack of coordination;
- cancer coordinators' assessment of their collaboration with several health care institutions and services situated within and beyond the jurisdiction of municipalities;
- arrangements of regular meetings with concerned parties in the municipality.

The results obtained in terms of these hypotheses are introduced in Chapter 6.

The fifth phase of the analysis consisted of bivariate analysis. The decision to conduct bivariate analysis appeared after obtaining the results of the univariate analysis, which demonstrated some challenges of cancer coordinators' functioning. Several variables were recoded within the interval level of measurement in order to create contingency tables, to obtain appropriate correlations. Correlations were computed in Excel using chi-square tests.⁵ The results of these calculations were evaluated in accordance with conditional distributions between variables.⁶

The results of the analysis performed with the help of frequency distributions and contingency tables are presented in Chapter 5 and in Appendix 5.

4.7. Ethical considerations

This research was conducted in accordance with the guidelines of the Norwegian Social Science Data Services (NSD). It was exempted from the licensing requirement, but subject to notification (see Appendix 1).

Ethical issues were related to the protection of cancer coordinators' personal data. At the first stage of the investigation it was essential to ensure the anonymity of the participants

⁵ The chi-square statistic is used to show whether or not there is a relationship between two categorical variables. It can also be used to test whether or not a number of outcomes are occurring in equal frequencies or not, or conform to a known distribution. The chi-square statistic was developed by Karl Pearson. The chi-square equation is created based on the values of the observed and the expected frequencies. The test contains two hypotheses: H_0 and H_1 . H_0 implies the absence of the correlation, whereas H_1 implies the presence of the correlation between variables. Chi-square value and P-value are crucial for rejection of H_0 hypothesis (David Kremelberg 2011).

⁶ Proportions in relation to 100% among the variables presented in contingency tables or graphically may indicate conditional distributions or the nature of relationships between these variables (Gingrich 1992).

during collecting information from qualitative interviews. The respondents (cancer coordinators and nurses) were aware of the questions they would be asked and that a dictaphone would be used during conversation. All the respondents' e-mail addresses and personal correspondence were deleted from my e-mail box. Moreover, all the recordings were deleted after transcription of the texts, and the information obtained was fully anonymized. Besides, no direct quotes were used from the transcribed material. At the second stage of the investigation, particular attention was paid to the anonymity of the cancer coordinators who answered the questionnaire. Since the study was conducted in an electronic form, I, as a researcher, had access to e-mail addresses of the respondents. All e-mail addresses of the cancer coordinators were removed from my electronic e-mail archive immediately after the invitations for participation in the survey had been sent to them.

The LimeSurvey system allowed me to administer the questionnaire in a manner such that the respondents remained unidentified. I, as the survey administrator, did not have access to personal data relating to the cancer coordinators. Nevertheless, higher-level administrators were able to see the IP addresses of the respondents. This required consultation with NSD. After consultation with the representative of NSD, some changes were made in the information letter, so that respondents could understand how their personal data would be protected. As it is stated in the cover letter, all the information on respondents was to be removed from the system as soon as the data were available in the LimeSurvey system. The anonymous data file itself was thereafter transferred to Excel and Stata computer programs and did not contain any personal information at the stage of analyzing.

4.8. Relevance of data-collection and software tools to research question

The main question of the present research – *how has the implementation of cancer coordinators in Norwegian municipalities influenced cancer care provision at local levels* – may be operationalized in a quantitative manner and can be analyzed as such. An electronic quantitative questionnaire with closed-ended questions was thus chosen as the main data-collecting tool. By means of data extracted from this questionnaire I aimed to describe the current situation in the area of cancer care after the establishment of cancer coordinator positions. The questionnaire allowed me to obtain the data concerning main respondents' characteristics, provision of patient-centered care and provision of coordination from quite a large sample, so I could make a summary and attempt to

generalize. I decided not to use qualitative interviews with cancer coordinators as my primary data for analysis, because interviews would provide a narrower range of information compared to that I would gain by using a questionnaire. Furthermore, closed-ended questions were most preferable for this research because respondents' answers might be coded, measured and used for statistical analysis in a straightforward manner within the time frame allocated for a master's thesis.

An ideal investigation on the role of cancer coordinators in cancer care provision at local levels should have had responses from patients, their next-of-kin and various concerned parties as primary data for analysis. However, processes of data gathering and data analysis in this case could not be completed within the framework of a master's thesis. Timeline restrictions of the present master's project allowed me to evaluate the role of cancer coordinators solely from the perspective of cancer coordinators themselves, i.e. from the standpoint of cancer coordinators' perceptions of their own role.

Excel and Stata were chosen as main software tools for data analysis since these programs provide good statistical functions both for graphical presentation and for numerical analysis.

5. Results

5.1. General presentation of the respondents

Altogether 47 cancer coordinators took part in the online electronic survey and answered all or some of the questions in the questionnaire. The tendency tables presented in Appendix 5 and the graphs shown in this chapter include only those respondents who answered the respective question. The total number of respondents who answered the question is stated in parenthesis.

Altogether 17 of 47 respondents were 30-39 years old, 17 were 40-49 years old, and the remaining 13 respondents were 50 years old or older (Fig. 1). None of the cancer coordinators who answered the question were younger than 30 years.

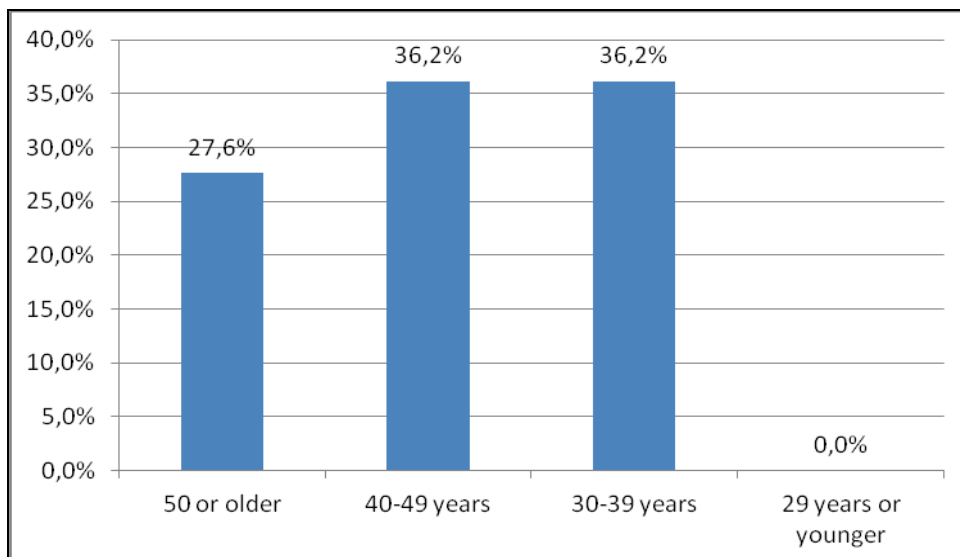


Figure 1. Age of the respondents (N=47)

When it comes to the general work experience of the respondents, it should be noted that 34 of 47 respondents had been working in the health care services of the municipality for more than five years. All but one respondent said that they were educated as nurses and had postgraduate training. Around 95% of those respondents who confirmed passing postgraduate training reported that they had received further education in the field of oncology and/or palliative care. When indicating their work experience in the field of oncology and/or palliative care, about 49% (19 of 39) of the cancer coordinators reported that they had been working in this field for more than ten years, about 36% (14 of 39) of the respondents stated that they had been working in the field of oncology and/or palliative care for five to ten years, and only about 15% of the respondents stated that they had been working in the field of oncology and/or palliative care for less than five years.

Altogether 38 cancer coordinators answered the question on the percentage of their coordinator role in the municipality. Half (19 of 38) of the respondents held a 50% cancer coordinator position, whereas the other half worked full-time as cancer coordinators. A total of 40 of 47 respondents stated the duration of their work experience as the cancer coordinators in municipalities. Around 55% (22 of 40) of the cancer coordinators reported that they had been working as cancer coordinators for almost two years, about 38% of the respondents said that they had been working as cancer coordinators for almost one year, and 5% of the respondents answered that they had been working as cancer coordinators for 11 months or less (Fig. 2).

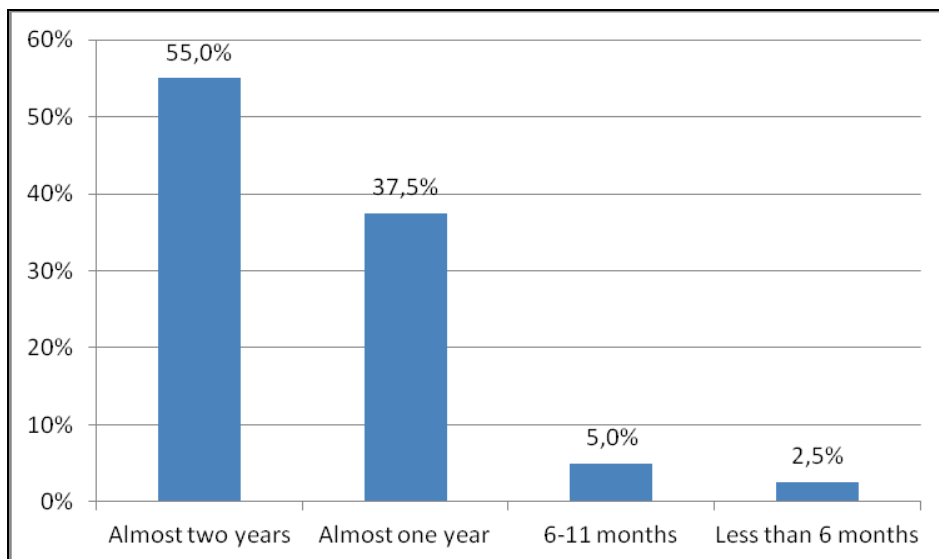


Figure 2. Work experience as a cancer coordinator in the municipality (N=40)

One question asked about the respondents' opinion on the patients' view of the main function of the cancer coordinator's role. Around 80% (32 of 40) responded that a cancer coordinator was a contact person who patients could talk to in case they needed it or if they were experiencing problems related to their illness(es), and that a cancer coordinator was a contact person who might help patients obtain necessary practical and medical assistance more efficiently (Fig. 3).

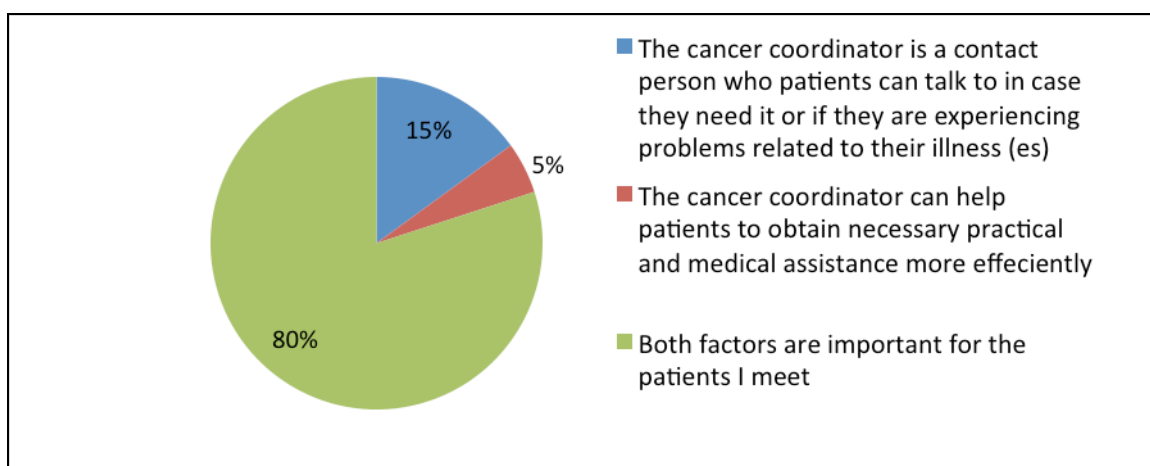


Figure 3. The most important function of the cancer coordinators' work (N=40)

As 'cancer coordinator' is a newly established position in municipalities from 2012 onwards, the period of time needed for the cancer coordinators to be known in the municipalities was examined in order to characterize the work and activities of the respondents. About 32% of the respondents (12 of 38) stated that they needed from nine months to one year to become known as cancer coordinators in their municipalities; about

26% (10 of 38) of the respondents stated that they needed more than one year to become well-known; but over 23% (9 of 38) reported that a period of around four months was sufficient for them to be known as cancer coordinators in their municipalities (Fig. 4).

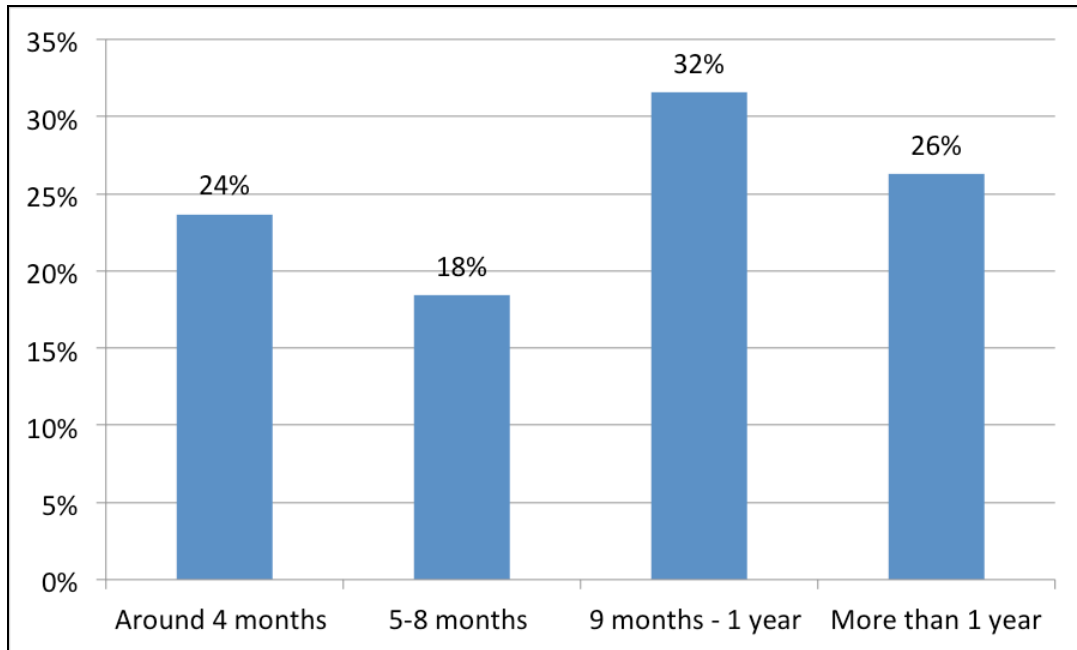


Figure 4. Period of time necessary to become known in the municipality (N=38)

Characterizing their activity related to improvement of coordination in municipalities, cancer coordinators were asked to indicate the period of time necessary to create an effective network of organizations and agencies that could help each individual cancer patient in the municipality. About 66% (23 of 35) of the respondents stated that they had spent one year or less for creating an effective network of organisations and institutions in order to meet the needs of individual cancer patients (Fig. 5).

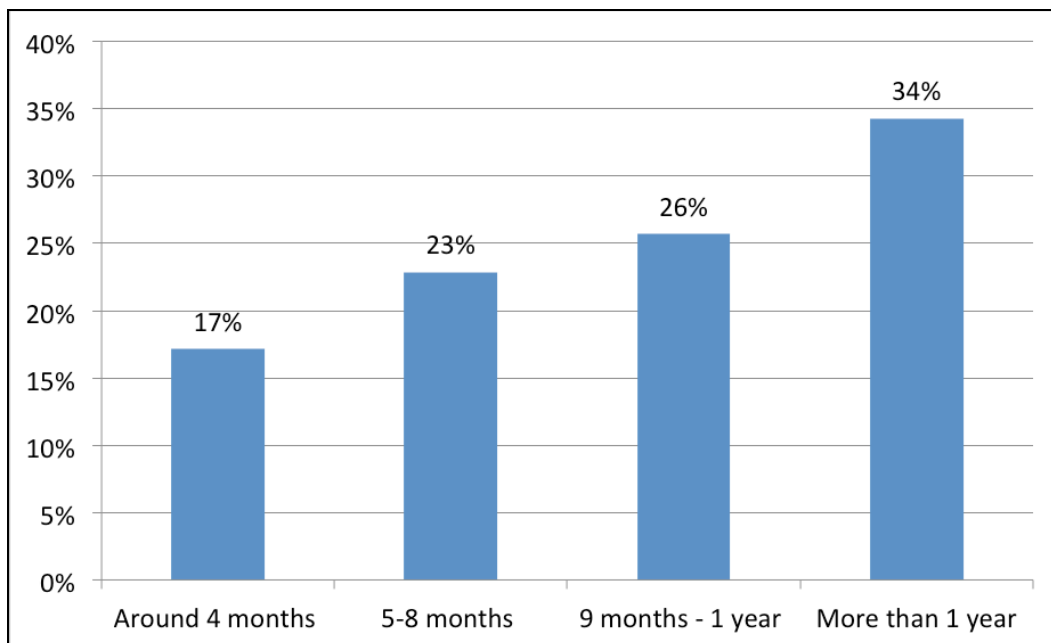


Figure 5. Period of time used to create an effective network of organizations and agencies that can help individual cancer patients in the municipalities (N=35)

To understand the context of the municipalities where the respondents worked, cancer coordinators were asked to indicate the number of inhabitants in their municipalities. The number of inhabitants can be used to deduce the probable number of cancer patients, although cancer incidence also varies to some extent depending on the age and risk structure (e.g. smoking levels) of the municipalities (Cancer Registry of Norway 2011; Brunborg 2007). About 57% (23 of 40) of the respondents reported that they worked in municipalities with a population from 10 000 to 50 000 inhabitants (Fig. 6).

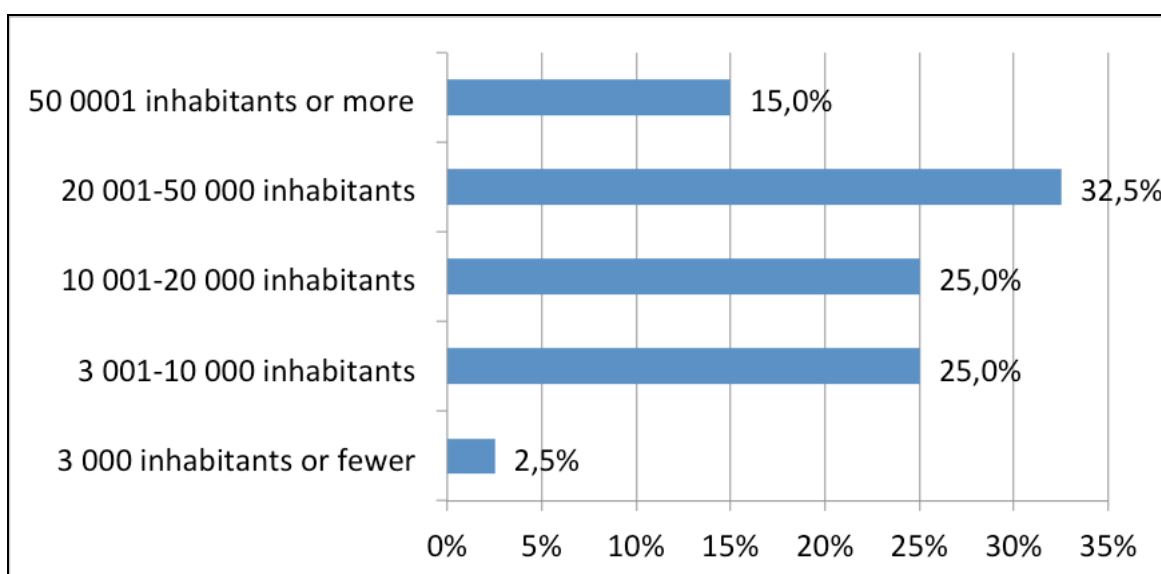


Figure 6. Population of the municipalities where the respondents work (N=40)

Cancer coordinators were also asked about perceptions of their work. Although the response rate to this question was quite low (77%), the basic tendency was that more than 63% of the respondents who answered loved their work (Fig. 7).

