Care coordinator as a means to improve continuity and quality of patient care

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Abstract

Care coordinators were introduced along with cancer care pathways in the Swedish health care system. This paper presents the results from a quantitative survey where the role, challenges and contributions of coordinators in cancer care pathways are studied. Three types of organising the coordination function were identified: coordination within a care unit, with the patient and at the system level. The study shows that there is no "one-type-fits-all" solution, but the conditions and needs in each pathway and care units have to be evaluated prior to appointing a coordinator to achieve best results and ensure an efficient use of resources.

Keywords: care coordination, continuity, cancer care pathways

Introduction

Rapid advances in medicine and technology create new opportunities for quicker and better treatment of patients, and contribute to a more complex and highly specialised care (Bodenheimer, 2008). Fragmentation, lack of continuity and long waiting times are all challenges originating from the structure and complexity of the current health care system (Groene et al., 2011). Navigating through this system have shown to be difficult and stressful for patients (Wells et al., 2008).

Lack of coordination and continuity is considered one of the most important development areas in Swedish health care (NBHW, 2016). Coordination can be defined as "*the deliberate organisation of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services"* (McDonald et al., 2007). Further, continuity is the degree to which patient's experience care over time as coherent, connected and consistent with their needs (Haggerty et al., 2003). Coordination and continuity are essential to quality, patient experience, and ultimately cost and requires collaboration between all health care providers involved in the care of the patient (McDonald et al., 2007). Health care is currently undergoing a paradigm shift in which the role of the patient changes from being a passive recipient to a more autonomous, active, or collaborative participant (Nordgren, 2008). Concepts like patient-centred care, patient involvement, patient participation and patient empowerment have gained much attention in recent years and imply that care

needs to be coordinated between health care providers and patients and their relatives (Lusk and Fater, 2013, McDonald et al., 2007).

In Sweden, multiple improvement programs have been launched during the last years to improve quality of cancer diagnostics. In 2015, the government decided on the latest effort, a national implementation of cancer care pathways (CCPs). The CCPs are not a new way of working but have also been implemented, for example, in Denmark, England and Norway (Askildsen et al., 2011, Jensen et al., 2015, Potter et al., 2007). CCPs are national guidelines for cancer diagnostics, which contain criteria for referral, predetermined medical examinations and tests, and limits for maximum waiting times (NBHW, 2016). As an important means to ensure the continuity in the diagnostic pathway and avoid unnecessary waiting time the function of care coordinator was established (NBHW, 2016). The proposal of introducing care coordinators were brought up in the Swedish cancer strategy already in 2009 and aimed to support medical professionals in the administrative work (SOU, 2009).

The care coordinators have shown to play a key role in ensuring continuity of care, particularly for patients with complex care needs during long episodes of time (Walsh et al., 2011) and in improving the patient's experience of the care process (Monterosso et al., 2016). Depending on the context, care coordinators may have different roles and responsibilities (Freijser et al., 2015). One important distinction is the role of coordinators in relation to patients and health care providers (Monterosso et al., 2016). For patients, the primary role is to ensure individualised care, provide psychosocial support, act as an advocate, and serve as a single point of contact in the complex, to the patient unfamiliar, health care system (Walsh et al., 2011, Freijser et al., 2015). For health care providers on the other hand, the coordinator's primary role is managing the overall care process and communicating the care plan with all involved health care professionals (Monterosso et al., 2016, Nutt and Hungerford, 2010).

The objective of this paper is to study the role, challenges and contributions of care coordinators in CCPs. We investigate how the coordinator function was designed and organised, what are the primary work tasks, and how coordinators perceive their role and contribution to the continuity and quality of patient care.

Theoretical framework

The coordinator function is not a new phenomenon in cancer care or generally in the health care system. The function can be tracked back to the 1970s and 1980s when the coordinator had primarily an administrative role. Back then, the focus was on coordinating health care efforts between health care providers and ensuring efficient use of resources (Shockney, 2010). In the 1990s, the focus shifted towards the patients and the coordinator became part of the multidisciplinary team with the primary task to facilitate communication and plan the care pathway with the patient. The aim was to ensure effective, safe and patient centred care for patients with chronic and complex diseases (Shockney, 2010). Sweden has a nurse specialisation called contact nurse with a nationally formulated role description to increase the patient centeredness (Larsson and Bjuresäter, 2016). The work tasks include answering patient questions, providing psychosocial support, coordinating patient pathways, and ensuring active transitions between health care providers (SALAR, 2013). Another well-established example is the rehabilitation coordinator. Rehabilitation coordinators provides the advantage of having a person with holistic view of the care process who can reach out to the different parts of the health care system (Gardner et al., 2010). In addition, the function contributes to a more efficient and quality assured sick leave process, which leads to shorter care processes for the patients (Shaw et al., 2008).

