Knowledge of Dutch GPs in caring for cancer patients using oral anticancer therapy at home

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Background. The GP’s role in cancer care is changing and will become increasingly important. One of the challenges for GPs in caring for cancer patients is their lack of specialized knowledge and the impossibility to keep up to date with developments in the field of oncology. We investigated GPs use of knowledge in the case of the increasing use of oral anticancer therapy at home.

Objective. The objective of the study was to find out the needs for knowledge improvement for GPs in caring for cancer patients at home, by analysing what kinds of knowledge Dutch GPs use and the ways they obtain knowledge in their daily practice of caring for patients using oral anticancer therapy at home.

Methods. Semi-structured in-depth interviews were conducted between July and November 2011 with 15 Dutch GPs. A thematic analysis of interview transcripts was conducted.

Results. GPs recognize their lack of specialized knowledge and their inability to keep up to date with developments in the field of oncology. The analysis shows that GPs use different kinds of knowledge and skills they already have to care for their patients and obtain valuable knowledge about oral anticancer therapy via and from their patients.

Conclusion. Apart from formal training, GPs may be supported to strengthen the strategies they already use, i.e. to actively mobilize different types and sources of knowledge and use the patient as a source of knowledge in caring for oncology patients at home.

Keywords. General practice/primary health care, knowledge, neoplasms, oral administration, qualitative research.

Introduction

In the Netherlands, increasing attention is being paid to the importance of primary care for patients with cancer. In 2007, the Dutch Health Council concluded that primary caregivers need to be more involved in the follow-up of patients with cancer. According to estimates, the number of cancer patients in the Netherlands will increase by 57% between 2010 and 2020, rising from 576 000 to 905 000. One of the reasons for this is the increasing aging of the population, as cancer is relatively common in the elderly. In addition, enhanced treatment possibilities are extending the lives of cancer patients. This implies an increasing demand for primary caregivers, who are usually involved from diagnosis to death or survival.

Another important development that may intensify the involvement of primary caregivers is the steady increase in the use of oral anticancer therapy in modern oncology (in the Netherlands, a 2- to 3-fold increase took place from 2000 to 2008). A shift from intravenous to more oral therapies for cancer could imply a larger role for primary care, because cancer patients using oral anticancer therapy at home will probably contact their GPs more often than patients who receive intravenous therapy in the hospital. The trend towards increasing the use of oral anticancer treatments has been described by some as ‘a paradigm shift’.

The question is if GPs are well equipped to provide proper care for these patients, and what kind of training they may need to do so. The idea that GPs need training in specialist oncology knowledge seems neither feasible nor desirable. In order to learn about GPs’ needs for knowledge improvement, we analysed empirically what different types of knowledge GPs used to care for their patients receiving oral cancer treatment at home, as well as the ways in which they obtain knowledge to do so in their daily practice. The questions of this paper are what types of knowledge do GPs use in their care for cancer patients who receive oral treatment at home? How do
they obtain knowledge when they need it? What does this imply for the future training of GPs?

Methods

We conducted a qualitative study using semi-structured in-depth interviews.

Recruitment and sampling

We approached 15 Dutch GPs by letter and telephone. All participants were sampled through the General Practice Department of the Academic Medical Center, University of Amsterdam. All agreed to participate in this study. Two were no longer in practice but currently hold professorships in the field of general practice. We first interviewed six GPs. We then recruited six more GPs, because of their affinity with our research subject. Finally, we recruited three more GPs in rural locations. To obtain sufficient variety, we approached seven female and eight male doctors, with different amounts of experience as GPs (2–29 years, with an average of 16 years), varying in workplace (academic setting, group practice or both) and different urban and rural locations.

Data collection

Interviews and topic list. The interviews were guided by a topic list, based on scientific literature. We refined it after an observational phase during which SLR, together with three oncology nurses and one GP, visited several patients who were living with cancer at home and used or had used oral anticancer treatment.

Data were collected from July to November 2011 through face-to-face, semi-structured in-depth interviews. Together with one of the interviewed GPs, we visited four cancer patients at home. All participants agreed to the interview and home visit being audio-taped. All interviews were transcribed verbatim and rendered anonymous.

We started each interview by asking about a specific of a particular patient receiving oral anticancer treatment and discussed the GPs role. We also asked questions concerning the role of the GP in the chronic phase of cancer care and about the changes they expected to occur if more patients receive oral anticancer treatment at home. After the first four interviews, the topic list was extended with some general topics.

Analysis

The transcripts of the interviews were analysed using Maxqda software. We first coded eight transcripts to identify key themes, using the themes from the topic list. New themes that the GPs mentioned became codes for further analysis.