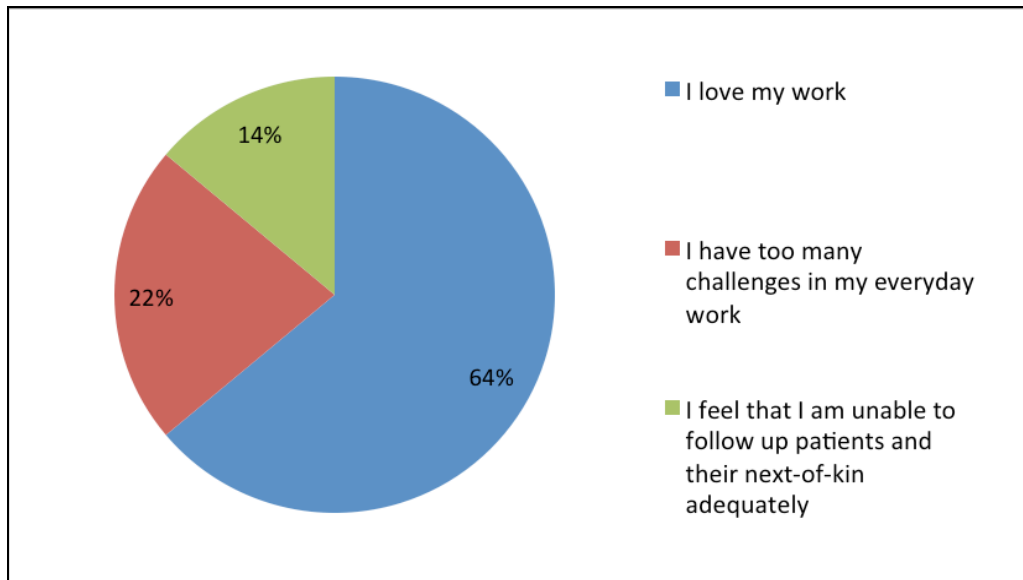


Figure 7. Work perception (N=36)

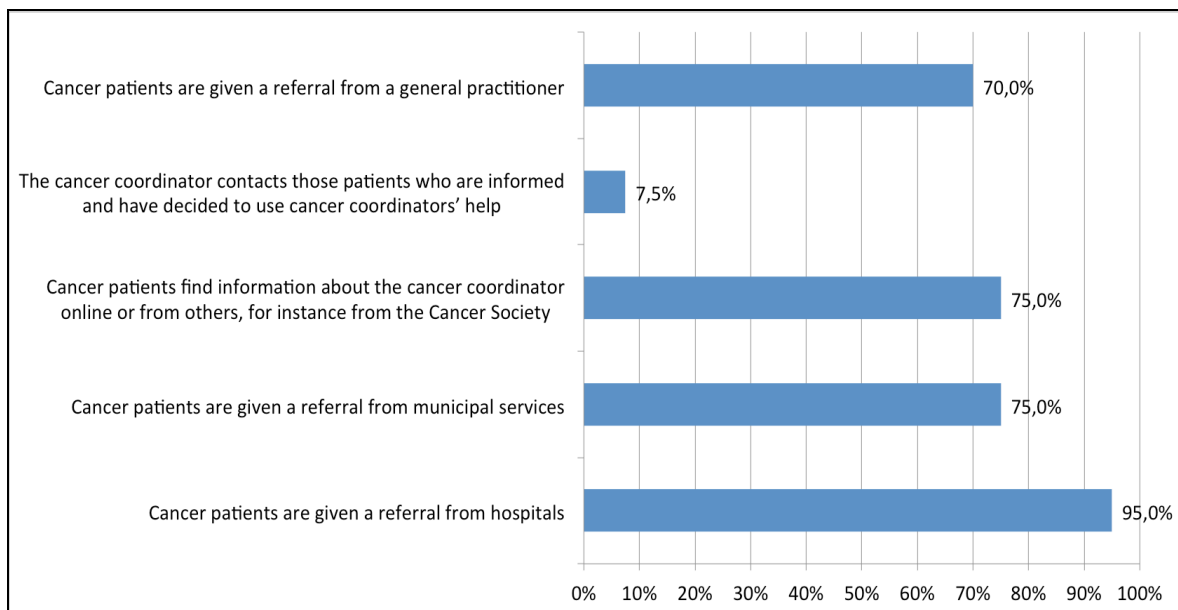
To summarize, the cancer coordinators who answered the questionnaire are mainly nurses who have a minimum of five years of work experience in the area of health care and particular experience in the field of oncology and/or palliative care. On average, it took them about a year to make their position known to the patients and organizations in the municipalities. They also needed a minimum of one year to create an effective network of organizations and institutions that could help individual cancer patients. Despite all the difficulties of adaptation to a new work role and place, most of the cancer coordinators love their work.

5.2. General presentation of the obtained results

This section presents general results that were obtained with the help of univariate and bivariate analyses, which relate to cancer patient care and coordination. The summarized results of the survey are described more specifically in Chapter 6 in the section on presentation of the obtained results in relation to hypotheses. Analyses of *all* the questions from the questionnaire are presented in Appendix 5, whereas only those relevant for the discussion in relation to the hypotheses are presented in more detail here.

In the evaluation of their communication with cancer patients, all but one (39 of 40) cancer coordinators reported that they were very satisfied with this aspect of their work and would assess their interaction with cancer patients as very good or good. Similarly, 39 of 40 respondents stated that they were capable of meeting cancer patients' needs, ensuring a positive impact of their activities on the patients' life situation.

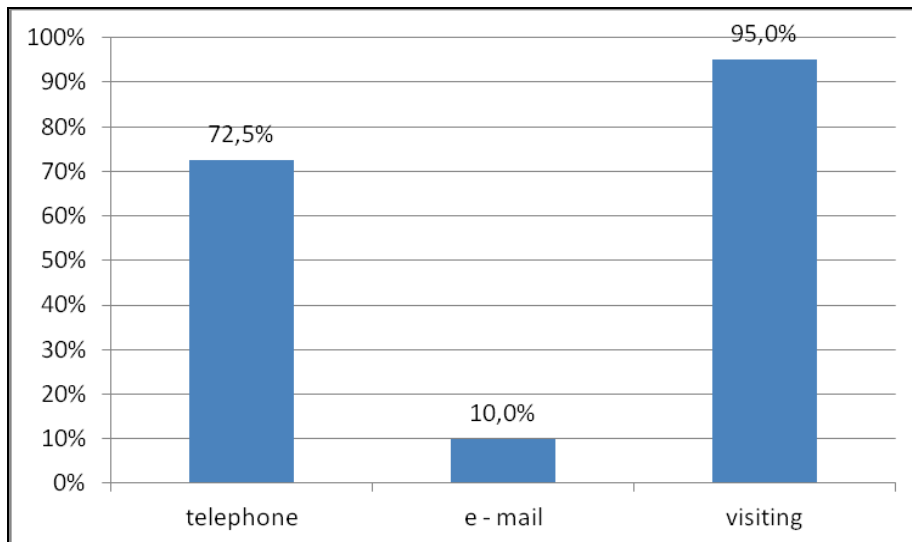
Cancer coordinators' initial contact with cancer patients took place in several ways, but patients most often got in contact with the cancer coordinators after referrals from hospitals or general practitioners (Fig. 8).



*Figure 8. Cancer coordinators' initial patient contact**

* The respondents could tick all the answers applied in this question.

The cancer coordinators reported that their position was quite visible and available for cancer patients and their families in the municipalities where they worked. Around 51% (20 of 39) of the respondents stated that the cancer coordinator position in the municipality was known by a large number of cancer patients and their families, whereas the remaining 49% responded that the cancer coordinator position was known to some extent. The cancer coordinators were shown to provide cancer care with the help of different means of communication, including home visits, telephone contacts and e-mail contacts (Fig. 9).



*Figure 9. Means of communication used in the interaction with cancer patients and their families**

* The respondents could tick all the answers applied in this question

The majority of the respondents confirmed that they used home visits to provide patient-centered care. As could be expected, the cancer coordinators who worked part-time (50% of full position) conducted fewer home visits than those cancer coordinators who worked full-time: about 84% of the cancer coordinators who worked part-time had on average three to eight home visits per week, whereas about 72% of the cancer coordinators who worked full-time conducted on average six to twelve or even more home visits per week.

About 57% (23 of 40) of the respondents reported that the duration of one consultation with a cancer patient or his/her next-of-kin lasted on average one hour, whereas about 32% (13 of 40) of the respondents reported that they used around two hours for one consultation with patients or members of patients' families (Fig. 10).

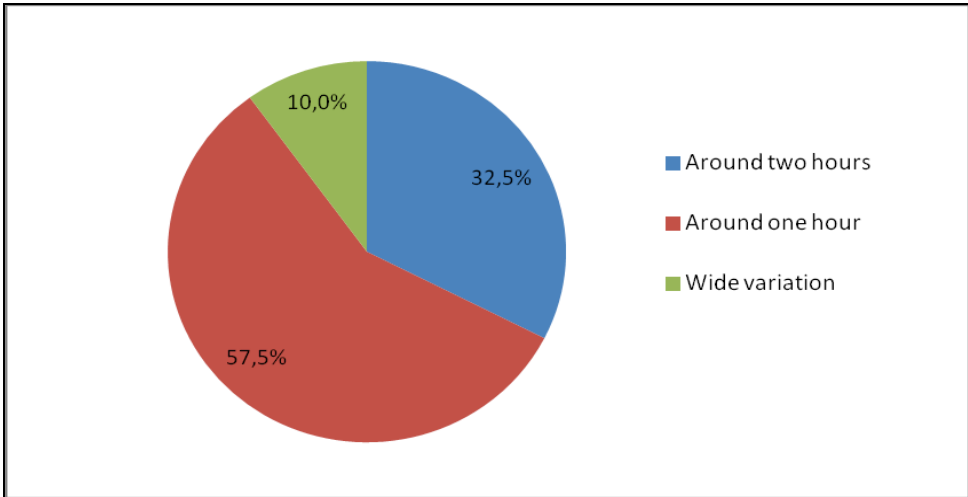


Figure 10. Average time per consultation (N=40)

More than 42% (16 of 38) of the cancer coordinators stated that they received training to improve their communication with cancer patients. In addition, about 18% (7 of 38) responded that they did not feel the need for additional training. Thus, altogether 60% of the cancer coordinators may be considered confident in their ability to communicate with cancer patients (Fig. 11).

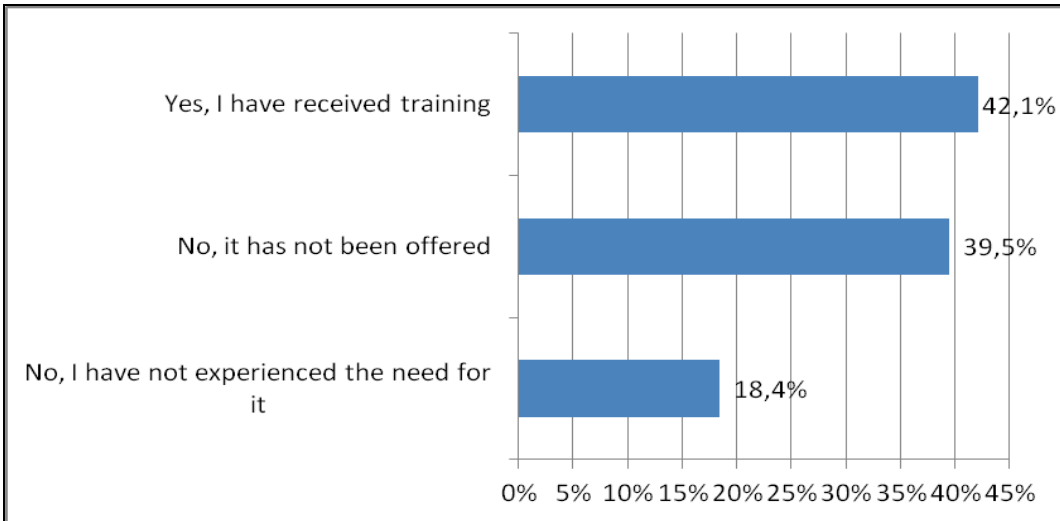


Figure 11. Training in communication with cancer patients (N=38)

About 52% (20 of 38) of the respondents expressed their assurance in the fact that the safety of cancer patients and their families had been improved due to the activity of the cancer coordinator, whereas about 42% (16 of 38) of the respondents reported that they supposed that the safety of cancer patients and their families had been improved thanks to the cancer coordinator.

Around 77% (30 of 39) of the cancer coordinators reported that they used 30-50% of their working time for communication with health care professionals and other concerned parties (Fig. 12).

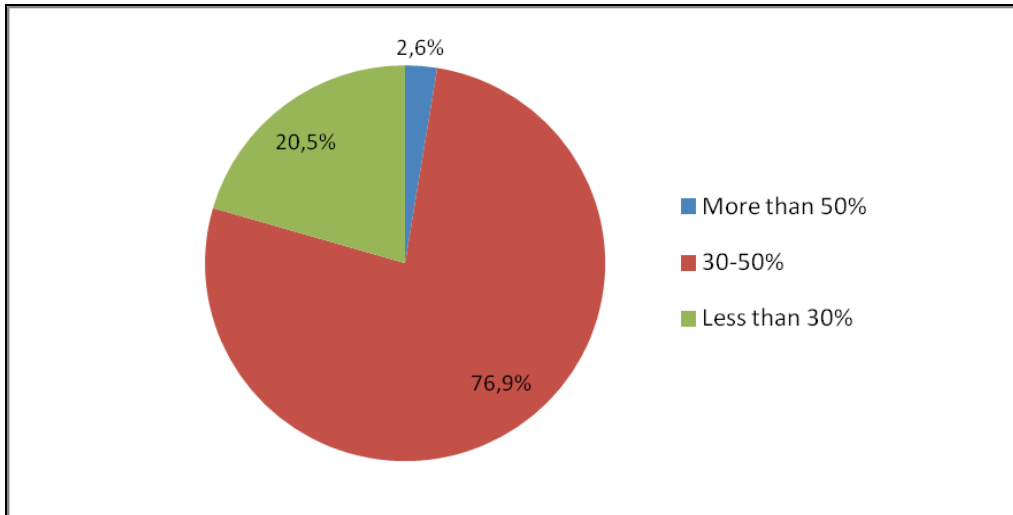


Figure 12. Percentage of working time which cancer coordinators use on health care professionals and other concerned parties other than patients (N=39)

Cancer coordinators tended to use a part of their working time to provide supervision and education to cancer patients and their families in municipalities. About 35% (13 of 37) of the respondents reported that they participated in activities related to supervision and education of cancer patients and their families every week, and the same amount of the respondents confirmed that they were involved in supervision and education of cancer patients and their families every month (Fig. 13).

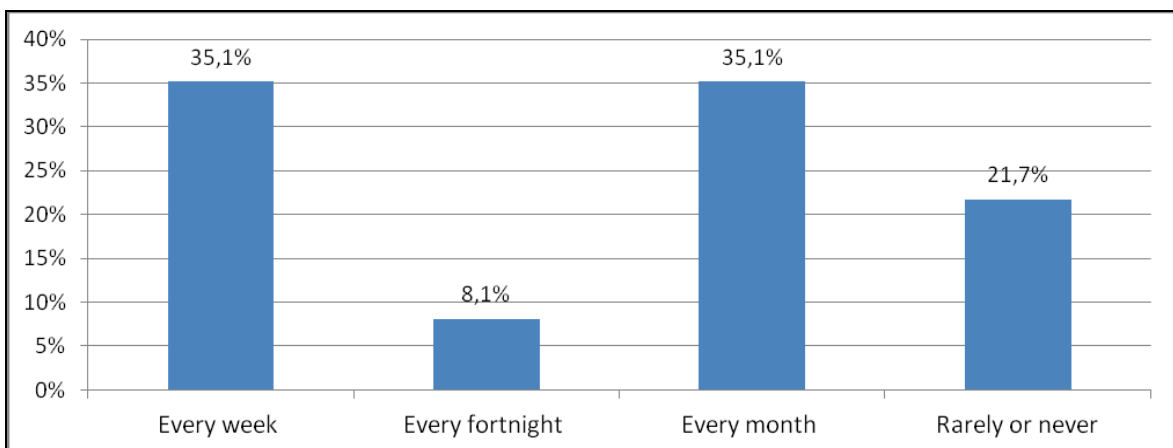


Figure 13. Participation in supervision and education of cancer patients and their families in the municipality (N=37)

Moreover, 71% (27 of 38) of the respondents stated that they participated in supervision and instruction of home-based nurses or other health workers of municipalities at least monthly (Fig. 14).

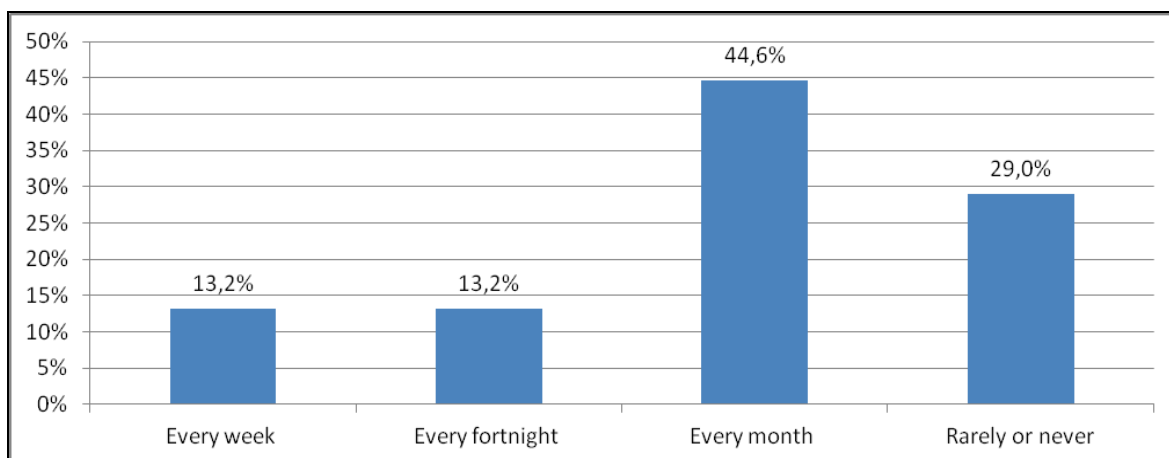


Figure 14. Participation in supervision and instruction of home-based nurses or other health professionals in the municipality (N=38)

Cancer coordinators were also asked to note aspects of communication and collaboration which could be improved. Most of the respondents (more than 82%) stated that better communication and collaboration with general practitioners about new and existing patients could make their work more effective. Around 73% of the respondents also stated that they needed better collaboration with hospitals, and about 70% of the respondents stated that they would benefit from better collaboration with municipal services (Fig. 15).