Experiences from Australia show that patients assigned a care coordinator were satisfied with being involved in decisions concerning their care and having a contact person to call with questions. Further, they were more likely to receive appropriate and timely referrals to psychosocial and other support services (Cancer Institute NSW, 2011). Coordinators may have different roles and responsibilities. Charns and Young (2011) describes two main types of coordinators in health care. The first type, *the liaison*, is placed within a care unit and is responsible for coordinating care with the patient and other care units. It focuses primarily on meeting the needs of its own unit rather than meeting the needs of other care units (Charns and Young, 2011). The second type, *the integrator*, is placed outside the typical speciality unit and has overall responsibility for coordinating all care units involved in the care pathway. It acts without executive power, needs to rely on its social skills and the perceived value of the function for different health care providers in the care pathway. This coordinator has a good overview and focuses on the whole, not individual needs of single units (Charns and Young, 2011). Freijser et al. (2015) describes coordination at three levels: individual, unit and system level. The individual level focuses on providing and coordinating care with the patients, the team level on communication and coordination within the unit, and system level on activities and strategies overarching units.

Previous research on care coordinators describes the diversity in work tasks performed by coordinators such as patient advocacy and contact, multidisciplinary communication and coordination, and administrative task (Monterosso et al., 2016). The most important role is to guide patients and their relative's through the health care system (Monterosso et al., 2016, Nutt and Hungerford, 2010, Walsh et al., 2011).

Method

This paper is based on a quantitative online survey. A survey is a useful tool when there is a large target population and to obtain a wide range of information in order to get a broader understanding of a certain phenomenon (Churchill and Iacobucci, 2009). In this case we are interested in the role and work of coordinators working with CCPs. The study was carried out in cooperation with the National Board of Health and Welfare (NBHW). The NBHW works to ensure good health, social welfare and high-quality health and social care on equal terms through-out Sweden and has the responsibility for evaluating the CCP implementation.

The respondents included care coordinators working in all 21 county councils/regions (CCs) in Sweden during 2015-2017. The Swedish health care system is divided into 21 CCs that are responsible for health care provision and management with independent budgets. All CCs participate in the implementation of CCPs and the NBHW has an agreement with the CCs about participation in several studies, which facilitated the identification of the target population. Project leaders responsible for implementing CCPs in each CC assisted in identifying the coordinators to ensure that the correct respondents were included in the selection.

The respondents had six weeks to answer the survey with start in April 2017. Reminders were sent out twice, first after three weeks and again after four weeks had passed. In total 496 care coordinators were asked to participate in the survey, which resulted in a response rate of 72%.

The design of the survey was a mixture of multiple choice, questions with a three or five point Likert scale and free-text questions. The survey contained questions about the respondents working background and current employment, working tasks and responsibilities, challenges, prerequisites and perceived contribution to health care

improvements. The respondents also had the possibility to leave a comment after each question and at the end of the survey.

The responses were analysed using descriptive statistics (mean values and percentage units) and hypothesis testing (ANOVA and Chi-two tests) in SPSS. Qualitative content analysis (Bryman, 2004) were used for the analysis of the comments and the free text questions. All comments were read through several times and categorized on topics. Thereafter, the number of comments in each category were counted and summarized. Several individuals have been involved in the analytical process as well as the compilation in the analysis work.

Result

In the following section, the results from the survey on how coordinators perceive their work and their function are presented.

General information about the coordinator function

The coordinators have different professional background. The largest group of coordinators have a background as medical secretary (35 percent), followed by contact nurse (30 percent), nurse (19 percent), assistant nurse (9 percent) and other (7 percent) which includes among others care administrators, midwifes and surgery planners. Most CCs have coordinators with a variety of professional backgrounds but there are also CCs which have chosen to have coordinators from primarily one professional background for example one CC has 53 percent assistant nurses and another has 88 percent medical secretaries.

Forty-six percent of the coordinators work less than 20 percent of their time with the coordinator function and only 13 percent work full time. This means that the majority of coordinators combines working as a CCP coordinator with other working tasks. Professional background affects how much of full time is assigned to the coordination function. Most of the assistant nurses work more than 50 percent as CCP coordinators while a large part of contact nurses (54.3 percent), specialist nurses (43.9 percent) and medical secretaries (56 percent) works less than 20 percent.

