

# Danish general practitioners only play a minor role in the coordination of cancer treatment

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## ABSTRACT

**INTRODUCTION:** Despite initiatives to integrate treatment and care across organisations, patient trajectories in Danish health-care are not well coordinated. Coordination among many health-care professionals is essential, and it is frequently suggested that a single person should perform the task of coordination. The aim of the article is to discuss whether general practitioners (GPs) may play a coordinating role for individual patients in Danish cancer treatment?

**MATERIAL AND METHODS:** This study is based on individual interviews and focus groups analyzed by meaning condensation.

**RESULTS:** The GP's potential to coordinate patient trajectories was limited by lack of involvement of the GPs by other health-care professionals and lack of needed information. Furthermore, many patients do not regard their GP as a coordinator. Patients who contacted their GP during treatment typically had a close relationship with their GP prior to their cancer diagnosis. In cases with a more distant relationship, patients did not see a need for the GP's involvement. The majority of patients' trajectories were decided within hospitals. The level of information provided to GPs varied much between hospitals and wards. In the majority of cases, GPs had no access to information or were not informed about hospital decisions affecting the patients' trajectories, and they were therefore unable to perform a coordinating role.

**CONCLUSION:** GPs only played a minor or no role at all as coordinators of individual cancer patient trajectories. The findings of the present study question the idea that coordination throughout the entire health-care system may be assigned to a single individual as the involved parties belong to different organizations with different goals, managements and economic resources.

Despite initiatives to integrate treatment and care across the organizations of the Danish health-care system, many physicians agree that patient trajectories are not well coordinated [1]. Treatment and care for the individual patient is provided across various organizational boundaries and by a host of health-care professionals. It may therefore be difficult to obtain the information needed to follow the patient throughout the entire health-care system [4].

Coordination among many health-care professionals is essential, and a single person is often seen as responsible for achieving well-coordinated patient trajectories. One example that coordination is seen as a single person task is captured in the Danish term *tovholder*. A *tovholder* is, among other aspects, expected to coordinate work and to ensure communication about individual cases across the entire health-care system [5-7].

The WHO as well as The Danish National Board of Health have recommended that primary care take on a coordinating role as a measure to improve coordination [8-10]. The Danish Government and the Danish Regions have agreed at the political level that measures will be instituted to ensure accurate information for cancer patients in order to solve problems of coordination [6, 7, 11-13]. In a publication the general practitioner's (GP) role as a coordinator in patient trajectories is described as one that spans sectoral and professional boundaries [5]. According to the Danish National Concept Council, a coordinator is: "affiliated to patients in order to coordinate health-care activities for the patient" [5].

In the Danish health-care system, most patients are listed with one GP. Some patients have ongoing contact with their GP throughout their lives, while others have a less close relationship. GPs are acting as gatekeepers to the rest of the health-care system. However, many GPs lose contact with their cancer patients after they have been referred to the hospital [14]. Research shows that about half the patients do not seek support from their GP about their cancer treatment or related issues during the treatment period [2, 3].

In relation to the above description of a coordinator, the aim of this article is to discuss whether GPs may play this role for single patients during cancer treatment. Focus is on the period from GP referral for further diagnosis until treatment is concluded and follow-up starts.

## MATERIAL AND METHODS

The study data consists of:

- Twelve individual semi-structured interviews with patients. The inclusion criteria were: patients with either colorectal, pulmonary or prostate cancer,

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undergoing treatment at a minimum of two hospital wards. Patients were chosen at random and their participation was requested by a nurse or oncologist at Næstved Hospital. Six patients with pulmonary cancer, four with colorectal and two with prostate cancer were included.

- Two focus groups with the patients' GPs or colleagues from the same district.
- One focus group with hospital physicians at the wards where patients were treated at Næstved Hospital. One oncologist, one pulmonary disease specialist and one urologist.
- Two focus groups with nurses, one from the outpatient departments and one from the wards at Næstved Hospital. In the first group, two oncology nurses and two abdominal surgery nurses participated. The second group comprised two urology nurses, two abdominal surgery nurses, two oncology nurses and a stoma specialist.
- One focus group with homecare nurses in municipalities where the patients were living.