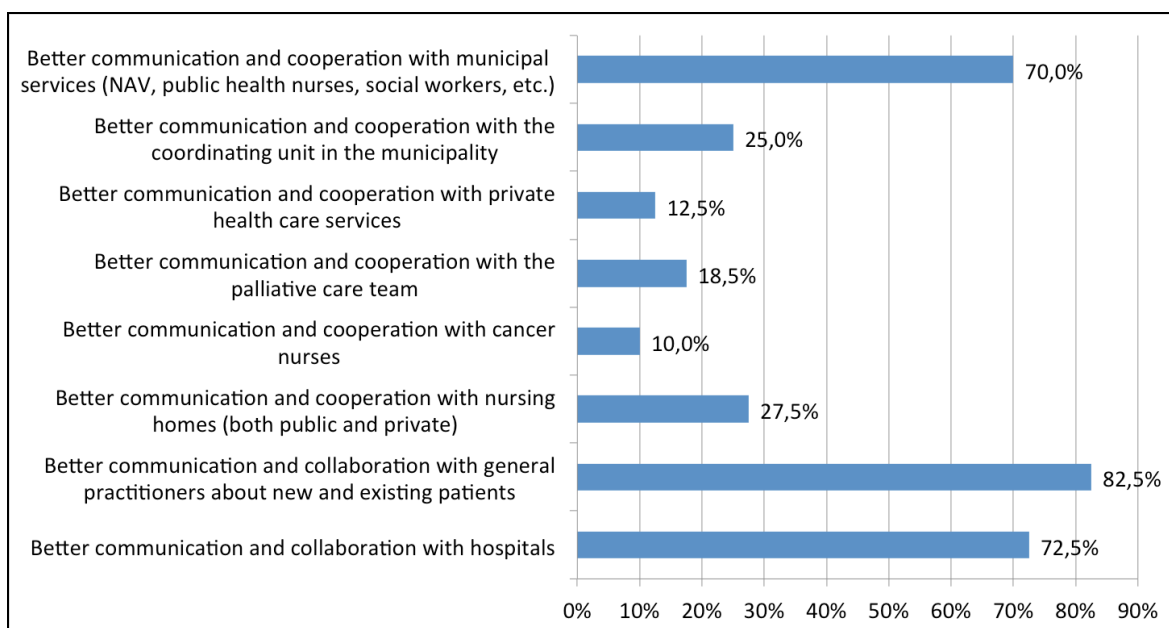


Figure 15. What can help make the cancer coordinators' work more effective*

* The respondents could tick all the answers applied in this question

Furthermore, it should be noted that less than one half of the respondents perceived themselves as a part of the coordinating unit in the municipality to a great extent, perhaps illustrating some difficulties in coordination (Fig. 16). This might, however, have been a less optimal framed question, as some cancer coordinators are formally organized as part of the coordinating unit, whereas others are not. This organizational aspect may have influenced the interpretation of this question.

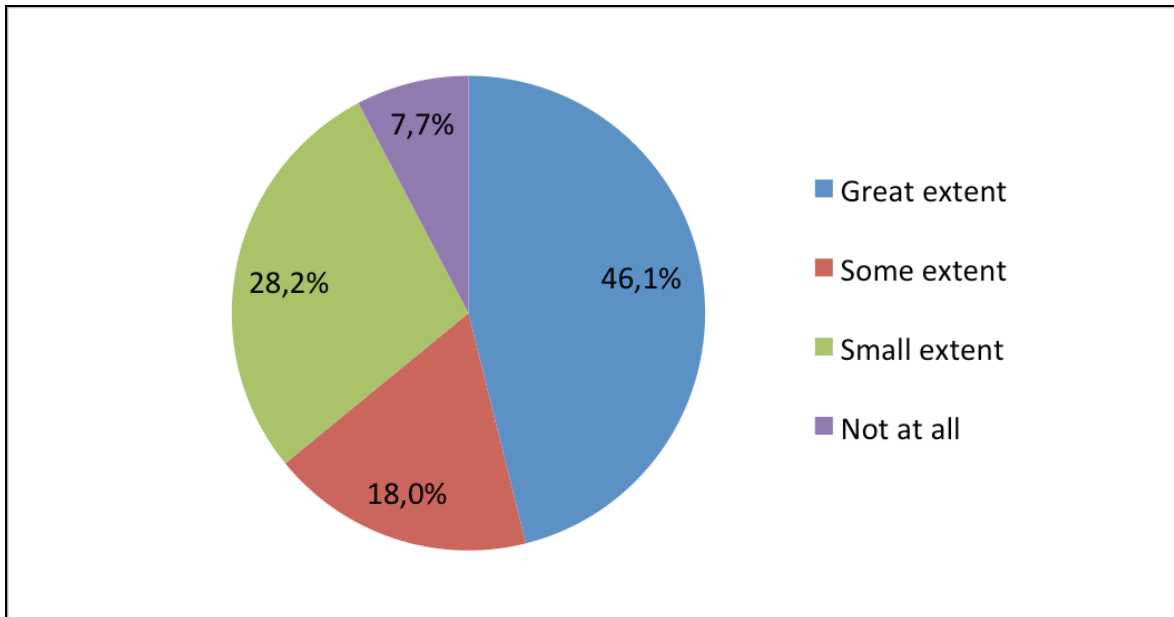


Figure 16. The extent to which cancer coordinators perceive themselves as a part of the coordinating unit in the municipality (N=39)

Arrangements of regular meetings with various concerned health, social and spiritual workers in the municipality was considered as an indicator of enhanced coordination and a promise for future collaboration in the area of cancer care. Around 18% (7 of 38) reported that they did not have regular meetings with nurses, assistant nurses, general practitioners, physiotherapist and/or priests at least monthly. About 49% (19 of 39) of the cancer coordinators stated that they did not arrange regular meetings with occupational therapist, participants of the effort team and/or rehabilitation team, transport and practical assistants, volunteer coordinators and substance abuse, dementia or rehabilitation counselors at least monthly. The results of the bivariate analysis indicate that the arrangement of regular meetings with medical and service workers is correlated with the percentage of a 100% position and cancer coordinators' work experience in the municipal health care services. Those cancer coordinators who worked full-time reported that they arranged regular

meetings more often than those who worked part-time (50% of position; $p < 0.05$). In addition, those respondents who had been working in the municipal health care services for five years or more attended or arranged regular meetings with concerned parties more often than those respondents who had been working in the municipal health care services for less than five years ($p < 0.001$).

In evaluating the communication and collaboration with concerned parties, about 40% (12 of 40) reported that it was sometimes not possible or quite difficult to communicate and collaborate with general practitioners in the municipality. The remaining 60% indicated, however, that they had developed good or very good collaboration with general practitioners (Fig. 17).

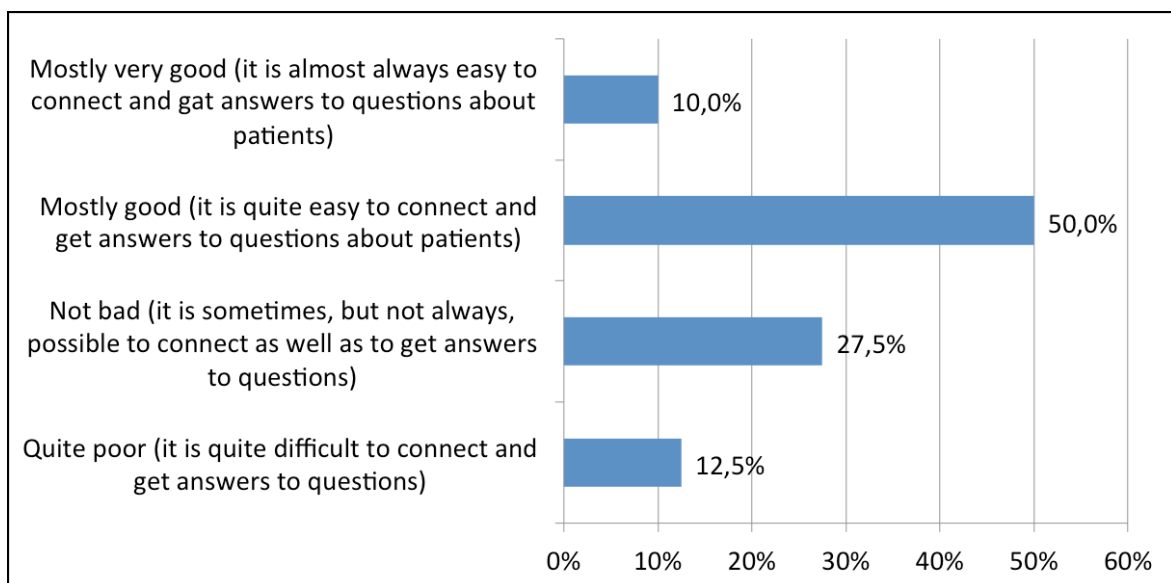


Figure 17. Assessment of the communication and collaboration with general practitioners in the municipality (N=40)

The results of the bivariate analysis have demonstrated that there is a correlation between the cancer coordinators' assessment of their communication with general practitioners and their work experience in the health care services of the municipality and work experience in the field of oncology and palliative care. The cancer coordinators who had been working in the health care services of the municipality for five years or more assessed their communication with general practitioners as good or very good more often than the cancer coordinators who had been working in the health care services of the municipality for less than five years ($p < 0.001$). Similarly, those cancer coordinators who had been working in the area of oncology and/or palliative care for five years or more assessed their

communication with general practitioners as good or very good more often than the cancer coordinators who had been working in the area of oncology and/or palliative care for less than five years ($p < 0.01$).

Around 15% (5 of 33) of the respondents stated that it was quite hard or even impossible to collaborate on patients or their next-of-kin with schools and kindergartens, and only 33% (11 of 33) of the respondents evaluated their collaboration with schools and kindergartens as good and very good. The results of the bivariate analysis have shown that the cancer coordinators' assessment of the collaboration with schools and kindergarten is correlated with the percentage worked of a 100% position. Those cancer coordinators who worked full-time assessed their collaboration with schools and kindergartens as good or very good more often than those who worked part-time ($p < 0.01$).

Around 28% (11 of 39) of the respondents reported that it was quite hard or even impossible to collaborate with NAV (Fig. 18).

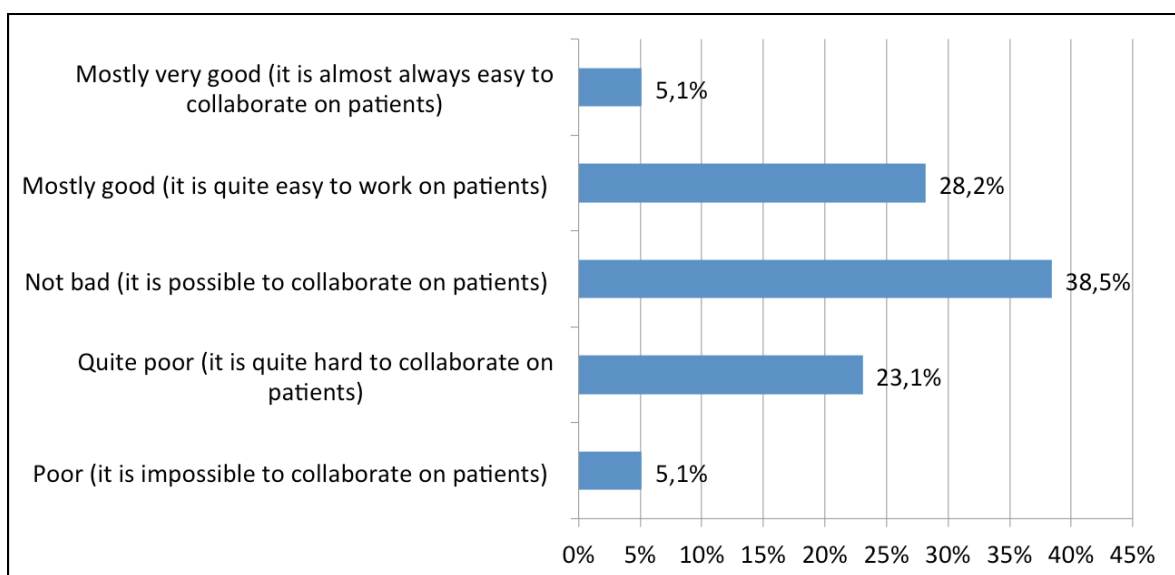


Figure 18. Assessment of the interaction and collaboration with NAV in the municipality (N=39)

The results of the bivariate analysis have demonstrated that there is a correlation between the cancer coordinators' assessment of their collaboration with NAV and their work experience in the health care services of the municipality. The cancer coordinators who had been working in the health care services of the municipality for five years or more assessed their collaboration with NAV as good or very good more often than the cancer

coordinators who had been working in the health care services of the municipality for less than five years ($p < 0.05$).

About 92% (34 of 37) of the cancer coordinators noted the presence of good or very good collaboration with cancer care nurses or palliative care nurses, and 70% (28 of 40) of the respondents reported good or very good interaction with nursing homes. In characterizing the collaboration with several concerned parties situated beyond the jurisdiction of municipalities, the majority of the cancer coordinators reported that they had achieved a good level of interaction: around 92% (36 of 39) of the respondents stated that they had developed mostly good or very good interaction and collaboration with palliative care departments situated in the area of their work; about 85% (33 of 39) of the cancer coordinators reported that their communication and collaboration with the oncological outpatient department situated in the area of their functioning was mostly good or very good; and about 87% (34 of 39) assessed the communication and collaboration with other cancer coordinators or the Cancer Society representatives in the area of their work as good or very good.

A great number (around 61%) of the respondents stated that they rarely or never experienced the lack of coordination, which could have a direct negative influence on the effectiveness of their work with cancer patients or their families (Fig. 19).

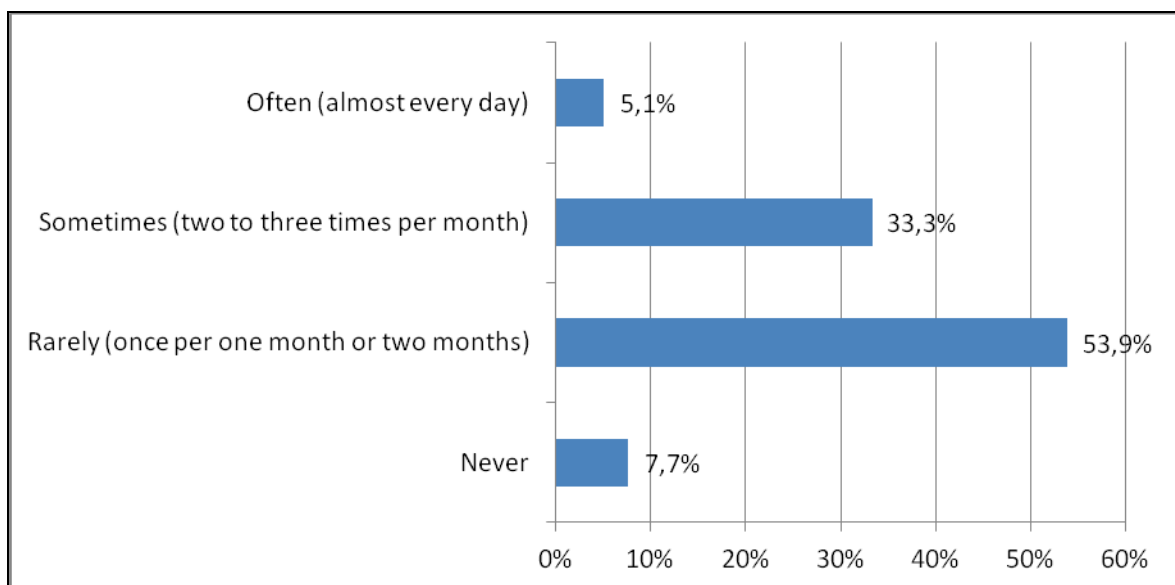


Figure 19. Assessment of the lack of adequate cooperation with concerned parties, which makes the cancer coordinators' work with patients or their families less effective (N=39)

Some key issues should be emphasized in summing up the general presentation of the obtained results.

- Cancer coordinators mostly assess their interaction with cancer patients and their families as very good or good. Moreover, cancer coordinators consider that their ability to meet cancer patients' needs is adequate, ensuring a positive impact of their activities on the patients' life situations.
- To provide patient-centered care and enhanced follow-up, cancer coordinators have developed different tools, such as home visits, telephone contacts and e-mail contacts.
- The majority of cancer coordinators use minimum 50% of their working time for communication and collaboration with patients and their families.
- Besides, over 60% of cancer coordinators state that they rarely or never experienced the lack of coordination, which could negatively influence the effectiveness of their work with cancer patients or their families.
- On the other hand, over 80% of cancer coordinators emphasize that better communication and collaboration with general practitioners about new and existing patients could make their work more effective; and about 70% state that better interaction and collaboration with hospitals and municipal services would be likely to positively influence their work.
- Around 90% of cancer coordinators denote good or very good collaboration with palliative care and cancer care nurses, oncological outpatient departments and palliative care departments.
- However, good or very good communication and interaction with general practitioners is reported in only around 60% of cases.
- Cancer coordinators' work experience in the health care services of their municipalities and in fields of oncology and/or palliative care is associated with the cancer coordinators' assessment of their communication with general practitioners.
- Good and very good communication and interaction with NAV services is reported in only 33% of cases, and cancer coordinators' work experience in the health care services of their municipalities has influenced cancer coordinators' assessment of their communication with NAV.
- About 80% of cancer coordinators arrange meetings with nurses, assistant nurses, general practitioners, physiotherapist and/or priests at least monthly; but only about

50% of cancer coordinators arrange meetings at least monthly with such concerned parties as occupational therapist, participants of the effort team and rehabilitation team, transport and practical assistants, volunteer coordinators and substance abuse, dementia, or rehabilitation counselors.

- The arrangement of regular meetings is related to the cancer coordinators' work experience in the health care services of their municipalities and the percentage they work of a 100% position.

As such, the results show that the implementation of cancer coordinators in Norwegian municipalities has had a significant influence on cancer care provision at local levels. In this perspective, the patient-centered care has been improved due to the cancer coordinators' functioning. However, the issue of coordination could be further developed and improved in certain remaining areas.

5.3. Validity and reliability of the obtained results

All measurements are associated with measurement errors, to smaller or lesser extents. In general, one can distinguish between random and systematic errors. In the following, I will tie the concept of reliability to random errors,⁷ and the concept of validity to systematic errors,⁸ as this is a commonly applied distinction in social sciences (Judd et al. 1991; Engel and Schutt 2009).

Reliability often concerns consistency, stability and accuracy of measurements (Engel and Schutt 2009). The value of any survey depends in part on the reliability of the instruments applied. Main types of reliability include test-retest reliability and internal consistency (ibid).

The present study was not repeated to assess test-retest reliability. Therefore, internal consistency was the only indicator that could be applied to assess reliability. According to Engel and Schutt (2009, 67), internal consistency is identified if multiple items measure a single concept. The stronger the association among the individual items and the more items included, the higher the reliability of the scale (ibid). In case of the present study, internal

⁷ Random errors are unpredictable in terms of their effects. Random errors may emerge due to the experience or current condition of respondents (Engel and Schutt 2009).