The coordinators were asked how many CCPs they coordinate and if they coordinate the whole or parts of the CCP. The survey shows that the coordinators are usually responsible for 0-5 CCPs (88 percent). As many as 45 percent coordinate only one CCP and only 5 percent coordinates more than 10 CCPs. The more CCPs coordinated, the more time is spent on the function. The coordinators can coordinate the whole pathway (45 percent or a part of the care pathway (48 percent or both (3 percent, and in same case even the part after start of first treatment (4 percent).

The study shows that not all coordinators have a written work statement. In total 51 percent of the coordinators have a work statement where 77 percent of the assistant nurses and 34 percent of contact nurses states to have one. The personal prerequisites and competence is perceived to be good and the coordinators are satisfied with the information and support provided to perform the work. On the other hand, there seems to be room for improvement when it comes to having back-up when on sick leave or vacation and having enough time to perform the work tasks. Most satisfied with the available time to spend on the work tasks are the assistant nurses.

The coordinators had the opportunity to express how the prerequisites for the coordination function could improve. Among the comments, there were several requests for training and supervision for the role, to be part of a coordinator network and attend study visits at other hospitals, and get checklists, guidelines and templates for work tasks.

Coordinators working in CCs which have offered introductory coordinator training, mention in the comments that this has been helpful for the assignment.

The coordinators work tasks

The coordinators were asked what kind of work tasks they perform in their day-to-day work. In this question, the coordinators could choose multiple alternatives from a list with specified work tasks. As indicated in table I the most common work tasks are booking appointments, serving as a contact person for the patients, registering and reporting lead times for CCPs and monitoring the patient status to meet the limits for waiting times. Appointments can mainly be booked within the own care unit and only coordinators from a few CCs mention having the possibility to book appointments outside the own unit.

Table I: Work tasks for the coordinators.

Work task	***N***	***Percent***
Book appointments	274	71%
Serve as a contact person for the patients	254	66%
Register and report lead times for CCPs	236	61%
Monitoring lead times/waiting times	235	61%
Ensure active handovers between health care providers	214	56%
Inform the patient and relatives about the next steps in the cancer investigation	201	52%
Ensure transitions to other health care providers outside the own unit/organisation	196	51%
Participate in multidisciplinary conferences	189	49%
Serve as a contact person for referring physicians	185	48%
Guide the patient to psychosocial support when needed	167	43%
Register and report data to quality register/cancer register etc.	105	27%
Respondents	385	

The analysis also shows that the professional background influence what work tasks the coordinator performs (table II). Ninety-one percent of the contact nurses states that they serve as a contact person for patients while only 42 percent of medical secretaries and 59 percent of assistant nurses states to perform this task. On the other hand, 80 percent of the medical secretaries register and report lead times in comparison with 37 percent of the contact nurses and 51 percent of the nurses doing this work task.

Table II: Work tasks for coordinators with different professional backgrounds.

Coordinator with professional background as			
Nurse	***Contact nurse***	***Medical secretary***	***Assistant nurse***
Book appointments (83%)	Serve as a contact person for patients (91%)	Register and report lead times/waiting times (80%)	Register and report lead times/waiting times (85%)
Serve as a contact person for patients (72%)	Inform the patient and relatives about the next steps in the cancer investigation (91%)	Book appointments (65%)	Book appointments (68%)
Inform the patient and relatives about the next steps in the cancer investigation (71%)	Guide the patient to psychosocial support when needed (86%)	Serve as a contact person for referring physicians (46%)	Participate in multidisciplinary conferences (68%)

Challenges with the coordinators' work

The coordinators have described in total 370 different challenges, which were categorized in eight major challenges. The description of the five biggest challenges follows below.

The first challenge concerns *time shortage and difficulty switching between roles and tasks.* The coordination function is often combined with other roles as for example being

a contact nurse or a medical secretary. The combination requires the coordinators to switch between different work task during the day. A situation which is perceived to be hard to manage both when it comes to time management and having to switch between roles. Several of the contact nurses expresses in the survey that their place is with the patients and not doing administrative tasks. At the same time do several of the medical secretaries articulate difficulties when it comes to patient related tasks. Especially medical secretaries with a limited knowledge about individual cancer diagnoses and psychosocial care experience challenges when patients have questions about their diagnosis or the following steps of the pathway.