The researcher who carried out the interviews (SLR) discussed the results intensively with other researchers from various backgrounds, two of whom are experienced qualitative researchers. After interviewing all 15 GPs, we discussed our findings with members of our project group until we reached consensus on the most outstanding themes.

Knowledge being one of the themes in the interviews, the analysis revealed how GPs use and acquire knowledge. In conformity with qualitative methodology, we did not define knowledge beforehand but followed the concepts used by our respondents.

Results

GPs reported on their lack of specialized knowledge and their inability to keep up to date with developments in the field of oncology.

But those real chemotherapeutics, I haven't dealt with them much until now, because of course that is very specialized, so I know very little about them. So, if that would come our way, we'd need some extra schooling. I would, in any case. (GP6)

As the quote states, GPs feel they lack the specialist knowledge for the care for cancer patients at home. However, based on the interviews we (i) unravelled four types of knowledge that GPs use. The analysis shows that (ii) GPs find ways to obtain valuable knowledge not only through formal training but also via their patients’ networks and from their patients’ experiences.

Four types of knowledge

In this section, we discuss four types of knowledge that GPs use in caring for cancer patients using oral chemotherapy.

The first type is of a medical technical nature. GPs measure blood levels, perform physical examinations and explain the functioning of the body and medicines to their patients. During a home visit to a cancer patient whose entire coffee table is covered with the various medications he needs to take, the GP says,

[…] that little tablet, that’s that Nortrilen […] That’s those little tablets […] specifically for neurological pain. Those make you a little drowsy […] (house call GP3)

This GP knows what Nortrilen is (a drug inside that white box), what it looks like outside the box (a little tablet), what it is used for (treating neuralgia) and what possible side effect it has (sedation). By explaining this, the GP creates order in the chaos for the patient who needs to deal with different kinds of medication.

These medical matters are closely connected to a second type of knowledge GPs use: ‘knowing their way’ in the medical system. GPs consult colleagues
from other disciplines, refer patients to a specific specialist and sometimes mediate between patient and hospital:

 [...] the tumour was bleeding and he had a blood level of 4, which is severe anaemia, and so I called the same internist and he was admitted straight away. (GP1)

A third type of knowledge in primary care for oncology patients is a practical one: it is about arranging the necessary affairs at home. This most often concerns different forms of aids patients can use and ways to keep life as comfortable as possible:

 You have to know what step to take to keep things more or less okay. Actually, with these patients, offering comfort is very important. [...] well, first we talked about going to the toilet, that there will be a toilet chair, that there will be a bed pan, that there will be a walking frame, that there will be homecare … (GP13)

The fourth knowledge type GPs use in caring for oncology patients receiving oral treatment at home is understanding what it means to suffer from cancer:

 I keep repeating: everyone is afraid! There is only one guy from Alpe d’Huez who thinks cancer is a challenge, that sort of thing, but with cancer you're scared, there's a threat of death, the pills smell like danger. After all they make you nauseous, if not today then the next day. (GP11)

GPs obtained these four types of knowledge through different sources: continuous medical education, scientific medical literature, daily experience, peer information, practical common sense and, in the fourth case, through their contact with and narratives from cancer patients. For all four types of knowledge, however, the patient may be used as a source.

Patient as a source of knowledge for the GP
In this section, we discuss how GPs actively learn via their patients and directly from their patients.

Via the patient. Caring for a patient using oral cancer treatment may encourage a GP to delve into a particular set of facts about his or her disease and treatment. This knowledge—acquired by following the patient—is new to the GP and of a specialist nature. GPs may make inquiries or consult databases if that is relevant to the situation of the patient. This type of knowledge is case specific:

 [...] when I have a patient like that, I care for that patient with those medicines using the information I got from the specialist. (GP8)

Cancer patients in primary care often present complex medical situations with which the GP has no experience. The particular problems of patients may motivate a GP to deepen his or her knowledge:

 [...] with a patient, I think you can check the oncology literature, of course it’s on the internet, so you can check what that treatment is [...] because a patient with a particular disease is also a good opportunity to get updated. (GP7)

This patient-linked learning of specialized oncological knowledge may demand consulting various specialist sources, such as medical doctors, oncology nurses and scientific and medical literature:

 [...] and if you can't figure it out with your basic knowledge, you give the specialist a call. (GP6)

 [...] yes, I try to figure out what the best treatment is at that moment. You do that by checking guidelines – Oncoline or CBO – or our own standards [NHG]. (GP14)

Thus, GPs actively learn via their patients: patients present individual and complex medical situations, and on that basis GPs actively consult various sources within the specialist networks surrounding them.