⁸ Systematic errors are considered to be predictable errors in terms of their effects. The process of avoiding systematic errors requires careful construction of scales and questions and the testing of these questions with different population groups (ibid).

consistency of the concept of coordination and the concept of patient-centered care was calculated with the help of the Cronbach's alpha coefficient. The Cronbach's alpha coefficient is a summary score of all possible split-scale combinations that can be computed with the help of statistical software (ibid, 68). In this study, the Cronbach's alpha coefficient for the concept of patient-centered care was .6169, whereas the Cronbach's alpha coefficient for the concept of coordination was .6132. According to Cortina (1993), a coefficient between .6 and .7 suggests that the internal consistency of the research is acceptable. In this case, it means that internal consistency of the study in terms of measuring both the concept of patient-centered care and the concept of coordination is adequate.

Validity may be split into measurement validity and external validity, or generalizability (Chambliss and Schutt 2010, 119-120). Measurement validity concerns questions such as:

- Do the persons who answer the survey interpret the questions and the possible answers in the same manner?
- Is there a sufficient association between the theoretical concept one is attempting to capture and what is measured, i.e. do the instrument measure what it is intended to measure?

Measurement validity implies content validity, which is used to show that the measure covers the full range of the concept's meaning (Engel and Schutt 2009, 69).

Several activities were undertaken during the process of creating the questionnaire in order to avoid systematic errors and improve content validity:

- negative sentences and questions were avoided whenever was possible;
- suitable characteristics and words in specific areas were selected after discussions with potential respondents during the initial qualitative interviews;
- questions were formulated in a manner respondents could quickly understand the meaning of;
- the majority of short variants of answers were explained in parentheses;
- an option to skip certain questions in the questionnaire was created for those respondents who did not wish to answer the particular question or who did not know the answer;
- the questionnaire was structured to be easy understandable;

- the questionnaire was tested by several cancer coordinators, and, as a result, changes and corrections were made before the activation of the electronic survey.

In addition, both the research in general and the survey in particular were presented to representatives of the Norwegian Cancer Society and were acknowledged for conduct by this organization.

This study lacks empirical validation, although it has been attempted assured by basing the questionnaire on already existing questions that have been applied in previous studies. Further, qualitative interviews were undertaken prior to the construction of the survey to help increase the validity of the questions and the response categories.

External validity concerns the degree to which the results from the survey may be generalized to a population beyond that of the sample (Aronson et al. 2007). The response rate of my survey was 52%. This is not a high response rate, but higher than many response rates of today's social studies (Babbie 2012). It is thus judged to be adequate. Further, as results have been compared to the evaluation report of the Norwegian Cancer Society who had a near complete response rate and the overlapping results are nearly identical, it appears that the selection in responses have affected the results only to a minor degree, if at all.

To conclude, reliability is a necessary, but not sufficient criterion for validity (Engel and Schutt 2009, 71). The reliability of the present study has not been assessed fully, but as has been argued above, it seems likely that the results are sufficiently reliable. Likewise the external validity of the study appears to be adequate. The measurement validity has been the most difficult aspect to assess satisfactorily. Nevertheless, as has been shown above, to the extent that the measurement validity has been provided, it appears adequate. I thus conclude that the reliability and validity of the present study appear to be of sufficient quality, so that the results may be trusted.

6. Discussion and interpretation of findings

6.1. Presentation of the obtained results in relation to hypotheses

Four hypotheses regarding the basic question of the study were introduced in Chapter 3 and were further explained in Chapter 4. The hypotheses were characterized by the cancer coordinators' answers to selected questions of the questionnaire. I will here shortly comment on findings of interest for the previously described hypotheses.

Hypotheses 1 and 3 related to patient-centered care. The characteristics of hypothesis 1 included twelve main points.

- Cancer coordinators' opinion concerning patients' perceptions: about 95% responded that patients viewed the cancer coordinator as a contact person who they could talk to in case they needed it or if they were experiencing problems related to their illness(es), and similarly about 85% responded that patients viewed the cancer coordinator as a contact person who could help them receive necessary practical and medical assistance more efficiently.
- Cancer coordinators use different means of communication, and home visits are common. About 95% of the cancer coordinators used home visits as a tool of communication with cancer patients and their families.
- Cancer coordinators conduct on average from three to eleven home visits per week. Besides, those cancer coordinators who work part-time conduct on average from three to eight home visits per week, whereas the cancer coordinators who work full-time conduct from six to eleven or even more home visits per week.
- Cancer coordinators have received training or have been prepared to communicate adequately with patients. About 60% of the cancer coordinators either received training in communication with patients, or felt that they were well prepared for communication with cancer patients.
- Cancer coordinators' ability to meet patients' needs: about 97% of the respondents assessed their ability to meet patients' needs as good or very good.
- Cancer coordinators consider needs of each curative cancer patient case individually. Average time they used for answering questions and solving problems of curative patients varied depending on situation. About 80% of the respondents said that there was a wide variation among individual patients in average time necessary for answering questions and solving problems of curative patients.
- Similarly, cancer coordinators consider needs of each palliative cancer patient case individually. About 84% of the respondents said that there was a wide variation in average time necessary for answering questions and solving problems of palliative patients.
- Cancer coordinators use 50% or more of their working time directly on cancer patients and their families.

- Cancer coordinators' feel that they have helped improve the safety of cancer patients and their families. Around 53% of the respondents felt assured, whereas 42% supposed, that the safety of cancer patients and their families had been improved due to the position of cancer coordinators in municipalities.
- Cancer coordinators' participation in supervision and education of patients and their families: around 78% of the cancer coordinators participated in supervision and education of cancer patients and their families at least monthly.
- Cancer coordinators' assessment of their communication with patients and their families: about 97% of the respondents assessed their interaction and communication with cancer patients and their families as good or very good.
- Cancer coordinators' visibility and availability in the municipality: about one half reported that their position was well-known to a large number of cancer patients and their families, while the remaining half reported that the position was known to some extent.

Characteristics of the cancer coordinators' activity supporting hypothesis 3 were not found during the evaluation of the obtained results.

Considering the aspects listed above, one may conclude that cancer coordinators work as qualified informants and visible contact persons, who can discuss with cancer patients their illnesses and help solve organizational and spiritual problems connected with these illnesses, thus improving patients' confidence and assurance thereby providing patient-centered care.

Hypotheses 2 and 4 related to cancer care coordination. The characteristics of hypothesis 2 include five main aspects.

- Cancer coordinators' opinion on the lack of coordination affecting their interaction with cancer patients and their families: about 62% of the respondents reported that they rarely or never experienced the lack of adequate cooperation with concerned parties reducing the effectiveness of the work with patients or their families.
- Cancer coordinators' assessment of their collaboration with health care institutions and services situated within and beyond the jurisdiction of municipalities: around 90% of the cancer coordinators denoted good and very good collaboration with palliative care and cancer care nurses, oncological outpatient departments and palliative care

departments, and around 70% of the cancer coordinators assessed their collaboration with nursing homes (both private and public) as good and very good.

- Cancer coordinators' assessment of the communication and collaboration with other cancer coordinators and/or representatives of the NCS in the area of their work: around 87% of the respondents assessed their communication and interaction with cancer coordinators of other municipalities and/or representatives of the NCS as very good or good.
- Cancer coordinators' initiation and maintenance of collaborative actions with several concerned parties in the municipality by means of arranging and/or attending joint meetings: about 81% of the cancer coordinators arranged regular meetings with concerned parties such as nurses, assistant nurses, general practitioners, physiotherapists and/or priests at least monthly.
- Cancer coordinators' participation in supervision and instruction of home-based nurses or other health professionals in municipalities: around 70% of the cancer coordinators participated in instruction of home-based nurses or other health professionals in municipalities at least monthly.

Characteristics of hypothesis 4 include four main issues.

- Cancer coordinators' diverse perception of their work within the coordinating unit of the municipality: only about 46% of the respondents perceived themselves as a part of the coordinating unit in the municipality to a great extent, around 28% perceived themselves as a part of the coordinating unit in the municipality to a small extent, whereas 7% responded that they did not perceive themselves as part of this unit.
- Cancer coordinators' assessment of their collaboration with several health care institutions and services situated within and beyond the jurisdiction of municipalities: about 40% reported that it was sometimes not possible or quite difficult to communicate and collaborate with general practitioners in the municipality. Besides, around 28% of the cancer coordinators stated that it was quite hard or difficult to collaborate on patients with NAV and only 33% of the respondents assessed their collaboration and interaction with NAV as good or very good. In addition, around 15% of the cancer coordinators said that it was quite hard or impossible to collaborate on patients or their next-of-kin with schools and kindergartens, and only 33% of the

respondents assessed their collaboration with schools and kindergartens as good and very good.

- Cancer coordinators' perception of the lack of meeting points and arenas for communication: about 18% of the cancer coordinators did not schedule regular meetings with nurses, assistant nurses, general practitioners, physiotherapists and/or priests, while about 50% of the cancer coordinators did not schedule regular meetings with occupational therapists, participants of the effort team and rehabilitation team, transport and practical assistants, volunteer coordinators and substance abuse, dementia or rehabilitation counselors.
- Cancer coordinators' perception of the lack of coordination affecting their work in general: over 80% of the cancer coordinators stated that they needed to improve their communication and collaboration with general practitioners about new and existing patients, and about 70% reported that they would be able to work better if the interaction and collaboration with hospitals and municipal services were to be improved.

In light of this, both hypothesis 2 and hypothesis 4 may be accepted to some extent. Thus, based on the results of this study, one can assume that cancer coordinators operate as moderators for cancer patients, their families and all possible concerned parties both within and beyond municipality, facilitating intersectoral and interdisciplinary coordination. However, the process of coordination between services, institutions and organizations situated both within and beyond the jurisdiction of municipalities is complicated and often exceeds the resources available to cancer coordinators.

6.2. Presentation of the obtained results in an international context

The results obtained from the survey suggest that cancer care in several Norwegian municipalities has been influenced by the introduction of cancer coordinators. A comparison with the situation in other countries can further enhance the understanding of the successes reported on, as well as aid in the interpretation of results where the results appear to be less optimal, as the effect of context may be essential to gain insight of the situation in Norway. I will thus first interpret the survey findings in an international perspective. It is reasonable to compare the Norwegian example of the implementation of cancer coordinator positions with the Australian (New South Wales) example of a virtually identical policy. General characteristics of the Norwegian and the Australian projects are

thus presented along with research findings from both countries in order to conduct a more complete comparison.

The comparative analysis, as well as the interpretation of the findings in an international context, is made based on this survey and document analysis of several papers, such as the Executive Summary regarding evaluation of the role of cancer coordinators, released by the New South Wales Cancer Institute in 2011, the Summary report: Evaluation of reports of the cancer services infrastructure support program, released by the New South Wales Cancer Institute in February 2012, and the information concerning the cancer coordinator initiative, released by the Norwegian Cancer Society in the beginning of 2012.

The main factors assessed in the Norwegian and the Australian examples are:

- period of the projects' implementation and funding;
- background and contents of the projects: general idea/broad framework, positions location and position description;
- aims of the projects;
- evaluation strategy;
- obtained results;
- future implications.

In my opinion, the Australian project does not explicitly state its theoretical foundation.

Table 4 provides a description of the projects on cancer coordinator positions in Norway and in Australia.

Table 4. Comparing the introduction of cancer coordinators in Norway and Australia (New South Wales)

Criteria for comparison	The introduction of cancer coordinators in Norway*	The introduction of cancer coordinators in Australia (New South Wales)**
Period of the implementation; funding of cancer	Started in 2012. Three to four years trial project. 75% of each position is funded by the Norwegian Cancer Society (NCS)	Approximate duration 2004-2010. Several years trial project. 100% of each position is funded by the Cancer Institute of New

coordinator positions	and 25% of position is funded by municipalities.	South Wales (NSW).
Background and contents of the project:		
General idea/ broad framework	The Coordination Reform	The Cancer Services Infrastructure Support Program
Positions location	97 positions which cover 126 out of 428 Norwegian municipalities (29 municipalities are covered by the cancer coordinators of the adjacent territory)	50 positions are located both in metropolitan and rural areas of New South Wales.
Position description	The position is placed in the jurisdiction of municipalities. The preferable operator is a nurse or health personnel with experience in cancer care or palliative care. Job functions are determined by the municipality, but must contain such duties as coordinating services for cancer patients and their families, supporting multidisciplinary and inter-sectoral cancer care and providing information, advice and guidance on diagnosis, treatment, rehabilitation, relief and care at life's end for cancer patients.	The position is placed in the jurisdiction of metropolitan institutions and rural communities of the state. The preferable operator is a nurse with clinical experience in cancer care or palliative care. Job functions include coordinating patient care and providing access to appropriate services either at the level of a single metropolitan institution or at the level of rural community with the strong component of interregional cooperation.
Aims of the	Ensure patient-centered care and	Provide patient-centered care

project	<p>facilitate life of cancer patients and their families in the best possible way providing information, advice and guidance on diagnosis, treatment, rehabilitation, relief and care at life's end.</p> <p>Provide coordination in the area of cancer care in municipalities supporting multidisciplinary and intersectoral collaboration among different concerned organizations, institutions and services, including non-municipal services.</p>	<p>creating an information and education resource for cancer patients and their families and facilitating access to appropriate services for cancer patients.</p> <p>Provide coordination of patient care supporting multidisciplinary care, fostering coordination and area-wide approach for cancer care.</p>
Evaluation methodology	<p>Based on the aims of the project implementation and own hypotheses; methods include own survey for cancer coordinators, a literature review of evaluations of other cancer coordinator roles and consultation with key staff of the Norwegian Cancer Society.</p>	<p>Based on the aims of the project implementation; methods include a survey for cancer coordinators, a literature review of evaluations of other cancer coordinator roles, consultation with key staff of the Cancer Institute of NSW, review of program documentation, eight service-level case studies, eight patient-level case studies, a patient perception survey distributed at each patient-level case study site.</p>
Obtained results	<p>Patient-centered care has been enhances as a consequence of cancer coordinators' activities.</p>	<p>Patient-centered care has been provided and improved thanks to cancer coordinators'</p>

	<p>According to cancer coordinators themselves and their administrative managers, the positions have facilitated life of cancer patients and their families. Cancer coordinators have provided information, advice and guidance on diagnosis, treatment, rehabilitation, relief and care at life's end for cancer patients and their families.</p> <p>Coordination in the area of cancer care and collaboration among different concerned organizations, institutions and services, including non-municipal services, have been supported by cancer coordinators, however, cancer coordinators' collaboration with several health care and municipal services (general practitioners, NAV, municipal service workers and municipal coordinating unit) needs to be improved.</p>	<p>functioning. Cancer coordinators have become the information and education resource for cancer patients and their families. Cancer coordinators have facilitated access to appropriate services for cancer patients and coordinated patient care.</p> <p>Multidisciplinary care, coordination and area-wide approach for cancer care have been provided and maintained by cancer coordinators; cancer coordinators have played an important role in multidisciplinary coordination teams in communities, however, cancer coordinators' collaboration and interaction with several health care services (general practitioners and multidisciplinary service workers) need to be improved.</p>
<p>Future implications</p>	<p>Preliminary reviews of the project suggest that the newly implemented positions have had some impact on patient-centered care and provision of coordination in the area of cancer care.</p> <p>After more complete evaluations,</p>	<p>The project has demonstrated a significant impact on service delivery models and the quality of patient care and support in the area of cancer care.</p> <p>The project could be used</p>

	<p>the initiative may be used to further improve cancer care coordination in Norwegian municipalities.</p> <p>The project has revealed cancer care organizational and communication difficulties, which need to be considered and resolved for improving high-quality care and cancer care coordination.</p>	<p>further to increase modern high-quality care coordination in the area of cancer care.</p> <p>The project has shown that new models and a more standardized approach to cancer care coordination need to be developed for responding to the increasing incidence of cancer.</p>
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* According to the Norwegian Cancer Society (2012).

** According to the New South Wales Cancer Institute (2011, 2012).

Table 4 presents two cancer coordinators projects implemented in two different countries. These projects have quite much in common both in the area of implementation and regarding the results obtained with the evaluation research. A comparison of the projects shows

- the presence of a trial period: three-four years for Norway and about six years for New South Wales;
- funding from the cancer related organizations: the NCS for Norway and the Cancer Institute of NSW for New South Wales;
- recruitment of health care personnel with experience in cancer and palliative care for cancer coordinator positions;
- similar aims, including improving patient-centered care, providing efficient access to appropriate services, supporting multidisciplinary and intersectoral care and developing information and education resources for cancer patients and their families (Kreftforeningen 2012; Cancer Institute NSW 2011).

Nevertheless, as is demonstrated in Table 4, the number of positions relative to the number of inhabitants and their location appear to be somewhat different in Norway versus Australia (New South Wales).

Although it appears as though there a similar base for the evaluation in both cases, the Australian example of policy implementation is underpinned by a more extensive use of

qualitative methods such as eight service-level case studies, eight patient-level case studies and a patient perception survey distributed at each patient-level case study site, which is currently much less evident in the Norwegian evaluation (ibid). This point underlines the necessity to explore the cancer coordinators' role in Norway at a more detailed level, including also patients' perceptions and those of collaborating parties. It should further be noted that even though both projects were primarily evaluated by the institutions, which had been the initiators of these projects, NSW Cancer Institute appears to conduct more investigations to evaluate the role of cancer coordinators.

The obtained results of the studies related to the cancer coordinators' functioning in the Norwegian and in the Australian cases appear to have quite a few similarities:

- both have enhanced the provision of patient-centered care;
- both have developed informational and educational resources for cancer patients and their families to provide advice and guidance on diagnosis, treatment, rehabilitation, relief and care at life's end for cancer patients;
- both have provided coordination in the area of cancer care and collaboration among different concerned organizations;
- improvements in collaboration with general practitioners in both countries appear warranted (ibid).

However, the results also indicate some challenges regarding coordination in the area of cancer care, and these challenges are different in Norway and Australia. Cancer coordinators' activity in Norway has shown the need for better communication and interaction with some municipal organizations and services including NAV, municipal service workers and municipal coordinating units, whereas cancer coordinators' functioning in Australia has demonstrated the need for better collaboration with multidisciplinary service workers (Cancer Institute NSW 2011).

Future implications concerning cancer coordinators' functioning in Norway suggest a positive impact of the policy on the patient-centered care and provision of coordination in the area of cancer care. The policy could further improve care coordination, as the project has revealed several cancer care organizational and communication challenges, which should be resolved in order to enhance high-quality care. Future implications in the Australian case imply that the Australian policy has demonstrated a significant impact on service delivery models and the quality of patient care (Cancer Institute NSW 2012).

Similarly to the Norwegian case, the policy could be applied to increase modern high-quality care coordination in the area of cancer care (ibid). The difference in future implications between the Norwegian and the Australian examples could be explained by the fact that the Australian policy were finalized and implications could thus be assessed in relation to the overall evaluation of the project, whereas the outcomes of the Norwegian project are preliminary and the policy will be fully evaluated towards the end of the trial period.