We interviewed the patients in their homes about their experience during their cancer treatment, and asked them how they saw the role of their GP, and whom they contacted with questions during their cancer treatment. Spouses often participated in the interviews. The patients' experience was subsequently presented as a constructed case in the focus groups mentioned. Each group of health-care professionals was asked to reflect on the patient's experience, and on how they saw their own role in relation to the case and in general during cancer patients' trajectories. The authors conducted the patient interviews and the focus groups from the autumn of 2007 to the autumn of 2008.

All patient and focus groups were transcribed and subsequently analyzed independently by two persons using meaning condensation and abridging the perspec-

tives expressed by the interviewed respondents [16]. The analyses focused on identifying central aspects of the GP's coordinating role. Results were extracted from all patient interviews and focus groups. This paper is part of a broader analysis of how coordination is taking place among health-care professionals. Other aspects of the analysis will be presented in future publications.

## RESULTS

Overall, the results revealed that the GP's potential to coordinate patient trajectories was limited by lack of involvement of the GP by the hospitals and due to lack of information from other health-care professionals. Moreover, it was hampered by the fact that patients did not regard their GP as a coordinator. The two main themes in the analysis were the GP-patient relationship and the GP's lack of contact and information.

### Relationship between patient and GP

The majority of patients did not contact their GPs or feel any need for their GP during their treatment. When they had questions or encountered problems, they usually contacted the health-care professional they felt closest to, frequently a hospital nurse.

Patients who contacted their GP during treatment typically had a close relationship with their GP prior to their cancer diagnosis. In cases characterized by a more distant relationship prior to the cancer diagnosis, patients most often did not see a need for the GP to become involved during their treatment. A more distant relationship arose for various reasons: The patient wanted a more superficial relationship; the patient had only rarely seen the GP before being diagnosed with cancer; the GP had recently arrived at the clinic or the patient had recently changed to another GP and did not know him or her well; or the patient had been dissatisfied with the GP's contribution when she/he presented the symptoms.

Patients approached their GP during cancer treatment if the GP had shown an interest in their overall situation – not only in their disease. Some patients stated that a quick response and initiation of further diagnosis were seen as positive and confidence-building measures on the part of the GP. Furthermore, patients positively assessed GPs who had contacted them by phone or letter for test results or follow-up. A few quotes may illustrate these points:

When asked about special and positive aspects of their contact with the GP during their cancer treatment, two patients stated:

"You feel that he knows you because you have had contact before the cancer disease. That he understands and asks how I am. Not only how my disease is."

The other patient:

Can general practitioners solve the coordination puzzle?



“It is not so much because we have any questions about the disease itself, because we can get those answered at the hospital. It is the human part of it.”

Even patients who saw their GP for reasons other than cancer sometimes did not talk about the cancer with the GP. After his cancer treatment had ended, one patient described how he visited his GP due to hypertension. During the visit neither he nor the GP mentioned the cancer. When asked in the interview if he wanted to talk with his GP about it, he said no. The reason was mistrust related to previous anticoagulant treatment.

Patients frequently felt that they needed a specific reason related to their cancer to contact their GP during treatment. A patient put it as follows:

“He [the GP] has told me that his door is always open for me to come and all that. But it is like there hasn't been anything we wanted to burden him with.”

#### **GP's lack of information and participation**

Analysis of patient interviews and focus groups with health-care professionals showed that most of treatment and care decisions were taken within hospitals. The level of information provided to GPs from hospitals varied considerably between hospitals and wards (according to the GPs). In the majority of cases, the GPs did not have access to, nor did they receive information from hospitals about these decisions and decision processes (according to all health-care professionals), and they were therefore unable to play a coordinating role. The GPs stated that they typically received no or only very little information from involved hospitals about developments in the patient's treatment. Typically, they did not receive any information before receiving the discharge letter from hospital physicians. When patients asked their GPs questions about further treatment plans or had specific questions regarding treatment, the GP often did not have the necessary information about further plans, test results, or treatment (according to GPs and patients). Most patients expected their GP to be informed, and they were surprised by the lack of communication between the health-care professionals.

