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Title

General practitioners' role in shared decision-making about palliative cancer treatment: qualitative study.

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Abstract

Background: General practitioners (GPs) are well-positioned to enhance shared decision-making (SDM) about treatment for patients with advanced cancer. However, to date, little is known about GPs' views on their contribution to SDM.

Aim: To explore GPs' perspectives on their role in SDM about palliative cancer treatment and the preconditions to fulfil this role.

Design and setting: Qualitative interview study among Dutch GPs.

Method: GPs were sampled purposefully and conveniently. In-depth semi-structured interviews were conducted, recorded and transcribed verbatim. The transcripts were analysed by thematic analysis.

Results: Most GPs reported practices that potentially support SDM: checking the quality of a decision, complementing SDM and enabling SDM. Even though most GPs felt that decision-making about systemic cancer treatment is primarily the oncologist's responsibility, they do recognise their added value in the SDM-process because of their gatekeeper position, the additional opportunity they offer patients to discuss treatment decisions and their knowledge and experience as primary healthcare provider at the end of life. Preconditions for supporting the SDM-process were 1) good collaboration with oncologists, 2) sufficient information about the disease and its treatment, 3) sufficient time, 4) a trusting relationship with patients and 5) patient-centred communication.

Conclusion: GPs may support SDM by checking the quality of a decision and by complementing and enabling the SDM-process to reach high quality decisions. This conceptualisation may help understand how SDM is carried out through interprofessional collaboration and provide tools for how to adopt a role in the interprofessional SDM-process.

Keywords: shared decision-making, general practice, qualitative interview study, hospital treatment, cancer

How this fits in:

Shared decision-making is essential for patients with advanced cancer to ensure care that matches patients' values and preferences. This study shows that general practitioners (GPs) fulfil a supporting role in such treatment decision-making by checking the quality of the decision (to be made) and by complementing or enabling SDM. This conceptualisation helps understanding how SDM is – or could be – carried on through relationship-based care and interprofessional collaboration, thereby exposing complexities in interprofessional boundaries. Increased insight in and awareness of GPs' contribution to the decision-making process may render their involvement more conscious, and hence more effective.

INTRODUCTION

Patients with advanced cancer often deal with complex treatment decisions which depend on patients' values and preferences and, hence, require shared decision-making (SDM) (1-3). SDM is the process of decision-making in which the healthcare professional and patient jointly discuss pros and cons of different treatment options as well as patient's values and preferences to come to an agreed-upon treatment decision (3-5). Besides the ethical considerations of patient-centred care and patient autonomy (6), SDM's relevance is underscored by its positive effect on patient outcomes (7-13). Moreover, in the context of palliative cancer care, most patients wish to be involved in making treatment decisions (14-16). Nevertheless, SDM is not always visible in observational studies, which suggest insufficient discussion of patients' values and the option to refrain from disease-targeted treatment (17-20).

It is increasingly recognised that SDM often takes place across multiple encounters with and between different clinicians (21, 22). Although oncologists have expert knowledge about cancer treatment and often make final treatment choices with patients, GPs are well-positioned to enhance SDM and contribute to high quality decisions (23). GPs have continuous relationships with their patients, thereby understanding patients' medical and psychosocial context (24-26). They are accustomed to a holistic approach to health problems and, generally, receive training in effective communication (24). A recent survey among cancer patients showed that the majority appreciates involvement of the GP in cancer care after diagnosis (27). Moreover, GPs' involvement may lead to higher patient satisfaction, e.g. with the decision (28) and with GPs' involvement (29), and may reduce decisional conflict for patients with advanced cancer (30).

While GPs are involved in cancer screening, diagnosis, follow-up and terminal palliative care, they seem to be barely involved in cancer treatment decision-making (25, 29, 31-34). Despite suggestions that GPs should collaborate with oncologists to discuss treatment decisions with patients throughout the palliative phase (35-37), still little is known about how GPs could contribute to SDM about advanced cancer treatment. We set out to explore this from GPs' own perspective. By conceptualising GPs' existing practices in SDM about advanced cancer treatment, we intend to identify ways of strengthening their contribution and ultimately guarantee patient-centred care for people with advanced cancer. Therefore, the aim of this study is to explore GPs' perspectives on their role in SDM about palliative cancer treatment and the preconditions to fulfil this role.

METHODS

Design

Semi-structured, in-depth interviews with GPs were conducted. Data were analysed thematically. This report meets the Standards for Reporting Qualitative Research items (38).

