

ORIGINAL ARTICLE

A doctor close at hand: How GPs view their role in cancer care

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Abstract

Objective. To explore GPs' own views on their role in cancer care. **Design.** Qualitative study based on semi-structured interviews. **Setting.** Norwegian primary care. **Methods.** The stories of 14 GPs concerning 18 patients were analyzed for core content and abstracted into general ideas, to create a broader sense of the experienced professional role. **Results.** The GPs claimed to have an important role in cancer care. In our analysis, three main aspects of GPs' work emerged: first, as a flexible mediator, e.g. between the patient and the clinic, interpreting and translating; second, as an efficient "handyman", solving practical problems locally; and third, as a personal companion for the patient throughout the illness. **Conclusion.** The interviewed GPs see their place in cancer care as being close to their patients. In their many tasks we found three main aspects: the mediating, the practical, and the personal.

Key Words: *Family practice, neoplasms, primary health care, professional role, qualitative research*

A third of people in developed countries will develop cancer in their lifetime [1,2]. From small restricted lesions to infiltration of vital organs, cancer means many different diseases. Treatment can be anything from watchful waiting or one curative surgical resection, to months and years with radiation, chemo-, and hormone therapy. The biological possibility of recurrence and spread sets the stage for both treatment and follow-up of cancer, and also gives the diagnosis of cancer its existential meaning. In palliative treatment this meaning is evident.

In Norway, the general practitioner (GP) is the only doctor who ideally could accompany the individual patient with cancer through the whole course of the illness. GPs could be key people for coordination and palliation, and during end-of-life care, but often they are not. Patients with cancer might disappear from the GP's practice into hospitals [3,4] and GPs might miss the experience relevant to palliative treatment [5].

Patients and their carers have been asked about the role of primary care during cancer illness. They saw GPs as having a unique role during the whole cancer course, offering continuity of care and information [6,7]. Patients appreciated GPs being accessible,

having time to listen, talking about feelings, and relieving symptoms [8,9]. Some patients missed the GP's engagement, in both diagnosis and follow-up of cancer, and felt left alone [10,11].

In this situation, we found it important to ask GPs themselves, in an exploratory interview study:

- How do they perceive and describe their place in health care for people with cancer?
- What are the challenges and dilemmas that they face?

People with cancer share the experience of being thrown out of their ordinary lives into an insecure existence [12]. Other chronic conditions mainly set other terms for people's lives. Studying GPs' work in the heightened situation related to cancer might tell us something about the "general" in general practice [13].

Materials and methods

Almost every Norwegian is registered with a GP for primary health care. Most GPs work in group practices. Patients need referral from GPs to see specialists,

GPs can be seen in cancer treatment as either peripheral or having a unique role, offering continuity of care and information throughout the illness.

- GPs can accompany patients through the whole cancer journey.
- GPs talk about significant tasks in interpreting illness, mediating in the healthcare system, and handling many practical issues.
- Support of seriously ill patients and their families is seen both as very challenging and as deeply meaningful work.

who mainly work in public hospitals. Division of tasks between primary and secondary care varies between regions. Norway has vast rural areas with sparse populations, and the distance to a hospital can be more than a three-hour drive.

We carried out a purposive sampling of GPs, recruited through a national survey on cancer and general practice (Table I). Fourteen GPs were interviewed, talking about 18 patients whom they had followed recently. Ten patients had died by the time of the interview with their GP: four died at home, four in hospital, and two in a nursing home. Six were receiving palliative treatment and only two were survivors, so survival was not a main issue in this study.

The interviews were conducted face to face in the GP's surgery (by M-LJ). In the dialogue, the interviewer related to an interview guide (Table II). Interviews lasted for about an hour, and were recorded digitally and transcribed by the interviewer. Data were managed using NVivo computer software, which facilitates sorting and coding.

Table I. Participants.

Interviewed GPs	Gender	Place of practice	Years as GP
GP 1	Female	Rural	6
GP 2	Female	Rural	21
GP 3	Male	Rural	27
GP 4	Male	Rural	25
GP 5	Male	Small town	14
GP 6	Male	Small town	5
GP 7	Male	Rural	28
GP 8	Female	Rural	10
GP 9	Male	City	8
GP10	Male	Rural	1
GP11	Male	Rural	13
GP12	Male	Rural	6
GP13	Female	Rural	5
GP14	Female	Small town	22

Table II. Interview guide.