6.3. Presentation of the obtained results in the Norwegian context

The context of ‘country’ may be an important platform for interpretation of the results of a particular policy implementation. Moreover, in the framework of one country, there is always a possibility to conduct similar surveys or studies with the same aims. Comparative analysis of two different studies with the same or similar aims may allow researchers to identify inconsistencies and emphasize commonalities. In light of this aspect, I will compare the findings of the survey presented in this thesis with the results of a different Norwegian study launched by the Norwegian Ministry of Health and Care Services on the role of individual plan coordinators. In my opinion, this comparison may help with in the interpretations of the findings in a national context, as well as give a broader view of the coordination initiative in general in Norway. Furthermore, I will also collate the findings of the survey on the role of cancer coordinators presented here with the results obtained by the multi-disciplinary study of the Norwegian Cancer Society in the same field.

6.3.1. Comparison of the obtained results with the results of a fairly similar, but more general, Norwegian policy

The policy concerning the introduction of coordinators of an individual plan was chosen for a comparative analysis since it is related to the coordination initiative in the national context. The main characteristics of the two policies are assessed, along with obtained results to help increase the understanding for the background of this policy implementation. The comparative analysis is made based on the results of own survey and several papers, such as the booklet “Coordinator role - for those who are or will be the coordinator of the individual plan” (own translation), released by the Norwegian Directorate of Health in 2010, the report “I have a plan” (own translation), released by the Norwegian Directorate of Health in 2009, the report “Mapping of individual plans in the

municipalities” (own translation), released by the Norwegian Directorate of Health in 2011, and information concerning cancer coordinator initiative, released by the Norwegian Cancer Society in the beginning of 2012.

The main criteria for comparing two Norwegian examples remain the same as those listed in the international comparative analysis. An explicit theoretical foundation for the project regarding coordinators of an individual plan was not found. Table 5 demonstrates the description of two Norwegian policies: one of those is connected with the functioning of cancer coordinators; the other one is related to the functioning of coordinators of an individual plan.

Table 5. Comparing the introduction of cancer coordinators and the introduction of coordinators of an individual plan in Norway

Criteria for comparison	The introduction of cancer coordinators in Norway*	The introduction of coordinators of an individual plan in Norway**
Period of the implementation; funding of coordinator positions	Started in 2012. Three to four years trial project. 75% of each position is funded by the Norwegian Cancer Society (NCS) and 25% of each position is funded by municipalities.	Approximate duration is 2008-2015. Several years project. 100% of each position is funded by municipalities.
Background and contents of the project:		
General idea/broad framework	The Coordination Reform (2012-2016)	National Strategy for habilitation and rehabilitation (2008-2011), the National Strategy for Quality Improvement in Health and Social Services (2005-2015), the Coordination Reform (2012-

		2016)
Positions location	97 positions which cover 126 out of 428 Norwegian municipalities (29 municipalities are covered by the cancer coordinators of the adjacent territory)	349 municipalities are covered by the positions of coordinators of an individual plan
Position description	The position is placed in the jurisdiction of municipalities. The preferable operator is a nurse or health personnel with experience in cancer care or palliative care. Job functions are determined by the municipality, but must contain such duties as coordinating services for cancer patients and their families, supporting multidisciplinary and inter-sectoral cancer care, and providing information, advice and guidance on diagnosis, treatment, rehabilitation, relief and care at life's end for cancer patients.	The position is placed in the jurisdiction of municipalities. Various professionals from various sectors can handle the position. Job functions are determined by the municipality and include creating an individual plan for multiple types of users (not only 'patients', but individuals with special needs); monitoring, evaluating and updating the plan; and coordinating user's care and providing access to appropriate services.
Aims of the project	Ensure patient-centered care and facilitate life of cancer patients and their families providing information, advice and guidance on diagnosis, treatment, rehabilitation, relief and care at life's end. Provide coordination in the area	Provide individual assistance and care by means of creating and following an individual plan together with the user. Coordinate individual care and

	of cancer care in municipalities supporting multidisciplinary and intersectoral collaboration among different concerned organizations, institutions and services, including non-municipal services.	provide access to appropriate services, as well as support multidisciplinary and intersectoral care.
Evaluation methodology	Based on the aims of the project implementation and own hypotheses; methods include own survey for cancer coordinators, a literature review of evaluations of other cancer coordinator roles and consultation with key staff of the Norwegian Cancer Society.	Based on the aims of the project implementation; methods contain the review of the official documents, released by the Norwegian Ministry of Health and Care Services, regarding the evaluation of the role of coordinators of an individual plan, including patients comments and perceptions.
Obtained results	<p>Patient-centered care has been enhanced as a consequence of cancer coordinators' activities. According to cancer coordinators themselves and their administrative managers, the positions have facilitated life of cancer patients and their families. Cancer coordinators have provided information, advice and guidance on diagnosis, treatment, rehabilitation, relief and care at life's end for cancer patients and their families.</p> <p>Coordination in the area of cancer</p>	<p>Individual assistance and care have been provided by means of creating and following an individual plan in some areas of interest (mental diseases, drug addiction and children/youths with special needs). Coordinators of an individual plan have worked together with users and their families to ensure individual care providing spiritual and psychological support.</p> <p>Coordination of individual care</p>

	<p>care and collaboration among different concerned organizations, institutions and services, including non-municipal services, have been supported by cancer coordinators, however, cancer coordinators' collaboration with several health care and municipal services (general practitioners, NAV, municipal service workers and municipal coordinating unit) needs to be improved.</p>	<p>has been successful in terms of communication and interaction between the coordinator of an individual plan and the user. Difficulties regarding providing an access to appropriate services, as well as supporting multidisciplinary and intersectoral care have been associated with the lack of collaboration with the concerned parties in municipalities.</p>
<p>Future implications</p>	<p>Preliminary reviews of the project suggest that the newly implemented positions have had some impact on patient-centered care and provision of coordination in the area of cancer care.</p> <p>After more complete evaluations, the initiative may be used to further improve cancer care coordination in Norwegian municipalities.</p> <p>The project has revealed cancer care organizational and communication difficulties, which need to be considered and resolved for improving high-quality care and cancer care coordination.</p>	<p>The project has shown a positive effect in the area of provision of individual assistance and care for several types of users (those with mental diseases, special needs and drug addiction).</p> <p>The project needs further development to improve coordination between various services and organizations in municipalities.</p> <p>The project has revealed organizational and communication difficulties which need to be considered and resolved for improving individual care.</p>

* According to the Norwegian Cancer Society (2012).

** According to the Norwegian Directorate of Health (2009, 2010, 2011).

Table 5 presents two Norwegian projects intended to improve the coordination at the level of municipalities. However, the cancer coordinator project is focused on the fulfillment of needs of cancer patients and their families, including individual approaches for coordination, whereas the project about coordinators of an individual plan is supposed to cover any user who is in need of an individual plan and thus an individual approach for coordination (Kreftforeningen 2012; Helsedirektoratet 2009, 2010, 2011). The following issues are common for both projects:

- implementation in the framework of the Coordination Reform;
- coordinator positions placed in the jurisdiction of municipalities;
- aims, including coordinating individual care, providing access to appropriate services and supporting multidisciplinary and intersectoral care (ibid).

Nevertheless, as it is shown in Table 5, the project concerning cancer coordinators differs from the project about coordinators of an individual plan on the following points:

- the status of the project (trial, temporary versus real permanent and based in laws);
- number of positions and coverage (126 versus 349 municipalities);
- the preferable operator (nurse or health personnel with experience in cancer care and/or palliative care versus various professionals from various sectors);
- job functions (coordination mainly for cancer patients and their families versus coordination for everyone who needs it).

Although it appears as though there a similar base for the evaluation in both cases, the project on coordinators of an individual plan is supported by the official documentation and evaluation report of the Norwegian Directorate of Health, including patients' comments and perceptions. It is also included in various health laws, and thus formalized to a much greater extent than the project on cancer coordinators.

The obtained results of the evaluation studies in both cases appear to have a few similarities, and there is a general tendency concerning providing patient-centered care/individual care and assistance for patients/users in the appropriate way. However, the obtained results also indicate some challenges regarding coordination in Norway both in the area of cancer care and in the area of collaboration between municipal services and organizations for patient groups with extensive needs for coordinated services (ibid).

The project about cancer coordinators' activity and the project about the coordinators of an individual plan have similarities in future implications due to the fact that both are currently ongoing and point to some difficulties of collaboration between concerned parties in municipalities. Both projects have also demonstrated a positive impact on patient/user individual care and may be used to further enhance best possible patient-centered care/individual care and assistance for those persons who need it (ibid).

6.3.2. Comparison of the obtained results with the results of the evaluation report of the Norwegian Cancer Society

The Norwegian Cancer Society, the main initiator of the project concerning cancer coordinators' activity in several Norwegian municipalities, has by March 2014 prepared two evaluation reports on the cancer coordinator initiative. The first report was released in September 2013 and consisted of a thorough analysis of multiple areas of cancer coordinators' activity based on the data collected by means of questionnaires for cancer coordinators and their managers. The second report was released in February 2014 and mostly discussed changes in obtained results compared to the first report. Questionnaires included both open-ended and closed-ended questions and covered such issues as cancer coordinators' organizational location, percentage of position held, intermunicipal collaboration, distribution of working time, cancer coordinators' visibility and availability for patients and their families, the role of the position for patients and their families, cancer coordinators' cooperation with internal concerned parties in the municipality, cancer coordinators' collaboration with external concerned parties and various additional features (Kreftforeningen 2014, 9). As a consequence of my collaboration and cooperation with representatives of the Norwegian Cancer Society, both reports were made available for review and examination in order to compare the results of the reports with the results of the survey presented in this thesis.

The present comparative analysis is mostly based on the last report of the Norwegian Cancer Society. Table 6 portrays the main similarities and differences in design and obtained results concerning the issues of interest. So far as these two investigations describe and analyze the same project, the comparison of the project's backgrounds and aims, which was presented in previous paragraphs, has been omitted.

Table 6. Comparing the results obtained by the Norwegian Cancer Society and the results of the present survey

Criteria for comparison	The evaluation made by the Norwegian Cancer Society on the cancer coordinator initiative*	The evaluation made with the help of the present empirical research about the role of cancer coordinators
Design	Mixed (both quantitative and qualitative): electronic questionnaires consisted of open-ended and closed-ended questions for cancer coordinators and their managers	Quantitative: electronic questionnaires contained only closed-ended questions, and were solely distributed to cancer coordinators
Response rate	<p>Participation was obligatory.</p> <p>100% (91 cancer coordinators), not all cancer coordinators answered all questions.</p> <p>98% (89 managers of cancer coordinators), not all managers answered all questions.</p>	<p>Participation was voluntary.</p> <p>52% (47 respondents), not all cancer coordinators answered all questions.</p>
Results regarding care for cancer patients	<ul style="list-style-type: none"> - The majority of cancer coordinators use 50% or more of their working time on patients and their families. - Cancer coordinators provide care and assistance for patients and their next-of-kin when it comes to support conversation, economical and financial rights, pain relief, nutrition, contacting hospitals, 	<ul style="list-style-type: none"> - The majority of cancer coordinators use 50% or more of their working time on patients and their families. - Cancer coordinators consider their interaction with cancer patients and their families as very good or good; moreover, cancer coordinators consider that they maintain a high ability to meet

	<p>physical activity, death at home, side effects of treatments, information about learning and activity centers, patient associations and work.</p> <p>- According to opinions of cancer coordinators' managers, positions of cancer coordinators in municipalities facilitate life of cancer patients. As such, cancer patients develop a better understanding of their disease, receive psychological assistance and have appropriate measures undertaken in the area of cancer care.</p>	<p>cancer patients' needs, ensuring a positive impact of their activities on the patients' conditions.</p> <p>- Cancer coordinators work as qualified informants and visible contact persons who can discuss with cancer patients their illnesses and help solve organizational and spiritual problems connected with these illnesses, improving patients' confidence and assurance thereby facilitating enhanced patient-centered care.</p>
<p>Results regarding coordination</p>	<p>- Cancer coordinators cooperate mostly with health care professionals and organizations such as</p> <ul style="list-style-type: none"> • nurses (91% communicate often), • cancer care nurses (65% communicate often), • doctors (63% communicate often), • oncological outpatient departments (58% communicate often), • cancer care departments (55% communicate often). 	<p>- The majority of cancer coordinators noted good or very good collaboration with such health care professionals and organizations such as</p> <ul style="list-style-type: none"> • palliative care and cancer care nurses (92%), • oncological outpatient departments (85%), • palliative care departments (92%). <p>About 81% of cancer coordinators arrange and/or attend regular meetings with concerned parties such as</p>

	<p>- Cancer coordinators cooperate less frequently with</p> <ul style="list-style-type: none"> • NAV (12% communicate often, 27% communicate seldom or never), • schools (2% communicate often, 64% communicate seldom or never), • kindergartens (1% communicate often, 80% communicate seldom or never), • volunteer centers of municipalities (6% communicate often, 52% communicate seldom or never), • learning and coping centers of municipality (3% communicate often, 85% communicate seldom or never), • public health coordinators (9% communicate often, 71% communicate seldom or never). <p>Around 47% collaborate with the coordinating unit in the municipality often, whereas 28% communicate with the coordinating unit in the municipality seldom or</p>	<p>nurses, general practitioners, physiotherapist and/or priests at least monthly.</p> <p>- Cancer coordinators evaluate their collaboration with schools, kindergartens and NAV as good or very good less often:</p> <ul style="list-style-type: none"> • NAV (about 33% assessed their collaboration as good or very good, and 28% assessed it as quite poor or poor), • schools and kindergartens (about 33% assessed their collaboration with schools and kindergartens as good or very good, but about 13% assessed it as quite poor), • Only about 50% arrange and/or attend regular meetings with such service workers as occupational therapist, participants of rehabilitation teams, transport and practical assistants and/or volunteer coordinator at least monthly. <p>Around 46% perceive themselves as a part of the coordinating unit to a great extent, around 28% perceive themselves as a part of the coordinating unit to a small</p>
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	never.	extent, whereas around 8% do not perceive themselves as a part of the coordinating unit in the municipality.
Future implications	<p>The initiative has contributed to interdisciplinary collaboration and improved coordination.</p> <p>Almost all the municipal managers who participated in the project would recommend other municipalities to establish cancer coordinator positions.</p> <p>The project has revealed a lack of collaboration between several concerned parties, which needs to be considered and resolved to further enhance cancer care coordination.</p>	<p>The project suggests a potential positive impact on patient-centered care and provision of coordination in the area of cancer care.</p> <p>The initiative may be used to further improve cancer care coordination in Norwegian municipalities.</p> <p>The project has revealed cancer care organizational and communication difficulties, which need to be considered and resolved to further improve high-quality care and cancer care coordination.</p>

* According to the Norwegian Cancer Society (2014).

The evaluation report of the Norwegian Cancer Society is much more comprehensive, inclusive and complete compared to the present research, although it lacks a clear theoretical foundation. Furthermore, it was designed as an evaluative project, and not research per se, and was thus exempted from standard ethical research guidelines such as voluntary participation (Kreftforeningen 2014). As it was obligatory to respond to ensure continued funding, the answers might be more prone to information bias. Moreover, as the evaluation was conducted by the funding agency itself, it does not provide an independent assessment in a strict sense.

On a positive note, this provided a response rate close to 100%. Furthermore, the NCS's evaluation includes the usage of both quantitative and qualitative methods. In addition, information was sought also from managers of cancer coordinators (ibid). Taking into

account both the advantages of the design as well as the disadvantages listed, the high level of concordance between the results obtained in the survey presented in this thesis and the results obtained by the NCS may strengthen the belief in the validity of the present research.

The results of the perceived impact on patient care appear to be very similar in both cases, as demonstrated in Table 6. However, utilizing information also from cancer coordinators' managers strengthens the evaluation conducted by the NCS as compared to the present research that uses using the information solely from cancer coordinators. Both studies are, however, void of information from patients or other user groups, which appears warranted, should one conclude fully on the impact cancer coordinators have made to enhance patient-centered care. Future studies should strive to include also this bottom-up perspective.

The results regarding coordination are also quite similar. It should nevertheless be noted that the evaluation report of the NCS primarily provides facts and frequencies of the cancer coordinators' collaboration with a great amount of concerned parties both within municipalities and beyond, whereas the present research to a larger extent reflects the cancer coordinators' assessment of their collaboration with several concerned parties both within the municipality and beyond.

The differences between the suggested future implications may be a consequence of the fact that the report of the NCS includes assessments of cancer coordinators' activity by cancer coordinators' managers, whereas the present research is based solely on cancer coordinators' assessment of their position, working process and collaboration.

The investigation conducted by the Norwegian Cancer Society is a good example of a possible evaluation of the cancer coordinators' functioning. The information extracted from their investigation portrayed in Table 6 for the purposes of undertaking a comparative analysis is just an extraction of a more extensive report. The two repeated evaluations which have been undertaken by the NCS is conducive to improved reliability and allows for a follow-up of changes in cancer care coordination emerging at different speeds as a consequence of cancer coordinators' activity in municipalities over time.

7. Conclusion

This thesis has attempted to assess features related to the establishment of cancer coordinator positions as a potential policy measure in Norway in order to provide more efficient care to individuals and their next-of-kin who face cancer.

Due to population aging, the incidence and prevalence of cancer is rising in the whole world, and especially in developed countries (Ferlay et al. 2008). Norway is no exception. Since Norway is a country where the provision of appropriate treatment and care is considered a pertinent public health issue, Norwegian policymakers are constantly working to improve the health care system and maintain costs.

The area of health care in Norway is nowadays passing through relatively broad changes due to recently implemented reforms at national and local levels. The Norwegian Ministry of Health has begun the implementation of the Coordination Reform since the start of 2012 in order to manage three distinctive challenges of the Norwegian health care: lack of coordinated services for patients, suboptimal levels of services toward disease prevention and changing disease patterns due to the aging of population (Norwegian Ministry of Health and Care Services 2009).

The presuppositions of the Coordination Reform are likely broad changes in the area of public administration (Christensen and Lægveid 2011). Since the concepts and main characteristics of post-NPM ideas correspond well with the Norwegian health care model, the Coordination Reform may be viewed as an example of an implementation of post-NPM concepts, which manifests itself within the framework of health care cooperation improvement and the joining of both regional and local levels of health care provision (ibid).

Along with the Coordination Reform, a three-four year trial project implementing cancer coordinator positions in several Norwegian municipalities began in 2012, at the initiative of the Norwegian Cancer Society. The role of cancer coordinators according to the Coordination Reform and in the framework of the trial project of the Norwegian Cancer Society may be considered to be an expression of post-NPM ideas at the local level. A more thorough examination of the official information concerning cancer coordinators' activity and a review of the municipal requirements for cancer coordinators reveal several

items which correspond rather well with typical post-NPM features, such as providing horizontal coordination, public value management and pro-active leadership.

The results of the theoretical part of the thesis indicate that post-NPM concepts laid the ground for the implementation of cancer coordinators. These concepts may thus be relevant to enhance the understanding of the basic aspects underlying the Coordination Reform and the establishment of cancer coordinator positions in particular, and may thus help characterize the broad changes currently on the way within the Norwegian health care system, and in cancer care in particular, in a systematic manner.

The empirical analysis has provided answers to the main research question of this thesis. According to the results of the present study, the implementation of cancer coordinators in Norwegian municipalities has positively influenced cancer care provision at local levels. Cancer coordinators have been shown to provide patient-centered care and facilitate life of cancer patients and their families by providing information, advice and guidance on diagnosis, treatment, rehabilitation, relief and care at life's end. The results have also demonstrated that coordination in the area of cancer care and collaborations among various concerned organizations, institutions and services, including non-municipal services, are strengthened by cancer coordinators, although cancer coordinators' interaction with several health care and municipal services (general practitioners, NAV, municipal service workers and municipal coordinating units in particular) warrants improvement. Thus, the process of coordination between health care services, institutions and organizations situated both within and outside municipalities is complicated and exceeds the resources available to cancer coordinators in terms of establishing and maintaining collaboration.