From the patient. Most of the GPs we interviewed stated that they are aware that patients often know more than they do and that they use the patient’s knowledge to keep themselves informed. The following respondent actively encourages his patients to share this knowledge:

[Then I say to these patients:] So there are things that are very impressive to you and I don't know anything about them and you think “Yeah, the doctor knows.” But the doctor sometimes doesn't know and so it's very good if you take the initiative yourself and let me know. (GP3)

Here is an example of a patient’s wife who told her GP about the kind of oral chemotherapy that she and her husband were receiving from the specialist and about the treatment regimen:

 And they got me up to date with what the pulmonologist had given them for chemotherapy and that they had to take a pill every day, that sort of thing. (GP5)

Patients then function as experts from whom GPs can learn:

And you also learn a lot from patients, because they also give you information. They also tell you what happened; so that's a learning moment too. (GP7)

So it's important that patients are well informed about their disease and what other possible
problems are. The patient is almost more of an expert than you are, as a GP. (GP12)

Patients develop expertise about their own medical pathway, such as the treatments they receive, their physical complaints, particular side effects from medications and the practical solutions they develop.

Most patients not only become experts in matters related to their illness and medical pathway but are also experts when it comes to living with cancer and the role of values and goals. GPs use this latter expertise to tailor treatment to the individual patient and maybe other patients:

[…] within the realm of what is possible, what is available, this is the colour against which you can discuss with a patient: ‘What’s important to you, how do you see the future, what are your goals, and what can and can’t you handle’? (GP7)

Compared with other physicians, such as oncologists, GPs are in the unique position of visiting their patients at home. When they are particularly worried or more intensive contact is required, they visit their cancer patients and address any problems that may have arisen. In the Netherlands, GPs make more home visits to cancer patients than to non-cancer patients.8

Physicians also obtain knowledge from their patients by acting as a kind of ethnographer in the home situation, observing closely how a patient succeeds in living with cancer. The GP in the following example realizes that she will miss important knowledge if she does not visit her patients at home. ‘Seeing how things are going’ provides her with knowledge—supplied by patients—about how patients are living with cancer at home:

Then I went on my own initiative, or I’d just say ‘I’ll come and visit you once in a while and check whether there are any problems’. Because I thought: this will never go right. Yeah, okay, then I also want better contact with someone. I also want to go to their homes and see how things are there. (GP1)

Thus, GPs actively learn from their patients by regarding the patient as an expert, by learning about the patient’s illness, by learning about the values and goals of the patient and by visiting them at home and getting an ‘insider’s view’.

Conclusion

The GP’s role in cancer care is changing and will become increasingly important. One of the challenges that GPs encounter in caring for cancer patients is their lack of specialized knowledge and the impossibility to keep up to date with developments in the field of oncology.

The goal of this study was to learn about knowledge improvement needs of GPs, by exploring what kind of knowledge GPs already use in caring for cancer patients who use oral treatment at home and how they obtain knowledge they do not have. We call this an empirical epistemological study, in which we empirically studied types and sources of knowledge used in a specific practice. This is different from analytical–philosophical studies like the one published by Toulmin in the 1970s9 and also from normative epistemology, in which criteria for ‘good knowledge’ are formulated. We did not define knowledge beforehand but learned from our interviews how GPs define, use and acquire knowledge. Thus, rather than adopting a normative or theoretical approach to knowledge, we used a bottom-up empirical approach to explore the types and sources of knowledge that GPs use when they actively engage in caring for oncology patients using oral anticancer treatment.10

This study indicates that, despite the pronounced uncertainty about knowledge, GPs involved in caring for oncology patients at home do already mobilize and acquire different types of knowledge. Our study suggests that patients form a crucial starting point for meeting the knowledge needs of GPs. Patients living with a (chronic) disease develop expertise about their treatment and care trajectory.

This multifaceted understanding of medical knowledge development helps to understand the knowledge that GPs need in order to tackle the challenges they face in caring for an increasing amount of oncology patients.

Of course, formal training in oral anticancer treatment and other aspects of oncology is required. However, GPs can be supported and facilitated to strengthen the strategies they already use, which is to actively mobilize different types of knowledge, and use the patient as a source of knowledge in caring for them and their rare diseases.

Although this paper is on oral cancer treatment at home, we are confident that we can generalize the results to other cancer treatments that the GP becomes involved in, as well as to other diseases that require specialized medical care and that are infrequent in their practice. The results are relevant to other countries where primary care is facing an increase in the amount of home treatment for cancer patients.

Acknowledgement

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Declaration

Ethical approval: Dutch Law did not require a review by an ethics committee because the four observations we conducted were not burdensome to patients.
Conflict of interest: none.
References