Recruitment

GPs were eligible to participate if they reported experience with advanced cancer patients. We used purposeful and convenience sampling. Eleven participants were recruited through the researchers' network, one through snowballing and three GPs responded to an invitation sent by the Academic Network of GPs of our institute. We aimed for a diverse sample of GPs with respect to gender, work experience, patient population, location (urban/suburban/rural) and type of practice (solo/duo/group practice). Interested GPs were sent information and an informed consent form.

Data collection

The interviews were conducted face-to-face by DB (background in health sciences, i.e. Master of Science in multidisciplinary perspectives on and strategies for complex health issues) and RH (background in medicine) in GPs' consultation rooms. Their different backgrounds combined a conceptual approach to healthcare with practical experience in medicine, which helped refining the interview guide and comprehending the experiences of GPs.

An interview guide was set up (Table 1) and pilot tested with two GPs, resulting in small modifications. The interview started with the participant reading the example case (Table 1) to set the scene to discuss the interview topics. The example case presented a patient diagnosed with advanced stomach cancer considering palliative chemotherapy with a median survival gain of five months. While discussing the GPs' role in the example case, the interviewer probed for general reflections and opinions on the following topics: the current and desired role of GPs in (conversations about) treatment decision-making as well as the preconditions and needs for fulfilling this role. The interviews lasted 30 to 45 minutes and took place between October 2018 and January 2019.

Data analysis

Interviews were audio recorded, transcribed verbatim, anonymised and analysed by thematic analysis (39). Coding was performed using MAXQDA software 2018 and 2020. Our approach was largely inductive; no coding sheet was set up beforehand. Yet, the final categorisation of some (sub)themes was informed, and likely influenced, by the simultaneous analysis of interviews with hospital nurses on their role in SDM about palliative treatment (40). Four interviews were double-coded independently by DB and RH and discussed until consensus was reached. DB and NV (background in medical psychology) repeated this for another four interviews. As coding agreement was high, the consecutive seven transcripts were coded by either DB or NV, who discussed uncertainties until consensus was reached.

During analysis, we did not code the segments that referred to decision-making in settings other than cancer care in the early palliative phase. Data saturation was monitored and considered achieved when no new substantial codes appeared in the final four interviews. A tree of main and subcategories was developed throughout the analysis. Potential overarching themes were refined by DB and IH and the content of these themes was analysed to generate clear definitions and names for each theme (Table 2). Participants received a short summary of the analysis for a member check; twelve GPs responded which resulted in small refinements.

Ethics

Ethical clearance was obtained from the Human Ethics Committee at the Amsterdam UMC, location AMC. Participants signed informed consent forms. Time reimbursement was offered to all GPs.

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RESULTS

Fifteen Dutch GPs from eleven different health centres, representing fourteen different practices located in two provinces surrounding Amsterdam participated (Table 3).

Conversations about treatment decision-making

Most GPs mentioned having conversations with patients about their physical and psychological well-being at several moments throughout the cancer trajectory: before referral and after patients received the diagnosis or other bad news, e.g. disease progression. These latter conversations were mentioned as possible starting points for GP involvement in the SDM-process.

Often, when someone has received bad news, I'm definitely involved. So I get in touch with them and tell them I'd love to drop by and talk to you about this. (...) To hear what you've learned. And whether you've decided for yourself yet?

(GP10)

GPs differed in their opinion on who should initiate such conversations: patients, oncologists or GPs. A main consideration was the importance of tailoring contact to patients' needs, with some GPs awaiting patients' initiative and others contacting patients more proactively. Some GPs mentioned that, during cancer treatment, patients generally did not express needing GP involvement. Occasionally, oncologists actively referred patients to GPs to discuss treatment options.

Only in rare cases, the oncologist goes: talk to your GP about this. Then it's usually in the letter, uhm, and that's of course fine by me. And that's generally to do with me knowing the circumstances just that bit better.

(GP01)

Supporting role

All GPs reported practices that potentially support SDM. We categorised these descriptions into three categories: 1) checking the quality of the decision, 2) complementing SDM and 3) enabling SDM. GPs appear to deploy these strategies to ensure treatment decision-making is conscious, well-informed, and appropriate, i.e. aligned with what matters to patients. This is visualised in Figure 1.

The first category involved practices to check the quality of the decision. GPs mentioned checking patients' choice awareness, information level and/or values and treatment preferences. For example, GPs reported how they queried the patient-oncologist decision-making conversation, tried to gauge patients' understanding of treatment information and probed for patients' thoughts about and expectations regarding the proposed treatment. By doing so, GPs attempted to reveal any hesitations or deficiencies for making a high quality decision.