Comparisons of the results of the presented empirical investigation with results of studies conducted in similar areas in international and national contexts have indicated the presence of common features particularly with regard to the difficulty in maintaining an appropriate level of coordination. On the other hand, a comparison of the presented results with the results reported by the Norwegian Cancer Society has shown that the present study has accurately captured the role of cancer coordinators in providing cancer patient care and coordination for the targeted population.

8. Suggestions for further research

The present research has focused on selected aspects of the cancer coordinators' functioning in Norway. Since the cancer coordinator initiative is a relatively new concept, any contribution to investigations, however small, may help improve the understanding of coordination in cancer care in Norway and thus be useful in practice and as a foundation for future research.

A multiperspective study should be conducted for a more comprehensive evaluation of the project of the Norwegian Cancer Society. This study can take into account and examine the feedback from cancer patients and their families, general practitioners, nurses with education in the field of oncology and palliative care, medical professionals of the oncological outpatient and inpatient departments, as well as cancer coordinators' managers, employees of coordinating units and municipal services. It is also important to assess the economic component of the project, which is likely to be the most essential aspect for the municipalities in deciding whether or not to extend the project on their own cost after the trial period finishes. In addition, to ensure the usefulness and effectiveness of cancer coordinators' activity, one can compare cancer statistics, feedback from cancer patients, medical personnel and managers from municipalities, which have established cancer coordinator positions, with the similar information from municipalities, which have not established cancer coordinator positions.

As such, a full examination of the trial project concerning the implementation of cancer coordinator positions in Norwegian municipalities suggests several opportunities for further studies, which, by and large, may provide additional knowledge on the potential role of cancer coordinators in ensuring optimal patient care and coordination.

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Appendices

Appendix 1: Letter from NSD [in Norwegian]

Norsk samfunnsvitenskapelig datatjeneste AS
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Postboks 4 St. Olavs plass
0130 OSLO

Vår dato: 20.11.2013

Vår ref: 36031 / 2 / IB

Deres dato:

Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 23.10.2013. All nødvendig informasjon om prosjektet forelå i sin helhet 19.11.2013. Meldingen gjelder prosjektet:

<i>36031</i>	<i>Kreftkoordinatorers rolle i kommunene</i>
<i>Behandlingsansvarlig</i>	<i>Høgskolen i Oslo og Akershus, ved institusjonens øverste leder</i>
<i>Daglig ansvarlig</i>	<i>Erika Kathleen Gubrium</i>
<i>Student</i>	<i>Nataliia Moshina</i>

Personvernombudet har vurdert prosjektet og finner at behandlingen av personopplysninger er meldepliktig i henhold til personopplysningsloven § 31. Behandlingen tilfredsstiller kravene i personopplysningsloven.

Personvernombudets vurdering 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, 01.07.2014, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Vigdis Namtvedt Kvalheim

Inga Brautaset

Kontaktperson: Inga Brautaset tlf: 55 58 26 35

Vedlegg: Prosjektvurdering

Kopi: Nataliia Moshina moshina75@yahoo.com

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

Appendix 2: Interview guide [in Norwegian]

Interview guide for cancer coordinators and cancer care nurses⁹

Høgskolen i Oslo og Akershus (HiOA) og Statistisk Sentralbyrå (SSB) gjennomfører en undersøkelse knyttet til samhandlingsreformen og innføringen av kreftkoordinatorer i flere norske kommuner. Prosjektet skal lede til en masteroppgave i sosialt arbeid ved HiOA, samt en internasjonal artikkel i et fagfelleverdert tidsskrift.

Vi er interessert i både positive og negative endringer i palliativ bistand for kreftpasienter og forandringer i sykepleieres arbeidssituasjon som kan knyttes til kreftkoordinatorers aktivitet. Vi planlegger å utvikle et spørreskjema for kreftkoordinatorer og sykepleiere i hjemmetjenesten som arbeider med kreftpasienter. Vi kommer til å gjennomføre seks intervjuer ansikt-til-ansikt for å kunne utarbeide gode kvantitative spørreskjema om problemområder og positive konsekvenser av innføringen av ordningen med kreftkoordinatorer, for pasienter og helsepersonell. Du er en av dem vi ønsker å intervjuer kvalitativt, og vi ser frem til et fruktbart samarbeid. Vi garanterer anonymitet i arbeidene som resulterer, og vi vil ikke benytte direkte sitater med mindre dette er eksplisitt avklart. Nedenfor ser du et eksempel på spørsmål som vi ønsker å stille deg når vi møtes. Siste spørsmål åpent og spør om det er noe du ønsker å tilføye eller snakke mer om, og det er flott om du selv bidrar med tema eller områder du opplever som ikke adekvat dekket hos oss. Vår liste er basert på tidligere forskning på dette området fra utlandet, i hovedsak Australia.

Informanten: kjønn, alder, etterutdanning, hvor lenge han/hun jobbet innen helse og omsorg, hvor lenge i tjenesten (sykehus, sykehjem eller kommune) som informanten jobber i dag.

Spørsmål til kreftkoordinator i kommune:

1. Kan du som kreftkoordinator fortelle om din typiske arbeidsdag? Hvilke utførelser møter du hver dag? Hvordan organiserer du arbeidet ditt? Har du en spesiell plan? Holder du deg til planen? Hvor mange kreftpasienter kommuniserer du med i løpet av en vanlig dag, i gjennomsnitt? Hvor stor andel av pasientene du møter eller bistår trenger palliativ behandling? Hva konkret består arbeidsoppgavene dine av?

2. Hvorfor bestemte du deg for å bli kreftkoordinator i kommunen? Hva forventet du da begynte du å jobbe som kreftkoordinator i kommune? Oppfyller arbeidet dine forventninger?

3. Hvor lenge har du jobbet som kreftkoordinatorer kommune? Hva har vært mest vanskelig i denne perioden? (samhandling med sykehus, sykehjem, pasienter; tildeling av tid og prioriteringer; etablering kontakter med partene som krever koordinering).

⁹ The text of the information letter is available in English by request.

- 4. Hvor mange kreftpasienter som trenger palliativ behandling har du på din listen akkurat nå? Hvor mange kreftpasienter som trenger palliativ behandling har du på din liste siden du begynte i jobben din?** Hvor ofte ringer eller bruker du e-post med pasienter (hver dag, hver uke)? Hvor ofte ringer eller skriver deres pårørende?
- 5. Hva er spørsmålet eller området palliative pasienter trenger oftest hjelp til?** Kan du stort sett hjelpe dem, enten ved å svare adekvat eller henvise de til rett instans? Kan du utføre deres forespørsler? Oppfordrer du palliative kreftpasienter til å kontakte sykehuset? Hvis ja, hvor ofte? Oppfordrer du palliative kreftpasienter til å kontakte sykehjem? Hvis ja, hvor ofte?
- 6. Hvor mye tid trenger du gjennomsnittlig for å utføre oppgaver for pasienter?** Hvor mye tid trenger du for å snakke med kreftpasienten om problemer han/hun kan ha og om sykdommen sin? Hvor mye tid trenger du, i gjennomsnitt, til å snakke med pårørende? Hvor ofte snakker du med dem og gjelder dette både unge og gamle pasienter?
- 7. Hvilke slags av kreftpasienter er mest vanskelig å kommunisere?** Bruker du en hjelp av psykolog for å forbedre kommunikasjonen? Hvor ofte?
- 8. Hvem kan du spørre og bruke for å løse pasientens problemer?** Har du et nettverk av helseinstitusjoner som kan bistå deg? Har du en liste over sykehus, leger, sykehjem, onkologisk poliklinikk og frivillige eller kompetansenettverk av ressurspsykepleiere du kan spørre om hjelp?
- 9. Hvor ofte og hvilke slags kreftpasienter oppfordrer du til å ta kontakt med onkologisk poliklinikk?** Har du et godt eller dårlig samarbeid med smerteklinikk? Eller kommuniserer du bare med sykehusavdelinger, leger og sykehjem?
- 10. Hvor ofte trenger kreftpasienter eller dere pårørende hjemmebasert omsorg og behandling?** Har du en liste over sykepleiere som kan gi hjemmebasert omsorg og behandling? Hvor ofte spør pasienter om dette?
- 11. Hvordan vurderer du samarbeid med hjemmebaserte tjenester?** Er hjemmebaserte tjenester samlokalisert? Drar hjemmebaserte sykepleiere sammen til pasienter? Fordeler de arbeidsoppgaver? Driver du opplæring og veiledning av hjemmebaserte sykepleiere? Er det stor forskjell om kommunen har egne kreftsykepleiere eller ikke?
- 12. Opplever du at noe gjør det vanskelig å jobbe med pasienter?** Hva eller hvem gjør det vanskelig for å arbeide? Hvorfor det? Opplever du at noe gjør det vanskelig å samarbeide med sykehus og sykehjem?
- 13. Får du nok finansiering og midler fra kommunen for å bidra til å løse kreftpasienters problemer?** Har du nok teknisk støtte og praktisk informasjon om pasientene, ledige leger, tilgjengelige senger på sykehus eller sykehjem for et effektivt arbeid? Hva slag teknisk utstyr bruker du vanligvis på jobben?

14. Hva er dine mål for på kort sikt (for de neste to månedene)? Hva er dine mål for ditt arbeid det kommende året?

15. Er det noe annet du vil si/tilføye?

Spørsmål til sykepleier på sykehjem/hjemmebaserte tjenester:

1. Har det skjedd noen endringer i samarbeidet med sykehus/sykehuspersonell mot kreftpasienter på grunn av fremveksten av kreftkoordinatorer? Hvordan opplever du samarbeidet med sykehuspersonell og kreftkoordinatorer (godt/dårlig) i sykehjemmet/tjenesten du jobber i? Endring etter at reformen trådte i kraft? Har sykehjemmet/tjenesten (og kommunen) elektroniske meldingssystem med sykehus eller kreftkoordinatorer? Har dette kommet på plass i forbindelse med samhandlingsreformen? Har mengden eller omfanget av tilstrekkelig dokumentasjon/informasjon om kreftpasienter endret seg etter reformen? Opplever du at kreftkoordinatorer kompliserer og/eller forenkler samhandling mellom sykehus (onkologisk poliklinikk, regionale palliative senteret) og sykehjem/hjemmebaserte tjenester. Hvorfor det?

2. Har det skjedd noen endringer i kreftpasientgruppen eller i antallet av de kreftpasientene på sykehjemmet/tjenesten du jobber i? Har det skjedd noen endringer i palliasjonsgruppen? Har du flere kreftpasienter enn du hadde før reformen? Opplever du at terskelen for å legge inn/registrere kreftpasienter i sykehjemmet/hjemmebaserte tjenester har endret seg? Økt eller redusert antallet kreftpasienter i sykehjemmet/tjenester du jobber i?

3. Har det skjedd noen endringer i oppgaver du utfører nå etter reformen? Mer komplekse? Mer varierte og spennende oppgaver? For vanskelige? For mange?

4. Har kreftkoordinatorers aktivitet innvirkning på arbeidet ditt med kreftpasienter som trenger palliativ omsorg på sykehjem/i tjenesten du jobber i? (positiv eller negativ) Hva er effekten? Opplever du at kreftpasienter, som trenger palliativ omsorg, er lettere å jobbe med, hvis de samhandlet med kreftkoordinatoren før de kommer til sykehjem/tjenesten? Opplever du at du har mer eller mindre tid å jobbe med kreftpasienter enn du hadde før reformen? Har du lagt merke til at kreftpasienter og palliative pasienter blir mer kunnskapsrike om sykdommene sine etter reformen? Har du nok tid å arbeide med alle kreftpasienter som du er ansvarlig på sykehjemmet/tjenesten du jobber i?

5. Hvem er det som oftest samtaler med kreftkoordinatoren på sykehjemmet/tjenesten du jobber i? Samhandler administrerende av sykehjemmet/tjenesten med kreftkoordinatorer seg selv over innkommende kreftpasienter? Hvor ofte (hver dag, ukentlig) kommuniserer kreftkoordinatorer med ansatte i sykehjemmet/tjenesten du jobber i, om å motta eller overføre kreftpasienter, som trenger palliativ behandling, fra et sykehus til sykehjemmet/tjenesten du jobber i?

6. Hvor mange kreftpasienter, som er nå på sykehjemmet/i tjenesten du jobber i, har sine kreftkoordinatorer? Når fikk du den første kreftpasienten, som var rettet mot ved

kreftkoordinatoren til sykehjemmet/tjenesten du jobber i? Har gjennomsnittlig antall kreftpasienter som har sine kreftkoordinatorer økt de siste seks månedene?

7. For sykepleier på sykehjem: Kommuniserer du eller andre ansatte av det sykehjemmet du jobber i, med kreftkoordinatorer når det er nødvendig for å skrive ut kreftpasienter som trenger videre palliativ omsorg på hjem? Hvis ja: hvor ofte? - om hver pasient eller når du har noen spesielt? Opplever du at det er enklere å samhandle med kreftpasienter, som blir overført fra sykehjemmet til et hjem?; hvis nei: hvem kommuniserer med pårørende og familie når det bør utskrives palliative kreftpasienter til hjem? Er det ansatte av sykehjemmet du jobber i?

8. Kommuniserer du eller andre ansatte av den tjenesten der du jobber, med kreftkoordinatorer når det er nødvendig for å rette mot kreftpasienter, som trenger palliativ behandling, til sykehus/sykehjem? Hvis ja: hvor ofte? Opplever du at det er enklere å samhandle med sykehus/sykehjem i slike tilfeller?; hvis nei: hvem kommuniserer med tjenesten du jobber i når det er nødvendig for å rette mot kreftpasienter, som trenger palliativ behandling, til sykehus/sykehjem?

9. Er det noe annet du vil si/tilføye?

Appendix 3: Information letter [in Norwegian]

Kjære kreftkoordinator!¹⁰

Høgskolen i Oslo og Akershus (HiOA) og Statistisk Sentralbyrå (SSB) i samarbeid med Den Norske Kreftforening gjennomfører en undersøkelsen som er knyttet til samhandlingsreformen og innføringen av kreftkoordinatorer i flere norske kommuner. Prosjektet skal lede til en Masteroppgave i sosial arbeid ved Høgskolen i Oslo og Akershus, samt en internasjonal artikkel i et fagfelleverdert tidsskrift.

Vi håper du kan delta i denne undersøkelsen om muligheter og utfordringer relatert til arbeidet ditt for kreftpasienter i kommunen du arbeider i.

Vi ønsker å utforske aktiviteten til kreftkoordinatorer i kommuner og få innsikt i hvordan du opplever situasjonen for pasienter og relasjonen til øvrig helsepersonell i kommunen. Målet er å få et bedre innblikk i arbeidssituasjonen din og av konsekvenser av arbeidet kreftkoordinatorer utfører innenfor rammen av den nylig innførte samhandlingsreformen i det norske helsevesenet.

Vi er interessert i din formening om både positive og negative endringer i kreftomsorgen. Vi har utviklet et spørreskjema for kreftkoordinatorer som arbeider med kreftpasienter for å systematisere tilbakemeldingene. Spørreskjemaet er basert på internasjonale erfaringer på området. Det tar omlag 5-10 minutter å besvare det. Du kan svare på spørsmålene ved å bruke linken nedenfor <https://survey.hioa.no/index.php/684988/lang-nb>. Spørreskjemaet er elektronisk. I selve spørreskjemaet ber vi ikke om navn eller andre identifiserende opplysninger, men siden undersøkelsen gjennomføres elektronisk, registreres din IP-adresse med besvart skjema ved innsending. Kun IT-avdelingen ved HiOA og vår databehandler Lime Survey har tilgang til IP-adressene, som slettes senest ved prosjektslutt. Vi som forskere vet ikke hvem som har svart. Prosjektet er meldt til Personvernombudet for forskning, Norsk samfunnsvitenskapelig datatjeneste (NSD).

Oppsummert blir altså opplysningene vi samler inn behandlet helt konfidensielt, og materialet blir presentert slik at enkeltpersoner og kommuner ikke kan kjennes igjen. Prosjektet avsluttes i løpet av våren 2014. Dersom du ønsker det, kan du kontakte med i slutten av juni 2014 slik at du får en elektronisk kopi av Masteroppgaven. Offentlig tilgjengelige epostadresser til kreftkoordinatorer er benyttet i utsendelsen av denne eposten.

Vi håper du velger å delta, da prosjektet vil gi kunnskap om beslutninger om prioriteringer på kommunenivå som er viktig for bedre forståelsen om hva bør endres i pleie- og omsorgssektoren for kreftpasienter. For mer informasjon om undersøkelsen, vennligst ta kontakt med undertegnede.

¹⁰ The text of the information letter is available in English by request.

Du kan svare på spørsmålene ved å bruke linken
nedenfor <https://survey.hioa.no/index.php/684988/lang-nb>.

På forhånd takk for hjelpen!

Med vennlig hilsen,

Nataliia Moshina

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Appendix 4: Questionnaire [in Norwegian]

Spørreskjema:¹¹ Undersøkelse om kreftkoordinatorers aktivitet og endringer i kreftomsorg etter opprettelsen av slike stillinger i forbindelse med Samhandlingsreformen

Innledningstekst

Høgskolen i Oslo og Akershus (HiOA) og Statistisk Sentralbyrå (SSB) gjennomfører en undersøkelsen som er knyttet til samhandlingsreformen og innføringen av kreftkoordinatorer i flere norske kommuner. Prosjektet skal lede til en masteroppgave i sosialt arbeid ved HiOA, samt en internasjonal artikkel i et fagfelleverdert tidsskrift.

Vi ønsker å utforske aktiviteten som drives av kreftkoordinatorer i kommunene, samt de første resultatene av kreftkoordinatorers arbeid innenfor rammen av Samhandlingsreformen i det norske helsevesenet. Vi er interessert i både positive og negative endringer i kreftomsorg. Vi utviklet et spørreskjema for kreftkoordinatorer som arbeider med kreftpasienter.

Opplysningene vi samler inn blir behandlet helt konfidensielt, og materialet blir presentert slik at enkeltpersoner og kommuner ikke kan kjennes igjen. Prosjektet avsluttes i løpet av våren 2014.

Vi håper du velger å delta, da prosjektet vil gi kunnskap om beslutninger om prioriteringer på kommunenivå som er viktig for utforming av gode rammebetingelser for virksomheten i pleie- og omsorgssektoren. Vi er svært takknemlig dersom du tar deg tid til å fylle ut spørreskjemaet. Det vil ta rundt 5 - 10 minutter. Du kan svare på spørsmålene ved å bruke linken nedenfor <https://survey.hioa.no/index.php/684988/lang-nb>. Spørreskjemaet er elektronisk. I selve spørreskjemaet ber vi ikke om navn eller andre identifiserende opplysninger, men siden undersøkelsen gjennomføres elektronisk, registreres din IP-adresse med besvart skjema ved innsending. Kun IT-avdelingen ved HiOA og vår databehandler Lime Survey har tilgang til IP-adressene, som slettes senest ved prosjektslutt. Vi som forskere vet ikke hvem som har svart. Prosjektet er meldt til Personvernombudet for forskning, Norsk samfunnsvitenskapelig datatjeneste (NSD).