Before turning on the tape recorder:

The interviewer should try to create an atmosphere that promotes a collegial, mutual exploration of the questions. Be open and honest; put the interview guide on the table. The doctor should feel like a privileged, professional, principal character who is asked for her opinion. Do not hesitate to ask what the GP feels about being interviewed.

Main question:

Tell the patient's history and how you were involved.

Subsidiary questions:

How were you, and the patient, informed about the diagnosis? How did you perceive your own role, after the diagnosis?

Who did what during the treatment period, and how was the division of tasks resolved?

Describe your cooperation with hospital, cancer nurse, district nurses, and nursing home.

Does the patient have other illnesses? Any previous medications?

Describe your relationship to the patient and the family.

In your conversations with the patient, what did you talk about? Was death a topic?

What is your role when the patient is facing death?

How have you learned your knowledge about cancer care?

How do you get advice when needed? Any guidelines that have been useful?

Is there anything that you have missed that could have helped you in caring for this patient?

Experiences from other patients with cancer that could be important for this research?

Tell me about a dilemma that you have felt in cancer care.

Have you experienced that you had to limit your involvement in cancer care?

We used qualitative content analysis aimed at the manifest content [14], first identifying units of meaning, then condensing into core contents, and abstracting into codes. These were sorted and grouped, re-sorted and re-grouped, until three main aspects of GPs' work emerged (Table III). Divided into typical GP *tasks* and the *tools* for solving them, sub-aspects were added (Table IV). M-LJ did the primary coding and categorization; CER revised and suggested changes, which we discussed until agreement was reached.

Results

Three important aspects of GPs' work related to cancer emerged: the GP as intermediary, as practical "handyman", and as personal companion. These aspects contain a multitude of tasks that GPs are faced with. The interviewees found the practical issues the easiest and the personal the most challenging, but also the most rewarding.

Dealing with such serious tasks is one of the most difficult, but also one of the most meaningful, things for me. (GP 4)

GPs emphasize these three aspects differently in their daily work, but all are essential throughout the

Table III. Three aspects of GPs' work in cancer care.

	Efficient – handyman	Flexible – intermediary	Touched – companion
Tasks	First aid Secretary Team worker Corner shop	Interpreter Advocate Second opinion	Supporter Guide Consoler
Tools	Learning by doing Prioritizing Planning ahead	Asking for advice Staying accessible Being comprehensive	Offering time Respecting wishes Adjusting

whole course of illness. The joint significance of GPs' work in cancer care is summarized by the following quote:

I think the GP has a natural role in following patients and following them up. We are closer to the patient, are easier to get at, we are nearly always the same person, and we can always contact the hospital doctor and get patients assessed the same day, if necessary. (GP 9)

GP as intermediary

We found that the GP mediated at many interfaces: between the patient's story and the medical history, between the patient and clinic, between the patient and local health services, and even between the patient and family. The language of doctors working on various frontiers had to be flexible, even diplomatic.

Tasks. GPs work as *interpreters* from the first consultation: faced with the first hunches of illness, they look, listen, touch, test, and think. Already here, at a preliminary explanation, interpretation becomes delicate: How does one mediate the suspicion of

cancer? Some GPs used open statements such as "this needs further investigation" and did not mention cancer unless patients did, whereas others asked directly: "Are you afraid this could be cancer?"

When diagnosis was confirmed and the patient informed, most often in hospital, patients could come back to their GPs for long talks. The medical explanation had to be translated, reiterated and re-evaluated.

They had told her, but I don't think she had understood it. We had some conversations about it afterwards.... "What did they tell you?" is a starting question.... If I am lucky, and the discharge letter has arrived, we go through it. (GP 8)

These talks were seen as difficult by many GPs, especially in the few cases when they were telling patients the diagnosis. A sense that people had not understood the meaning of their diagnosis after the first talk was often mentioned. Asking the patient and family about their version of the information that they had received was a way of promoting understanding. The next step could be to ask for their thoughts about the diagnosis, and about the future.

GPs sometimes had to *advocate* in-hospital investigations. They called to secure a prompt appointment, and read letters thoroughly to be sure that relevant examinations were being done. The sense of being responsible was high. Referring patients often meant handing over to a system without a named recipient. GPs had to speak up when admission was postponed, e.g. because different departments did not agree on whose responsibility the patient was. Such negotiations were frustrating and GPs could feel that patients were treated as not worthy and left

Table IV. Levels of analysis.