First, I check, like, what have you been told? What stuck? I ask them, what have you heard from the specialist and what did you understand and can you tell me that in your own words. Sometimes there's a discrepancy already there.

(GP05)

And then with a patient as in this [example] case, of course for myself I want to know a little bit more about, well, how do you feel about this treatment, have you got any doubts, what would be important to you in the near future.

(GP11)

The second category of practices described by GPs involved complementing SDM. This firstly comprised actions to increase patients' choice awareness. For example, GPs mentioned how they explained that a choice needed to be made between different treatment options.

And then I also like to say, as a GP: ok, that may seem like the only option to you, but another option is actually to not do the chemo. Are you aware of that, that that is also an option? To say no?

(GP10)

Additionally, GPs structured, clarified and added information when they noticed patients missed or misinterpreted information provided by the oncologist.

When I notice any doubts, then I'll definitely try to present as honest as possible a picture [of the consequences of the treatment] and explain that no treatment is also an option. And that it doesn't mean they are on their own and that their life will end in suffering.

(GP10)

Lastly, GPs sometimes supported patients' preference construction by exploring patients' values.

One could look more at the bigger picture, like: gosh, what is the meaning of life for you? What is quality of life for you? What do you expect from palliative chemotherapy? What do you expect to happen if you don't get it?

(GP02)

As a third category, GPs were found to enable SDM, i.e. organising additional activities to ensure that the SDM-process will continue beyond GPs' direct involvement. GPs' reports demonstrated how they acted as a patient-oncologist intermediary, aided patient-oncologist contact or helped preparing these conversations.

I have called the oncologist once or twice with, listen, you propose this, but I'm worried. This really is a very vulnerable person, we really shouldn't do this. And to have the specialist say: that's great, thank you for that, that gives me another angle into this conversation.

(GP10)

And if I don't think I can do it [explain information], they just have to make another appointment with the specialist and I will call the specialist to say they have not understood a thing, you have to discuss it again.

(GP07)

Interprofessional SDM: GPs' added value

Although they mentioned many examples of practices that support SDM about advanced cancer treatment, most GPs suggested that – when talking about SDM in abstract terms independent of patient cases – they were hardly involved. Cancer treatment decisions were considered mainly the expertise and responsibility of oncologists. Also, GPs reported that patients were primarily hospital-oriented and GPs only acted upon patient demand.

Usually, I have no say in this [treatment decision-making]. I don't see patients again until after they've made a decision with the oncologist. (...) They hardly ever come to me regarding a decision about whether to start chemotherapy. That's usually beyond my scope.

(GP09)

Moreover, some GPs mentioned being cautious about interfering with hospital treatment decision-making, reflecting their perception of the role boundaries between oncologists and GPs.

If they've even already decided on something with the specialist and started that, then it's a bit like... Well. Meddling in a decision that's already been taken. So you don't go, uhm, causing trouble.

(GP11)

Nevertheless, GPs recognised their potential added value in treatment decision-making and mentioned several reasons for this. Firstly, GPs pointed out their position as gatekeepers for specialised hospital care. GPs presume that their availability and accessibility may result in patients contacting them more easily.

Well, I do think that visiting a GP is an easier step than making a new appointment with a medical specialist in hospital. Many questions patients have, take us one or two phone calls to answer or ease their minds, whereas to see a medical specialist they need to make another appointment, another trip to hospital, waiting rooms, and you name it.

(GP05)

Moreover, in their view, GPs' longstanding relationship with patients enabled them to better tailor conversations about decisions by accounting for patients' medical history and social context, as compared to oncologists.

But I also think that a GP is better qualified to check certain motives, more so than a specialist would. Think of certain aspects, like, what will family think of specific decisions?

(GP14)

Secondly, GPs indicated that their involvement offers patients an additional opportunity to deliberate on their treatment decision, which possibly lowers the sense of urgency and emotional load that may be present shortly after diagnosis. This way, patients have time to let the news settle and think about questions regarding treatment options.

Of course, it's a very tense conversation, a bad news consultation like that. It often means decisions need to be made at short notice. I think the whole setting itself makes it difficult, where, once patients hear the word 'cancer', they miss out the rest of the conversation. So I think it's definitely a good idea to have a second conversation about it.

(GP07)

Thirdly, in the Netherlands, GPs become the primary healthcare provider in later stages of palliative care. Some GPs pointed out that because of their specific expertise in this phase, they are able to help patients to anticipate the care offered if they would choose to refrain from life-prolonging treatment or when no further life-prolonging treatment options exist.