The second challenge concerns *available resources, reducing lead times and avoiding push-out effects.* The coordinator plays a central role in avoiding unnecessary waiting times and meeting the limits for maximum waiting times, but this is a difficult task in a health care system with capacity constraints. The lack of capacity and resources are frequently mentioned throughout the survey. The problem is perceived to be greatest in radiology (25 percent of listed problems) but there are also problems with long waiting times for tests sent to pathology units, for surgery and some examinations for example colonoscopy and cystoscopy. Limited times for appointments with physicians is also a challenge. There is a hot debate about the push-out effects related to the CCP implementation, that means that the CCP implementation causes longer waiting times for patients with the same or higher medical need as CCP patients. The survey shows that 13 percent of the coordinators daily have to make decisions about patient prioritisation to avoid push-out effects. The majority of coordinators (56 percent) states that it happens more seldom than several times every month or never, but it is still an issue that concern the coordinators.

The third challenge concerns *getting everyone involved, create an effective teamwork around the patient and understanding the coordinators role.* There is a great challenge to design a new role, implement a new working way and reach out to all health care professionals throughout the whole health care system. Many health care professionals have heard of CCPs but have not been particularly involved or affected by its introduction in their everyday work. Sometimes the coordinators feel that they are the only ones who has knowledge and interest in CCPs. There is no common understanding and diverse expectations regarding the role by different health care professionals and in different care units, which makes the coordination work difficult.

The fourth challenge concerns *reporting of lead times, coding and referrals.* Prior to the CCP implementation, there was no national measurement system or requirement to follow-up of lead times. A national code system has been introduced to ensure a uniform reporting, but the challenge is to make sure that coding and monitoring is done in the same way. For coordinators it often implies an additional administrative task that takes time and creates frustration since the coding is often not correct or missing.

The fifth challenge concerns *insufficient administrative systems, availability of information and problems with monitoring the patients through the system.* A considerable amount of time is spent on manually monitoring the patient status to ensure that everything goes as planned. The IT-systems is not designed to support a process-oriented way of working. The information is locked up inside single care units with limited or complicated access for health care professionals from other care units. The units are constantly working on new routines and shortcuts to come around these problems to be able to book and keep track of patients outside own care unit.

Contribution to improvements for patients and health care practice

Despite several challenges the coordinators consider their role as important and meaningful. The respondents submitted several comments stating that the coordinators' work is stimulating and rewarding with much responsibility, but also grateful patients. Table III shows the coordinators perception about their contribution to improvements for patients and health care practice. The coordinators perceive that they mostly contribute to more effective diagnostic process and shortening waiting times. The aspects related to care continuity and cooperation between different health care professionals are also scored relatively high. The least contribution is perceived to be made in improving the cooperation between primary care and hospital care. The coordinators with the background as contact nurse valued their contribution to improvements significantly lower than coordinators with other backgrounds.

Table III: The coordinators contribution to improvements for patients and health care practice.

	N	Mean	SD
My role as coordinator contributes to			
... more effective diagnostic pathway	353	4.24	0.929
... shortening waiting times for patients	350	4.10	1.032
... improved cooperation between health care providers	322	4.07	0.919
... improved continuity and safety for the patient	296	4.02	1.057
... more equitable cancer care	277	3.96	1.033
... patients being well-informed	321	3.93	1.127
... increased patient involvement in the care	297	3.63	1.144
... more individualized cancer diagnostics	284	3.57	1.243
... increased cooperation between primary care and hospital care	293	3.36	1.173

Discussion

According to the national guidelines on CCPs, the purpose of the coordination function is *"to ensure continuity in the care pathways and avoid unnecessary waiting time"* (see CCP guidelines at cancercentrum.se). The guidelines do not contain any directives for how the coordination function is supposed to be organised. The implementation is locally driven, and the CCs design and adapt the function based on their own preferences, context and development priorities.

The study identified three general types of organising the coordination function which differ in terms of responsibilities, work tasks and the extent of patient contact, which is summarised in table IV.

The first type implies primarily an administrative function. Coordinators of this type are placed in care units and have responsibility for the whole or parts of CCPs, which include that particular care unit. The primary responsibility is to book appointments and act as gatekeeper for CCP steps and waiting times. They have no or very limited contact with patients. Most coordinators of this type are medical secretaries.

The second type has the primarily role to coordinate the care pathway between patients and health care professionals. Those coordinators are also placed within a care unit, but the major difference compared to the first type is the extent of patient contact. In many CCPs, the function as contact nurse was already established when CCPs were introduced into the Swedish health care system. The availability of the contact nurse varies between county councils, hospitals and care units but it is well-established for some cancer care

pathways (Larsson and Bjuresäter, 2016). The natural development was therefore to assign contact nurses to the coordination function introduced with the CCPs.

The last type implies introduction of centralised coordinators with an overall responsibility to plan, coordinate and manage the whole CCP within the health care system. These coordinators are placed outside care units at central coordination or diagnostic centres. The responsibility is to establish the first contact with the patient, ensure accurate referral pathways and transitions between health care providers.