Unit of meaning	Condensed	Code	Preliminary category	Aspect	Subspect
GP 1, line 102: He got it here, locally, once a week. To save him from the journey to the hospital; they asked us to do it.	Weekly cytostatic by GP, to avoid traveling	Giving cytostatic locally	Decentralized treatment	Practical tasks	Corner shop
GP 2, line 447: I think it was right the way it was done (by the hospital), but it had to be explained to the patient that it was done right.	Prove the hospital right and explain to patient	Mediate clinical decisions	Mediating between hospital and patient	Mediating tasks	Second opinion Interpreter

to worry. Sometimes GPs kept their opinions to themselves and accepted an assessment that they disagreed with.

GPs were often consulted by their patients for a *second opinion*, discussing treatment options, web advice, or lay views. They saw themselves as someone in whom the patients had confidence, but they could lack the specific knowledge that the patients asked for.

They come to us and ask: he said this and that, what do you think of it? ... It happens because hospitals ... are so fragmented.... This is challenging for the GP, because often we don't know. What we can do is interpret for them, or we can ask. (GP 2)

Tools. Getting hold of a specialist to *ask advice* could be time-consuming. It was easier if GPs personally knew hospital doctors for whom they could ask. Lack of relevant telephone advice when needed could eventually lead GPs to refer patients as emergencies. Most GPs made themselves *accessible* at all hours when their patients were terminally ill, even giving them their mobile numbers. They gave a *comprehensive* bid of services to their patients.

If someone wants to die at home we do everything to make this possible. (GP 13)

The GP as "handyman"

The GP as a practical "handyman" has to handle many kinds of problems, and do so with dexterity. Solutions have to be improvised without delay or, if considered non-urgent, postponed. Time has to be scheduled and shared, manual skills rehearsed or improvised, and heaps of papers sorted out and dealt with. Without the ability to be efficient, GPs would not have the resources to be a mediator or a personal doctor.

Tasks. The GPs saw themselves as the nearest doctor to call in acute deterioration, and also out of hours. As *first aid*, the GPs depended on a good discharge letter. They also acted as primary carers in palliative treatment. Pain relief was not a problem for GPs in this study, and even the youngest, with one year of professional experience, felt safe about the basic principles. Relief of sickness and constipation could be more difficult. They often saw that small efforts could improve quality of life. GPs felt that people with cancer, especially elderly people, often did not want to bother the doctor. They had to be asked directly about complaints.

When I visited her the first time, she was down. With relieving treatment ... she recovered, got her appetite back, started watching "Hotel Caesar" on TV again and bought pads for radio bingo. (GP 10)

The *secretarial* work of the doctor – filling out forms, certificates, and reports – can seem trivial and annoying, but makes a difference, for example, by helping patients and their carers obtain sickness benefits. Many GPs looked on themselves as *team workers*, as part of a "we", e.g. in the terminal phase of the patient's illness. The other team members were the district nurses and, in some cases, cancer nurses and family carers. GPs talked about themselves as members, consultants, or leaders of local teams.

We are working closely together.... During terminal care we are a tight team. I direct what should be done. We rarely use emergency services. (GP 12)

Rural GP surgeries that offer cytostatic treatment, so that their patients do not have to travel to town, can be seen as "*corner shops*": local dispensaries of hospital services. Side effects of cancer treatment given in hospital were often treated locally, also by urban GPs.

Tools. The GP as handyman could carry out a complicated procedure for the first time – *learning by doing*. Pragmatic GPs had to *prioritize* tasks and manage scarce resources. *Planning ahead* was seen as reassuring and preventing the use of out-of-hours emergency services.

If you say that you will come Thursday at three o'clock, it is incredible what can actually wait until then. You avoid the calls and the anxiety. On Fridays you must think about what could happen during the weekend. (GP 2)

The GP as companion

The relationship to the patient was seen as an important part of treatment. To be a companion, the doctor had to know the patient. The personal aspects of doctoring inspired and touched the doctors most deeply. Being a conversational partner concerning matters of life and death was challenging. But listening to other people's thoughts on existence was also seen as a gift, and a way of becoming wiser.

Tasks. From the time of diagnosis onwards, GPs saw themselves as *supporters* for patients and their families. People could lean on their GP when needed.

... you have to look after these patients in a totally different way than ... other patients. They need much more care and support than other diagnostic groups. (GP 6)

GPs can act as a *guide* because they know the patients and their families, the healthcare system and its stations, and they know something about what is ahead of the patient, at a physical, mental, social, and spiritual level.