Ditt svar på skjemaet vil være ditt samtykke til deltakelse i prosjektet. Dersom det er spørsmål du ikke har svar på kan du hoppe over disse.

Kjennetegn ved respondenten og kommunen

Spm 1. Hvor gammel er du?

1. 50 år eller eldre,

¹¹ The text of the questionnaire is available in English by request.

2. 40 – 49 år,
3. 30 – 39 år,
4. 29 år eller yngre.

Spm 2. Hvor lenge har du arbeidet i kommunehelsetjenesten?

1. 5 år eller mer
2. Under 5 år

Spm 3. Hvilken utdanning har du?

1. Sykepleier uten videreutdanning
2. Sykepleier med videreutdanning
3. Annen helsefaglig utdanning

Spm 4. Har du videreutdanning innen kreft- eller palliasjon?

1. Ja
2. Nei

Spm 5. Hvor lenge har du arbeidet innenfor kreft og/eller palliasjon?

1. Mer enn 10 år
2. 5-10 år
3. Mindre enn 5 år

Spm 6. Hvor stor prosentandel av en 100% stilling har du som kreftkoordinator?

1. 100%
2. 50%

Spm 7. Hvor lenge har du arbeidet som kreftkoordinator?

1. Nærmere 2 år
2. Nærmere 1 år
3. 6 - 11 måneder
4. Mindre enn 6 måneder

Spm 8. Hva tror du er den viktigste funksjonen for arbeidet ditt sett fra pasientenes ståsted?

1. Du er en kontaktperson som pasientene dine kan snakke med dersom de trenger det eller dersom de opplever problemer relatert til sin(e) sykdom(mer)
2. Takket være deg får pasientene raskere hjelp til nødvendig praktisk og medisinsk bistand
3. Begge alternativene er viktige for pasientene jeg møter

Spm 9. Velg det svaret som passer best for deg:

1. Jeg elsker jobben min
2. Jeg har for mange utfordringer i arbeidshverdagen min
3. Jeg føler at jeg ikke får fulgt opp pasienter og pårørende i tilstrekkelig grad

Spm 10. Hvor mye tid har du brukt for å bli kjent som en kreftkoordinator i kommunen?

1. Omtrent 4 måneder
2. 5-8 måneder
3. 9 måneder – 1 år
4. Mer enn 1 år

Spm 11. Hvor mye tid har du brukt for å lage et effektivt nettverk som består av organisasjoner og instanser som kan hjelpe til hver enkelte kreftpasienten i kommunen?

1. Omtrent 4 måneder
2. 5-8 måneder
3. 9 måneder – 1 år
4. Mer enn 1 år

Spm 12. Hva slags endringer i samarbeidet med berørte parter trenger du som kreftkoordinator for å forbedre arbeidet ditt og gjøre det mer effektivt? (flere svar mulig)

1. Bedre kommunikasjon og samarbeid med sykehus
2. Bedre kommunikasjon og samarbeid med fastleger om nye og eksisterende pasienter
3. Bedre kommunikasjon og samarbeid med sykehjem (både offentlige og private)
4. Bedre kommunikasjon og samarbeid med kreftsykepleiere
5. Bedre kommunikasjon og samarbeid med palliativt team
6. Bedre kommunikasjon og samarbeid med private helsetjenester
7. Bedre kommunikasjon og samarbeid med koordinerende enhet i kommunen
8. Bedre kommunikasjon og samarbeid med kommunale tjenester og organisasjoner (NAV, barnehager, helsesøstre, sosionom osv.)

Spm 13. I hvilken grad opplever du seg selv som en del av det koordinering teamet i kommunen du jobber i?

1. I stor grad
2. I noen grad
3. I liten grad
4. I ingen grad

Spm 14. I hvilken grad er stillingen din synliggjort overfor pasienter og pårørende?

1. I stor grad (stillingen er kjent med et stort antall kreftpasienter og pårørende i kommunen jeg jobber i)
2. I noen grad (stillingen er kjent med noen kreftpasienter og pårørende i kommunen jeg jobber i)
3. I liten grad (stillingen er kjent med en lite antall kreftpasienter og pårørende i kommunen jeg jobber i)
4. I ingen grad

Spm 15. Omtrent hvor mange innbyggere er det i i kommunen du jobber i?

1. Færre enn 3000 innbyggere
2. 3001-10 000 innbyggere
3. 10 001-20 000 innbyggere
4. 20 001-50 001 innbyggere
5. 50 001 innbyggere eller flere

Spm 16. I gjennomsnittet, hvor mange hjemmedødsfall av kreftpasienter har kommunen du jobber i, i løpet av en måned?

1. Flere enn 30
2. 21-30
3. 10-20
4. 5-10
5. Færre enn 5

Karakterisering av arbeidet med pasienter

Spm 17. Hvordan kommer pasienter (og pårørende) først og fremst i kontakt med deg? (flere svar mulig)

1. Kreftpasienter blir gitt en henvisning fra fastlege
2. Kreftpasienter blir gitt en henvisning fra sykehus
3. Kreftpasienter blir gitt en henvisning fra kommunale tjenester
4. Kreftpasienter finner informasjon om deg på nettet eller fra andre som for eksempel Kreftforeningen
5. Du får en liste over kontaktinformasjon av kreftpasienters i kommunen fra spesialisthelsetjenester og kontakter med alle
6. Du får en liste over kreftpasienter i kommunen fra spesialisthelsetjenester og kontakter med disse pasientene som ble informert om deg og bestemte seg til å bruke din hjelp

Spm 18. Hvordan vurderer du i hovedsak kommunikasjonen med pasientene du møter?

1. Meget god (både de og jeg kan spørre om noe ved behov, og jeg opplever at pasientene i hovedsak er fornøyd med kommunikasjonen vi har)
2. God
3. Ikke så verst
4. Dårlig

Spm 19. Hvordan opplever du at du er i stand til å møte pasientenes behov?

1. Meget god
2. God
3. Ikke så verst
4. Dårlig

Spm 20. Hvordan kommuniserer du som oftest med pasientene du møter?

1. Telefon

2. E-post
3. Faks
4. På besøk

Spm 21. Hvor mange hjemmebesøk har du hver uke, i gjennomsnitt?

1. Flere enn 12
2. 9-11
3. 6-8
4. 3-5
5. 2 eller færre

Spm 22. Hvor mye tid bruker du i gjennomsnitt per konsultasjon (om lag)?

1. Mer enn to timer
2. Rundt to timer
3. Rundt en time
4. Mindre enn en time
5. Stor variasjon

Spm 23. Hvor stor andel av pasientene dine har sin første kontakt med deg som kreftkoordinator før de kontakter andre kommunale tjenester?

1. 10-20%
2. 21-40%
3. 41-60%
4. 61-80%
5. Mer enn 80%

Spm 24. Har du fått opplæring i kommunikasjon med pasientene?

1. Ja
2. Nei, ikke ennå, men det er planlagt
3. Nei, jeg har ikke følt behov for dette
4. Nei, det har det ikke vært tilbud om

Spm 25. Tror du at pasientene dine og deres pårørende har fått en bedret trygghet pga din tilstedeværelse?

1. Ja, det mener jeg bestemt
2. Ja, det tror jeg
3. Jeg vet ikke
4. Jeg er usikker på dette
5. Ingenting har egentlig forandret seg for pasientene og/eller deres pårørende siden jeg begynte å jobbe som kreftkoordinator.

Spm 26. Opplever du at du ikke kan bidra tilstrekkelig ift pasientens eller pårørendes behov, fordi du ikke har tilstrekkelig godt samarbeid med andre aktører og berørte parter?

1. Ofte (nesten hver dag)
2. Noen ganger (to-tre ganger per måned)
3. Sjelden (en gang per en måned eller to måneder)
4. Aldri

Spm 27. Hvor mye tid bruker du for å løse problemer til kurative pasienter og svare deres spørsmål i gjennomsnitt?

1. Rundt en time
2. Rundt en dag
3. Rundt en uke
4. Mer enn en uke
5. Stor variasjon gjennom de enkelte pasienter

Spm 28. Hvor mye tid bruker du for å løse problemer til palliative pasienter og svare deres spørsmål i gjennomsnitt?

1. Rundt en time
2. Rundt en dag
3. Rundt en uke
4. Mer enn en uke
5. Stor variasjon gjennom de enkelte pasienter

Spm 29. Hvor stor prosentandel av arbeidstiden din bruker du på helsearbeidere, pårørende og andre aktører (bortsett fra pasienter)?

1. Mer enn 50%
2. 30-50%
3. Mindre enn 30%

Karakterisering av samarbeidet med interne berørte parter i kommunen

Spm 30. Hvordan vurderer du kontakten og samarbeidet med sykehjem (både offentlige og private)?

1. Dårlig (det er umulig å samarbeide om pasienter)
2. Nokså dårlig (det er ganske å samarbeide om pasienter)
3. Ikke så verst (det er mulig å samarbeide om pasienter)
4. Stort sett god (det er nesten alltid lett å samarbeide om pasienter)
5. Stort sett meget god (det er alltid lett å samarbeide om pasienter)

Spm 31. Hvordan vurderer du kontakten og samarbeidet med fastleger generelt?

1. Stort sett meget god (det er lett å få kontakt og jeg får svar på det jeg lurer på)
2. Stort sett god (det er ofte lett å få kontakt og jeg får stort sett svar på det jeg lurer på)
3. Ikke så verst (det er av og til mulig å få avtalt tider for kontakt samt svar på spørsmål)
4. Nokså dårlig (det er nokså vanskelig å få kontakt og svar på det jeg lurer på)
5. Dårlig (jeg sliter med å få kontakt og får sjelden svar på det jeg lurer på)

Spm 32. Hvordan vurderer du kontakten og samarbeidet med kreftsykepleiere og sykepleiere med videre utdanning i palliasjon?

1. Dårlig (det er umulig å samarbeide om pasienter)
2. Nokså dårlig (det er ganske hardt å samarbeide om pasienter)
3. Ikke så verst (det er mulig å samarbeide om pasienter)
4. Stort sett god (det er ganske lett å samarbeide om pasienter)
5. Stort sett meget god (det er alltid lett å samarbeide om pasienter)

Spm 33. Hvor ofte har du et fast møte med en eller flere av de følgende: sykepleiere, hjelpepleiere, fastleger, fysioterapeut, prest i kommunen du jobber i?

1. Hver uke
2. Hver fjortende dag
3. Hver måned
4. Sjelden eller aldri

Spm 34. Hvordan vurderer du kontakten og samarbeidet med skoler og barnehager?

1. Dårlig (det er umulig å samarbeide om pasienter eller deres pårørende)
2. Nokså dårlig (det er ganske hardt å samarbeide om pasienter eller deres pårørende)
3. Ikke så verst (det er mulig å samarbeide om pasienter eller deres pårørende)
4. Stort sett god (det er ganske lett å samarbeide om pasienter eller deres pårørende)
5. Stort sett meget god (det er lett å samarbeide om pasienter alltid eller deres pårørende)

Spm 35. Hvordan vurderer du kontakten og samarbeidet med NAV?

1. Dårlig (det er umulig å samarbeide om pasienter)
2. Nokså dårlig (det er ganske hardt å samarbeide om pasienter)
3. Ikke så verst (det er mulig å samarbeide om pasienter)
4. Stort sett god (det er ganske lett å samarbeide om pasienter)
5. Stort sett meget god (det er alltid lett å samarbeide om pasienter)

Spm 36. Hvor ofte har du et fast møte med en eller flere av de følgende tjenestearbeidere: ergoterapeut, innsatsteamet, rehabiliteringsteamet, transport- og hjelpemidlere, frivillighetskoordinator, rus-, demensrådgiver, rehabiliteringsrådgiver?

1. Hver uke
2. Hver fjortende dag
3. Hver måned
4. Sjelden eller aldri

Spm 37. Hvor ofte deltar du i opplæring og veiledning av hjemmebaserte sykepleiere eller andre helsearbeidere i kommunen?

1. Hver uke
2. Hver fjortende dag
3. Hver måned

4. Sjelden eller aldri

Spm 38. Hvor ofte deltar du i opplæring og veiledning av pasientene og pårørende i kommunen?

1. Hver uke
2. Hver fjortende dag
3. Hver måned
4. Sjelden eller aldri

Spm 39. Hvor ofte driver du kurs for lokalsamfunnet for å øke bevisstheten om kreft?

1. Hver uke
2. Hver fjortende dag
3. Hver måned
4. Sjelden eller aldri

Karakterisering av samarbeidet med eksterne berørte parter i kommunen

Spm 40. Hvordan vurderer du interkommunalt kontakten og samarbeidet med sonesaksbehandlere om kreftpasienter som er utenfor kommunen du jobber i?

1. Dårlig (det er umulig for å samarbeide om pasienter)
2. Nokså dårlig (det er ganske hardt å samarbeide om pasienter)
3. Ikke så verst (det er mulig å samarbeide om pasienter)
4. Stort sett god (det er ganske lett å samarbeide om pasienter)
5. Stort sett meget god (det er alltid lett å samarbeide om pasienter)

Spm 41. Hvordan vurderer du kontakten og samarbeidet med palliative enheter i ditt nærområde (for eksempel ved sykehus, medisinske sentre eller andre steder)?

1. Stort sett meget god (jeg kan henvende meg dit for råd og det er nesten alltid hjelp å få)
2. Stort sett god (jeg kan henvende meg dit for råd nokså ofte, og det er ofte hjelp å få)
3. Ikke så verst (jeg kan be om råd og de er behjelpelige i blant, avhengig av kapasitet)
4. Nokså dårlig (det er vanskelig å få kontakt og hjelp)
5. Dårlig (jeg har forsøkt å få kontakt men har ikke lyktes med dette)

Spm 42. Hvordan vurderer du kontakten og samarbeidet med palliativt team?

1. Kommunen jeg jobber i har ikke palliativt team
2. Nokså dårlig (vi bruker hverandre i svært liten grad)
3. Ikke så verst (vi bruker hverandre i blant)
4. Stort sett godt (vi har et ustrakt samarbeid og kan hjelpe hverandre ved behov)
5. Stort sett meget godt (vi har et svært tett samarbeid omkring palliative pasienter)

Spm 43. Hvordan vurderer du kontakten og samarbeidet med andre kreftkoordinatorer eller Kreftforeningens representanter i ditt nærområde?

1. Dårlig (det er umulig å samarbeide om pasienter)

2. Nokså dårlig (det er ganske hardt å samarbeide om pasienter)
3. Ikke så verst (det er mulig å samarbeide om pasienter)
4. Stort sett god (det er ganske lett å samarbeide om pasienter)
5. Stort sett meget god (det er alltid lett å samarbeide om pasienter)

Spm 44. Hvordan vurderer du kontakten og samarbeidet med onkologisk poliklinikk i ditt nærområde?

1. Stort sett meget god (jeg kan henvende meg dit for råd og det er nesten alltid hjelp å få)
2. Stort sett god (jeg kan henvende meg dit for råd nokså ofte, og det er ofte hjelp å få)
3. Ikke så verst (jeg kan be om råd og det er behjelpelige i blant, avhengig av kapasitet)
4. Nokså dårlig (det er vanskelig å få kontakt og hjelp)
5. Dårlig (jeg har forsøkt å få kontakt men har ikke lykket med dette)

Appendix 5: Summary and contingency tables

1. Characteristics of the respondents and their municipalities

Table A1. Age of the respondents

Age	%	Number of respondents
50 or older	27,6%	13
40-49 years	36,2%	17
30-39 years	36,2%	17
29 years or younger	0,0%	0
Total	100,0%	47

Table A2. Work experience in the health care services of the municipality

Work experience in the health care services of the municipality	%	Number of respondents
5 years or more	72,3%	34
Less than 5 years	27,7%	13
Total	100,0%	47

Table A3. Education

Education	%	Number of respondents
Nurse without postgraduate training	2,1%	1
Nurse with postgraduate training	97,9%	46
Other education in the area of health care	0,0%	0
Total	100,0%	47

Table A4. Education in the field of oncology and palliative care

Further education in the field of oncology and/or palliative care	%	Number of respondents
Yes	94,6%	35
No	5,4%	2
Total	100,0%	37

Table A5. Work experience in the field of oncology and palliative care

Work experience in the field of oncology and/or palliative care	%	Number of respondents
More than 10 years	48,7%	19
5-10 years	35,9%	14
Less than 5 years	15,4%	6
Total	100,0%	39

Table A6. Percentage of a 100% position

Percentage of a 100 % position	%	Number of respondents
100%	50,0%	19
50%	50,0%	19
Total	100,0%	38

Table A7. Work experience as a cancer coordinator

Work experience as a cancer coordinator	%	Number of respondents
Almost two years	55,0%	22
Almost one year	37,5%	15
6-11 months	5,0%	2
Less than 6 months	2,5%	1
Total	100,0%	40

Table A8. The most important function of the cancer coordinator's work

The most important function of the cancer coordinator's work	%	Number of respondents
The cancer coordinator is a contact person who cancer patients can talk to in case they need it or if they are experiencing problems related to their illness(es)	15%	6
The cancer coordinator is a contact person who helps patients obtain necessary practical and medical assistance more efficiently	5%	2
Both factors are important for the patients I meet	80%	32
Total	100%	40

Table A9. Work perception

Work perception	%	Number of respondents
I love my work	63,9%	23
I have too many challenges in my everyday work	22,2%	8
I feel that I am unable to follow up patients and their next-of-kin adequately	13,9%	5
Total	100,0%	36

Table A10. The period of time used to be known as the cancer coordinator in the municipality

The period of time used to be known as the cancer coordinator in the municipality	%	Number of respondents
About 4 months	23,7%	9
5-8 months	18,4%	7

9 months - 1 year	31,6%	12
More than 1 year	26,3%	10
Total	100,0%	38

Table A11. The period of time used to create an effective network of organizations and agencies that can help each individual cancer patient in the municipality

The period of time used to create an effective network of organizations and agencies that can help each individual cancer patient in the municipality	%	Number of respondents
About 4 months	17,1%	6
5-8 months	22,9%	8
9 months - 1 year	25,7%	9
More than 1 year	34,3%	12
Total	100,0%	35

Table A12. What can make the cancer coordinator's work more effective*

What can make the cancer coordinator's work more effective	%	Number of respondents
Better communication and collaboration with hospitals	72,5%	29
Better communication and collaboration with general practitioners about new and existing patients	82,5%	33
Better communication and cooperation with nursing homes (both public and private)	27,5%	11
Better communication and cooperation with cancer nurses	10,0%	4
Better communication and cooperation with the palliative care team	17,5%	7
Better communication and cooperation with private health care services	12,5%	5
Better communication and cooperation with the coordinating unit in the municipality	25,0%	10
Better communication and cooperation with municipal services (NAV, public health nurses, social workers etc.)	70,0%	28

* Respondents could tick all the answers applied in this question

Table A13. Extent to which cancer coordinators perceive themselves as a part of the coordinating unit in the municipality

Self-perception as a part of the coordinating unit in the municipality	%	Number of respondents
Great extent	46,1%	18
Some extent	18,0%	7
Small extent	28,2%	11
Not at all	7,7%	3
Total	100,0%	39

Table A14. Extent to which the cancer coordinator position is visible and available in the municipality