Much in line with the patients who did not see their GP as treatment coordinators, the other health-care professionals included in this project were unsure about the GP's role and did not include GPs in the planning of, e.g. follow-up or further tests. Furthermore, a substantial part of the other health-care professionals did not have the GPs in mind when planning patient trajectories.

The GPs included in the project were themselves divided more or less evenly into two groups in terms of their views of their own role. Some would like to have close and ongoing contact with patients during treatment, and some found it best if patients were primarily in contact with the hospital during cancer treatment.

#### **Discussion – Challenge to the “single coordinator” idea**

This study adds explanatory causes to prior studies which have shown that GPs only play a marginal role as coordinators in individual patient trajectories [12, 14, 16]. In the present study, the reasons why GPs cannot play a coordinating role centre on the relation between patient and GP and on the lack of involvement of the GP by the other health-care professionals and lack of information.

In Grøn, Obel & Bræmer's study on the role of Danish GPs, it was emphasized that GPs do not see themselves as organizational coordinators, but rather perceive themselves as relational partners for their patients [17]. Our study adds that the prior and existing relation between GP and patient is an important factor when determining if GPs may have a coordinating role.

Vinge et al stated that delegation of the coordination task does not work since the one person in charge of coordination does not have the managing rights needed to solve the structural problems of coordination [18]. Our study adds that the separation of the GP from the cancer treating team limits the GP's potential to assume a coordinating role during cancer treatment.

Our results indicate that there are various challenges to the “single coordinator” idea. Several actors are involved and many communication and decision processes remain unknown for the GP who therefore cannot either coordinate or influence this process. The health-care professionals involved belong to various organizations with different managements, goals and financial resources. The affected parties therefore have different perspectives and interests [19]. Furthermore, external coordination across organizational boundaries is a much more difficult task than coordinating within a single organization because much more cooperation is needed. In such a situation, positive and negative incentives do not exist as within a single organizational structure [20]. These considerations highlight the issue of how a single person from one organization should be able to coordinate the entire process across organizational boundaries, professions, etc.

The theoretical contribution by Alter & Hage points to an alternative to the “single coordinator” idea and addresses the importance of paying attention to the interfaces between different organizations and thereby focusing on linkages between the parties rather than on the parties themselves [19]. describe how continued interaction between interdependent units produces interfaces that can be seen as analytical units themselves.

Further investigation and discussion of the coordination aspect of treatment and care may add new insights by focusing on organizational interfaces that bring organizations together. Choosing linkage as a central

concept may facilitate examination of shared values, procedures and mutual expectations that regulate the interaction between the involved parties.

#### Are results transferable?

Our results highlight the GP's role in the coordination of individual cancer patients' trajectories. Our research covered patients and healthcare professionals in general practices and one hospital and its municipal area. We consider the results transferable to other GPs and settings as information from all respondents were well-aligned, thereby providing a solid contribution to the conclusions on several forms of cancer. Finally, our results are in line with previous research on the GP's role as coordinator [10, 12, 14]. The present study, however, mainly included patients with spouses and social resources. We do not know if patients with few resources have a different need for GP involvement.

#### CONCLUSION

The results of the present study demonstrated that GPs played only a minor or no role in the coordination of individual cancer patients' trajectories. One main factor determining the GP's role was whether the GP received ongoing information and was given the opportunity by hospital staff to become involved in the decision processes concerning the patient's trajectory and test results. Furthermore, the relationship between the GP and the patient prior to the cancer diagnosis was shown to influence whether patients and GPs had any contact about cancer during the treatment. Also, other healthcare professionals were uncertain about the GP's role, and the GPs themselves did not agree about their role in the coordination of the cancer patients' trajectories.

The findings challenge the idea that coordination throughout the entire health-care system may be assigned to a single individual since involved parties belong to various organizations with different managements, goals and financial resources. An alternative to a "single-coordinator" idea may be identified by focusing on organizational interfaces between the involved parties in order to examine linkages, shared values, procedures and mutual expectations that influence coordination across organizational boundaries.

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