They knew that I was the one who was going to accompany them, and that I am easy to get hold of, as opposed to a doctor far away. (GP 1)

Not all doctors felt that they were very close to the patient. There could be organizational or personal reasons for this. If they forgot the fundamental *consoling* significance of being a fellow human being, GPs could feel as though they were of little comfort to patients.

Facing such troubles, one feels a little poor. You cannot say things like "It will turn out well".... However, there is generally consolation just by listening to somebody, taking her worries seriously and being a fellow human being. (GP 9)

Tools. Offering time for supportive talks in a busy workday could be a great challenge.

I do take the time, but when patients have such questions at heart, we might spend an hour. Then there are a lot of angry people in the waiting room, and that day is spoilt. (GP 9)

Place of care and place of death are decisions that are both clinical and personal. The GPs wanted, in a given situation, to opt for a solution that meant *respecting the patient's wishes*, sometimes against others' opinions. Many GPs were not so concerned about official guidelines. They emphasized the individual meeting, *adjusting* to the needs of the person and the situation.

This is more about how you meet the patient as a person, but for this there are no guidelines to help you. And that meeting is perhaps the most important of all, when you go into palliative treatment. (GP 5)

Discussion

We asked GPs to recall the stories of whole trajectories of cancer illness, focusing on their own involvement. They could stay close to their experiences and relate what was of importance to them. We assume that GPs in this study, mainly rural practitioners,

have above-average involvement in the care of people with cancer, and can therefore reflect on and point to the opportunities of general practice. Generalization from this study is possible at the level of what *could be* [15]. Our experience is that general practice is practiced with considerable variations.

In our material there was a considerable wealth of information, driven by the informants themselves, on the relational aspects. These were not possible to analyze in full depth within the remit of this paper, which was to grasp the experienced role in its entirety. The GP–patient relationship during illness and dying from cancer therefore merits a separate paper.

All authors are GPs themselves, so professional loyalty is a trap. When doctors and their patients were interviewed separately, some studies highlighted a correlation [16,17], whereas others emphasized communication discrepancies [18]. The patients' voices are not directly heard in this study, and they might have told other stories and valued other aspects of their health care.

The mediating part was central in the GPs' stories. Heath [19] wrote that GPs "must mediate between the patient's subjective experience of illness and the scientific explanation". Such mediation is difficult when the long-recognized lack of communication between levels of health care does not improve [20–24], and GPs have problems with keeping in touch with their patients during and after cancer treatment [3,4,10]. Locally, most GPs saw themselves as part of a team. Teamwork could be the future of palliative care in the community, also including, it is hoped, access to specialist advice when needed.

It is interesting that GPs in our study avoided rushing and wanted to be accessible, although this could mean delays during working hours and working during their spare time. We sensed that the doctors were motivated by the meaning of their work. Patients can be afraid of taking doctors' time away from others who are sicker than they are [25], and both patients and specialists can think that GPs lack time and availability [26]. Out-of-hours emergencies during end-of-life care were, in our study, often solved voluntarily by the patients' own GP [27,28]. This standby during the final weeks of a patient's life was undertaken with no compensation. The GPs were conscious that their personal knowledge and trust could not be replaced by a doctor on duty. By scheduling home visits, they aimed for security and predictability. This can prevent out-of-hours calls and facilitate death at home [29,30].

As GPs are close to patients, family, and community, they are in the position to translate the

impact of disease and its treatment into meaning for people's lives. Having both biographical and biological knowledge of patients, and belonging to both the local community and the healthcare system, the GPs' position is an in-between one. This can be seen as a privileged place that they strive to bridge, but also as a squeezed space [31]. On the one hand, it is dominated by the size and scope of specialized medicine; on the other, there is the nearness to patients, being with them at their most vulnerable moments. Heath [32] reflects: "When the dying patient meets his or her doctor, both individuals are engaged in one of the most difficult tasks they will undertake."

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Ethical approval

The study has been approved by the Regional Committee for Medical and Health Research Ethics of Northern Norway (Ref 200503439-10/IAY/400) and by the Data Inspectorate of Norway (Ref 05/01607-9/CGN).

Competing interest statement

All authors declare that there are no competing interests.

Authors

The original idea for the study came from Holtedahl. All authors discussed the study design. Johansen and Rudebeck developed the protocol and performed the analysis. The article manuscript was written by Johansen, supervised by Rudebeck and critically revised by Holtedahl.

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