Extent to which the cancer coordinator position in the municipality is visible and available	%	Number of respondents
To a great extent (position is known by a large number of cancer patients and their families in the municipality)	51,3%	20
To some extent (the position is known by some cancer patients and their families in the municipality)	48,7%	19
Total	100,0%	39

Table A15. Population of the municipality

Population of the municipality	%	Number of respondents
Fewer than 3 000 inhabitants	2,5%	1
3 001-10 000 inhabitants	25,0%	10
10 001-20 000 inhabitants	25,0%	10
20 001-50 000 inhabitants	32,5%	13
50 001 inhabitants or more	15,0%	6
Total	100,0%	40

Table A16. Number of home deaths of cancer patients in the municipality

Average number of home deaths of cancer patients in the municipality	%	Number of respondents
11-20	2,6%	1
5-10	2,6%	1
Fewer than 5	94,8%	37
Total	100,0%	39

2. Characteristics of the interaction with cancer patients

Table A17. Initial contact with cancer patients*

Initial contact with patients	%	Number of respondents
Cancer patients are given a referral from hospitals	95,0%	38
Cancer patients are given a referral from municipal services	75,0%	30
Cancer patients find information about the cancer coordinator online or from others, for instance from the Cancer Society	75,0%	30
The cancer coordinator contacts those patients who are informed and have decided to use cancer coordinators' help	7,5%	3
Cancer patients are given a referral from a general practitioner	70,0%	28

* Respondents could tick all the answers applied in this question

Table A18. Assessment of the communication with cancer patients in general

Assessment of the communication with patients in general	%	Number of respondents
Very good (both they and I can ask anything if necessary and I find that patients are largely satisfied with the communication we have)	75,0%	30
Good	22,5%	9
Not so bad	2,5%	1
Total	100,0%	40

Table A19. Cancer coordinators' ability to meet patients' needs

The cancer coordinators' ability to meet patients' needs	%	Number of respondents
Very good	40,0%	16
Good	57,5%	23
Not so bad	2,5%	1
Total	100,0%	40

Table A20. Means of communication*

Means of communication	%	Number of respondents
Telephone	72,5%	29
E – mail	10,0%	4
Visiting	95,0%	38

* Respondents could tick all the answers applied in this question

Table A21. Average number of home visits per week (N=37)

Percentage of a 100% position	More than 12 visits	9-11 visits	6-8 visits	5-3 visits	2 or fewer visits	Total
100%	8,1%	16,3%	10,8%	13,5%		48,7%
50%		2,7%	21,6%	21,6%	5,4%	51,3%
Total	8,1%	19,0%	32,4%	35,1%	5,4%	100,0%

Table A22. Average time per one consultation

Time per consultation on average	%	Number of respondents
Around two hours	32,5%	13
Around one hour	57,5%	23
Wide variation	10,0%	4
Total	100,0%	40

Table A23. Percentage of patients who connected with the cancer coordinator without contacting any other municipal services

Percentage of patients who connected with the cancer coordinator without contacting any other municipal services	%	Number of respondents
10 - 20% of patients	15,4%	6
21 - 40% of patients	12,8%	5
41 - 60% of patients	38,5%	15
61 - 80% of patients	23,1%	9
More than 80% of patients	10,3%	4
Total	100,0%	39

Table A24. Training in communication with cancer patients

Have you received training in communication with patients?	%	Number of respondents
No, I have not experienced the need for this	18,4%	7
No, it has not been offered	39,5%	15
Yes, I have received training	42,1%	16
Total	100,0%	38

Table A25. Improving safety of cancer patients and their next-of-kin

Does the cancer coordinator improve safety of cancer patients and their next-of-kin?	%	Number of respondents
Yes, I am sure	52,6%	20
Yes, I suppose so	42,1%	16
I do not know	5,3%	2
Total	100,0%	38

Table A26. Lack of adequate cooperation with concerned parties, which makes the cancer coordinators' work with patients or their next-of-kin less effective

How often does the lack of adequate cooperation with other concerned parties make the cancer coordinators' work with patients or their families less effective?	%	Number of respondents
Never	7,7%	3
Rarely (once per one month or two months)	53,9%	21
Sometimes (two to three times per month)	33,3%	13
Often (almost every day)	5,1%	2
Total	100,0%	39

Table A27. Average time used for solving problems of curative patients and answering their questions

Average amount of time for solving problems of curative cancer patients and answering their questions	%	Number of respondents
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Around one hour	7,9%	3
Around one day	10,5%	4
More than a week	2,6%	1
Wide variation among individual patients	78,9%	30
Total	100,0%	38

Table A28. Average time used for solving problems of palliative patients and answering their questions

Average amount of time for solving problems of palliative cancer patients and answering their questions	%	Number of respondents
Around one day	7,9%	3
Around one week	5,3%	2
Wide variation among individual patients	84,2%	32
Around one hour	2,6%	1
Total	100,0%	38

Table A29. Percentage of working time cancer coordinators spent on health workers, nurses and concerned parties other than patients

Percentage of working time which cancer coordinators spent on health workers, nurses and concerned parties other than patients	%	Number of respondents
More than 50%	2,6%	1
30-50%	76,9%	30
Less than 30%	20,5%	8
Total	100,0%	39

3. Characteristics of the collaboration with internal concerned parties in the municipality

Table A30. Assessment of the interaction and cooperation with nursing homes (both public and private)

Assessment of the interaction and cooperation with nursing homes	%	Number of respondents
Quite poor (it is quite difficult to collaborate on patients)	7,5%	3
Not bad (it is possible to collaborate on patients)	22,5%	9
Mostly good (it is almost always easy to collaborate on patients)	42,5%	17
Mostly very good (it is always easy to collaborate on patients)	27,5%	11
Total	100,0%	40

Table A31. Assessment of the communication and collaboration with general practitioners

Assessment of the communication and collaboration	%	Number of
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with general practitioners		respondents
Quite poor (it is quite difficult to connect and get answers to questions)	12,5%	5
Not bad (it is sometimes, but not always, possible to connect, as well as to get answers to questions)	27,5%	11
Mostly good (it is often easy to connect and I quite often get answers to what I wonder about)	50,0%	20
Mostly very good (it is almost always easy to connect and I get the answers to what I wonder about)	10,0%	4
Total	100,0%	40

Table A32. Assessment of the collaboration with general practitioners in relation to the cancer coordinators' work experience in the health care services of the municipality (N=40)*

Assessment of the communication and collaboration with general practitioners	Work experience in the health care services of the municipality		
	5 years or more	Less than 5 years	Total
Mostly good or very good (it is easy to connect and get answers to questions)	77,8%	23,1%	60% (24)
Quite poor or not so bad (it is not always possible or quite difficult to connect and get answers to questions)	22,2%	76,9%	40% (16)
Total	100% (27)	100% (13)	100% (40)
P-value	0,001		
Degrees of freedom	1		
Chi-square	10,940		
Chi-square critical	7,879		

* Correlation is significant at the 0.005 level.

Table A33. Assessment of the collaboration with general practitioners in relation to the cancer coordinators' work experience in the field of oncology and palliative care (N=39)*

Assessment of the communication and collaboration with general practitioners	Work experience in the field of oncology and palliative care			
	More than 10 years	5-10 years	Less than 5 years	Total
Mostly good or very good (it is easy to connect and get answers to questions)	84,2%	42,9%	16,7%	59% (23)
Quite poor or not so bad (it is not always possible or quite difficult to connect and get answers to questions)	15,8%	57,1%	83,3%	41% (16)
Total	100% (19)	100% (14)	100% (6)	100% (39)

P-value	0,004			
Degrees of freedom	2			
Chi-square	9,210			
Chi-square critical	10,972			

* Correlation is significant at the 0.01 level.

Table A34. Assessment of the communication and collaboration with cancer care and palliative care nurses

Assessment of the communication and collaboration with cancer care and palliative care nurses	%	Number of respondents
Not bad (it is possible to collaborate on patients)	8,1%	3
Mostly good (it is quite easy to collaborate on patients)	40,5%	15
Mostly very good (it is almost always easy to collaborate on patients)	51,4%	19
Total	100,0%	37

Table A35. Arrangement of regular meetings with concerned parties (1)

Arrangement of regular meetings with one or more of the following: nurses, assistant nurses, general practitioners, physiotherapists and/or priests	%	Number of respondents
Every week	31,6%	12
Every fortnight	15,8%	6
Every month	34,2%	13
Rarely or never	18,4%	7
Total	100,0%	38

Table A36. Arrangement of regular meetings with concerned parties in relation to the cancer coordinators' work experience in the health care services of the municipality (N=38)*

Arrangement of regular meetings with concerned parties (general practitioners, nurses, physiotherapists etc.)	Work experience in the health care services of the municipality		
	5 years or more	Less than 5 years	Total
Minimum once a month	96,3%	45,5%	81,6% (31)
Rarely or never	3,7%	54,5%	18,4% (7)
Total	100% (27)	100% (11)	100% (38)
P-value	0,000		
Degrees of freedom	1		
Chi-square	13,660		
Chi-square critical	10,828		

* Correlation is significant at the 0.001 level.

Table A37. Arrangement of regular meetings with concerned parties in relation to the percentage of a 100% position (N=35)*

Arrangement of regular meetings with concerned parties (general practitioners, nurses, physiotherapists etc.)	Percentage of a 100% position		
	100%	50%	Total
Minimum once a month	94,4%	64,7%	80% (28)
Rarely or never	5,6%	35,3%	20% (7)
Total	100% (18)	100% (17)	100% (35)
P-value	0,028		
Degrees of freedom	1		
Chi-square	4,836		
Chi-square critical	3,841		

* Correlation is significant at the 0.05 level.

Table A38. Assessment of the interaction and collaboration with schools and kindergartens

Assessment of the interaction and collaboration with schools and kindergartens	%	Number of respondents
Poor (it is impossible to collaborate on patients or their next-of-kin)	3,0%	1
Quite poor (it is quite hard to collaborate on patients or their next-of-kin)	12,1%	4
Not bad (it is possible to collaborate on patients or their next-of-kin)	51,5%	17
Mostly good (it is quite easy to collaborate on patients or their next-of-kin)	24,3%	8
Mostly very good (it is almost always easy to collaborate on patients or their next-of-kin)	9,1%	3
Total	100,0%	33

Table A39. Assessment of the interaction and collaboration with schools and kindergartens in relation to the percentage of a 100% position (N=30)*

Assessment of the interaction and collaboration with schools and kindergartens	Percentage of a 100% position		
	100%	50%	Total
Mostly good or very good (it is easy to collaborate on patients and their next-of-kin)	56,3%	7,1%	33,3% (10)
Poor, quite poor or not good enough (it is impossible to collaborate or it is possible but with difficulties)	43,7%	92,9%	66,7% (20)
Total	100% (16)	100% (14)	100% (30)
P-value	0,004		
Degrees of freedom	1		
Chi-square	8,195		

Chi-square critical	6,635		
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* Correlation is significant at the 0.01 level.

Table A40. Assessment of the interaction and collaboration with NAV

Assessment of the interaction and collaboration with NAV	%	Number of respondents
Poor (it is impossible to collaborate on patients)	5,1%	2
Quite poor (it is quite hard to collaborate on patients)	23,1%	9
Not bad (it is possible to collaborate on patients)	38,5%	15
Mostly good (it is quite easy to collaborate on patients)	28,2%	11
Mostly very good (it is always easy to collaborate on patients)	5,1%	2
Total	100,0%	39

Table A41. Assessment of the interaction and collaboration with NAV in relation to the cancer coordinators' work experience in the health care services of the municipality (N=39)*

Assessment of the interaction and collaboration with NAV	Work experience in the health care services of the municipality		
	5 years or more	Less than 5 years	Total
Mostly good or very good (it is easy to collaborate on patients)	46,2%	7,7%	33,3% (13)
Poor, quite poor or not good enough (it is impossible to collaborate or it is possible but with difficulties)	53,8%	92,3%	66,7% (26)
Total	100% (26)	100% (13)	100% (39)
P-value	0,016		
Degrees of freedom	1		
Chi-square	5,719		
Chi-square critical	3,841		

* Correlation is significant at the 0.05 level.

Table A42. Arrangement of regular meetings with concerned parties (2)

Arrangement of a regular meeting with one or more of the following service workers: occupational therapist, effort team, rehabilitation team, transport and practical assistants, volunteer coordinator and substance abuse/dementia/rehabilitation counselors	%	Number of respondents
Every week	12,8%	5
Every fortnight	12,8%	5
Every month	25,7%	10
Rarely or never	48,7%	19
Total	100,0%	39

Table A43. Participation in supervision and instruction of home-based nurses or other health professionals in the municipality

Participation in supervision and instruction of home-based nurses or other health professionals in the municipality	%	Number of respondents
Every week	13,2%	5
Every fortnight	13,2%	5
Every month	44,6%	17
Rarely or never	29,0%	11
Total	100,0%	38

Table A44. Participation in supervision and instruction of cancer patients and their next-of-kin

Participation in supervision and education of patients and their families in the municipality	%	Number of respondents
Every week	35,1%	13
Every fortnight	8,1%	3
Every month	35,1%	13
Rarely or never	21,7%	8
Total	100,0%	37

Table A45. Conducting courses for the local community in order to raise awareness about cancer

Conducting courses for the local community in order to raise awareness about cancer	%	Number of respondents
Every fortnight	2,8%	1
Every month	11,1%	4
Rarely or never	86,1%	31
Total	100,0%	36

4. Characteristics of the collaboration with external concerned parties

Table A46. Assessment of the intermunicipal interaction and collaboration with zonal officers about cancer patients situated outside the municipality

Assessment of the intermunicipal interaction and collaboration with zonal officers about cancer patients situated outside the municipality	%	Number of respondents
Poor (it is impossible to collaborate on patients)	6,4%	2
Not bad (it is possible to collaborate on patients)	35,5%	11
Mostly good (it is quite easy to work on patients)	45,2%	14
Mostly very good (it is almost always easy to collaborate on patients)	12,9%	4

Total	100,0%	31
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Table A47. Assessment of the interaction and collaboration with palliative care departments in the area of work

Assessment of the interaction and collaboration with palliative care departments in the area (for example within hospitals, medical centers or elsewhere)	%	Number of respondents
Mostly very good (I can almost always ask for advice, and it is always helpful)	53,9%	21
Mostly good (I can contact for advice quite often, and it is helpful)	38,4%	15
Not bad (I can ask for advice and they can assist me in a while, depending on capacity)	5,1%	2
Quite poor (it is difficult to connect and get help)	2,6%	1
Total	100,0%	39

Table A48. Assessment of the communication and collaboration with the palliative team in the area of work

Assessment of the communication and collaboration with the palliative team	%	Number of respondents
The municipality I work in has no palliative team	60,5%	23
Not bad (we cooperate periodically, from time to time)	7,9%	3
Mostly good (we have an outstretched cooperation and help each other when needed)	13,2%	5
Mostly very good (we have a very close collaboration around palliative care patients)	18,4%	7
Total	100,0%	38

Table A49. Assessment of the communication and collaboration with other cancer coordinators or the Cancer Society representatives in the area of work

Assessment of the communication and collaboration with other cancer coordinators or the Cancer Society representatives	%	Number of respondents
Not bad (it is possible to collaborate on patients)	12,8%	5
Mostly good (it is quite easy to collaborate on patients)	25,6%	10
Mostly very good (it is almost always easy to collaborate on patients)	61,6%	24
Total	100,0%	39

Table A50. Assessment of the communication and collaboration with the oncological outpatient department in the area of work

Assessment of the communication and collaboration with the oncological outpatient department	%	Number of respondents
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Mostly very good (I can ask for advice, and it is always helpful)	43,6%	17
Mostly good (I can contact for advice quite often, and it is helpful)	41,0%	16
Not bad (I can ask for advice and they can assist me in a while depending on capacity)	12,8%	5
Quite poor (it is difficult to connect and get help)	2,6%	1
Total	100,0%	39

Appendix 6: Data coding

Table A51. Coding of the primary data

Variable (number of question)	1	2	3	4	5
6	100%	50%			
13	To a great extent	To some extent	To a small extent	In no degree	
14	To a great extent	To some extent	To a small extent	In no degree	
18	Very good	Good	Not so bad	Poor	
19	Very good	Good	Not so bad	Poor	
21	12 or more	9-11	6-8	3-5	2 or fewer
22	More than two hours	Around two hours	Around one hour	Less than one hour	Wide variation
23	10-20%	21-40%	41-60%	61-80%	More than 80%
24	Yes	No, not yet but it is planned	No, I have not experienced the need for this	No, it has not been offered	
25	Yes, I mean I am sure	Yes, I suppose so	I do not know	I am not sure about this	Nothing has really changed for the patients and/or their relatives since I started working as cancer coordinator
26	Often (almost every day)	Sometimes (two to three times per month)	Rarely (once per one month or two months)	Rarely (once per one month or two months)	
27	Around one hour	Around one day	Around one week	More than a week	Wide variation among individual patients
28	Around one hour	Around one day	Around one week	More than a week	Wide variation among individual patients

29	More than 50%	30-50%	Less than 30%		
30	Poor	Quite poor	Not bad	Mostly good	Mostly very good
31	Poor	Quite poor	Not bad	Mostly good	Mostly very good
32	Poor	Quite poor	Not bad	Mostly good	Mostly very good
33	Every week	Every fortnight	Every month	Rarely or never	
34	Poor	Quite poor	Not bad	Mostly good	Mostly very good
35	Poor	Quite poor	Not bad	Mostly good	Mostly very good
36	Every week	Every fortnight	Every month	Rarely or never	
37	Every week	Every fortnight	Every month	Rarely or never	
38	Every week	Every fortnight	Every month	Rarely or never	
39	Every week	Every fortnight	Every month	Rarely or never	
40	Poor	Quite poor	Not bad	Mostly good	Mostly very good
41	Poor	Quite poor	Not bad	Mostly good	Mostly very good
42	The municipality I work in has no palliative team	Quite poor	Not bad	Mostly good	Mostly very good
43	Poor	Quite poor	Not bad	Mostly good	Mostly very good
44	Poor	Quite poor	Not bad	Mostly good	Mostly very good

Appendix 7: Summary statistics

Table A52. Summary Statistics

Variable (number of question)	Number of observations	Mean	Standard Deviation	Min	Max
6	39	1.487179	.5063697	1	2
13	39	1.974359	1.038399	1	4
14	39	1.487179	.5063094	1	2
18	40	1.275	.5057363	1	3
19	40	1.625	.5400617	1	3
21	40	3.2	1.066987	1	5
22	40	2.875	.8529737	2	5
23	39	3	1.192079	1	5
24	38	2.552632	1.389096	1	4
25	38	1.526316	.6034514	1	3
26	39	2.641026	.7066295	1	4
27	38	4.236842	1.459993	1	5
28	38	4.552632	1.082973	1	5
29	39	2.179487	.4514185	1	3
30	40	3.9	.9001424	2	5
31	40	3.575	.8439073	2	5
32	37	4.432432	.6472395	3	5
33	38	2.394737	1.128009	1	4
34	33	3.242424	.9024378	1	5
35	39	3.051282	.971941	1	5
36	39	3.102564	1.071027	1	4
37	38	2.894737	.9806086	1	4
38	37	2.432432	1.191184	1	4
39	36	3.833333	.4472136	2	4
40	31	3.580645	.958269	1	5
41	39	4.435897	.7179969	2	5
42	38	2.184211	1.641609	1	5
43	39	4.384615	.9065662	1	5
44	39	4.25641	.7853242	2	5