Table IV: Three types of coordination functions.

Type 1: Coordination within a care unit	**Type 2: Coordination with the patient**	**Type 3: Coordination at the system level**
• Booking and informing patients about appointments • Registering and reporting lead times for CCPs • Acting as gatekeeper for CCP steps and waiting times • Registering and reporting data to quality register/cancer register etc.	• Serving as a contact person for the patients • Planning CCP with the patient • Coordinating between patient and health care system • Participating in multidisciplinary conferences • Guiding the patient to psychosocial care when needed	• Establishing referral pathways • Identifying patient needs and booking first appointments • Informing the patient and relatives about the steps in CCP • Serving as a contact person for referring physicians • Ensuring transitions between health care providers • Monitoring lead times

Similar categorisations of coordinators maybe found in other studies. For example, Freijser et al. (2015) categorise coordinators into three levels: individual, team and system. Further, Charns and Young (2011) describes two types of coordinators denoted as liaison roles and integrators. Type 1 and type 2 coordinators in this study show similarity with the liaison roles, where the coordinator primarily fulfil the coordination needs within a care unit. The third type of coordinators, similar to the categorisation by Charns and Young (2011), is an integrator that takes the system perspective and coordinates the whole care pathway with the focus on achieving the best outcome for the patient.

There is no "one-type-fits-all" solution on how to organise a coordination function since it depends on local conditions and needs (Charns and Young, 2011, Freijser et al., 2015). Our results show that the function was so far often established and organised ad hoc. In many cases, it was a quick fix solution using current available resources and functions. Many coordinators combine the function with other roles and their work tasks differ depending on professional background and type of CCP. The overall responsibility for assigning coordinators is on the CCs but in practice it was each care unit that decided how to organise the function. The consequence is that the responsibilities along the care pathway are unclear, work tasks overlap and not always the right competence is used. CCs made requests to define the coordination function nationally and some work was done in this respect. However, as our results show, will one type of coordinator with a standardised set of work tasks not be a suitable solution since different types of coordinators are needed. Some CCPs are more simple and standardised requiring less coordination with the patient compared to other CCPs that are complex, involve more care units and thereby require more coordination with the patient and between health care professionals. Further, CCs have different structures, conditions and challenges, which

requires locally designed solutions. Currently, the resources and competencies are not used optimally. For example, medical secretaries perceived a challenge to coordinate the CCPs with patient, whereas contact nurses complained about their competence being wasted on administrative tasks. It is important that the right type of coordinator is matched with the coordination needs of each CCP. Using nurses as coordinators is more common when there is a high focus on patient contact and taking care of psychosocial needs (Monterosso et al., 2016, Freijser et al., 2015). The primary focus in designing the coordination function should be on achieving an effective collaboration around the patient and ensuring that the right staff, with the right skills are in the right place. Creating a common understanding and respect of the individual roles in the care pathway is essential for the coordinator to be able to perform their role (Freijser et al., 2015). New routines and a clear distribution of responsibilities need to be established for each CCP locally rather than imposed uniformly by national guidelines.

The study shows that the coordinators considered their work as important and perceived several contributions to improvements. Among the highest perceived contributions were improved continuity and shorten waiting times for patients, which is in line with the purpose set for the coordination function with the CCPs. The contact nurses perceived their contributions as lower, which can be explained by the fact that their work overlap to some extent with the coordinator function. For the contact nurses the role as CCP coordinator didn't make a big difference, but frequently implied an additional administrative burden.

Conclusions

In a progressively complex and fragmented health care system coordinators are increasingly used as a means to improve continuity and quality of patient care. The study investigated the role, challenges and contributions of care coordinators in CCPs. Despite that the CCPs were nationally defined, the role of coordinators differs significantly between the county councils and regions, care units and pathways. Three general types of organising the coordination function were identified: coordination within a care unit, coordination with the patient and the coordination at the system level. The coordinators may have different professional backgrounds and responsibilities depending on how much the care activities need to be coordinated with patient and between different care units and health care professionals.

The coordination function introduced with the CCP contribute to the improved continuity and quality of patient care, but also requires further development. An important implication from this paper is that there is no "one-type-fits-all" solution for the coordination function. It is vital that the conditions and needs in each CCP and care units are evaluated prior to appointing a care coordinator to achieve best results and ensure an efficient use of resources. There is also a need to set routines and define roles and responsibilities for the coordinator and medical professionals working in the same CCP. As the role of CCP coordinator is new, further developmental work needs to be done to establish the function in the organisational structure and culture.

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