Then I'll also discuss my part in that [terminal phase], as in, what can I do for you. (...) I can make you as comfortable as possible, that's my part. So with regard to pain control, chest tightness, nausea, things like that, weight loss, to respond to that as well as possible. To me, that's my role as GP, to guide them in this, but definitely also to state very clearly what other options may be, or how I may help at home, outside of hospital.

(GP10)

As medical generalists, GPs indicated that they may be less focused on treating the disease than oncologists, thereby providing more space to consider refraining from disease-targeted treatment.

Well, I also explain a little, like... We ask a specialist to do what's possible, but not everything that's possible may be beneficial. (...) That is pretty much the specialist's tunnel vision: we provide treatment. Where we [GPs] come in from the angle of: what is good for you?

(GP04)

Multiple GPs mentioned that being involved in early palliative treatment decision-making also helped intensifying the relationship with the patient in preparation for the terminal phase.

Really, from the moment of diagnosis I make sure I keep in touch by calling now and then. And over time you see that contact intensifies slightly. And at a certain point, someone's treatment is exhausted and they're handed over to me. And I try to not make that moment the first time I see them and have to work up a plan.

(GP01)

Preconditions and needs

In the interviews, GPs identified four preconditions for their involvement in cancer treatment decision-making. First, good collaboration with oncologists was considered key for more and valuable

involvement of GPs. Many GPs indicated that insight into patient-oncologist conversations and adequate reporting of such conversations would be helpful.

Yes, I think I'd like to know more about that [treatment decision-making] process and what is discussed, because you get the idea people get a more positive image than I have. (...) I get the idea people think: now I'm cured. While I think: well yes, you got a stay of execution.

(GP09)

In their view, GPs' limited knowledge of and experience with cancer and cancer treatment restricted their contribution to decision-making. Some GPs mentioned the risk of providing patients with incorrect information. Information from oncologists about the diagnosis, treatment and prognosis was considered helpful, which we categorised as a second precondition.

But I notice, I'm not really trained to know: what chemotherapy, which side effects, life expectancy at which kind of metastatic cancer. But I'd certainly benefit from knowing that.

(GP08)

As a third precondition, multiple GPs mentioned the importance of having sufficient time to engage in conversations about treatment. Having ample time would reduce a sense of pressure and help building trust.

It's a conscious choice to visit someone at 5 p.m. And that's what I tell them: I'd rather not come around lunch time, because I'll have to rush and only have 10 minutes or 20 maybe. And this is not an in-between conversation, so I'll come by around 5 and we can discuss this at length.

(GP03)

Fourthly, a trusting relationship was mentioned as essential. GPs indicated having high quality contact and pre-existing relationships with patients was important for supporting patients emotionally, comforting them and building foundations for trust. According to some, relationship building helped discussing patient values and weighing these.

So you can say: gosh, you've had some really bad news. I know you've always... You've always said I want to turn 100 and how do you feel about that now?

(GP07)

Lastly, patient-centered communication was considered a precondition. GPs mentioned needing skills to adapt conversations to multiple patient characteristics such as patients' level of acceptance of their imminent death, health literacy and spirituality. The ability to set aside personal preconceptions and conversing neutrally and unprejudiced were also regarded necessary, to prevent influencing patients' decision-making process.

But I think the most important thing is just no taboos. Being open to discuss everything and really listen. Don't give your own interpretation of what would I do, if... But really hear what the patient's fear or need is. I think that's the most important thing. And then see if you can somehow combine that in such a way that you actually let patients answer that question [what to do] themselves.

(GP02)

DISCUSSION

Summary

General practitioners involved with incurable cancer patients report practices that potentially support SDM: checking the quality of the decision, complementing SDM and enabling SDM. Even though most GPs feel that decision-making about systemic cancer treatment is primarily the oncologist's responsibility, they do recognise their added value to interprofessional SDM. They referred to their accessibility and continuous relationship with patients, the additional opportunity they offer patients to discuss treatment decisions and their expertise as primary healthcare provider in the terminal phase. Reported preconditions for an optimal supporting role in SDM were a good collaboration with oncologists, sufficient information about the patient's disease and its treatment, sufficient time, a trusting relationship with patients and patient-centred communication.

Strengths and limitations

The qualitative design helped gaining an in-depth understanding of the experiences of GPs. By using an example case as conversation starter for the interview, we attempted to clearly focus the discussion on the early palliative phase and decisions about disease-targeted treatment. However, using this case could have unwarrantedly funnelled participants' responses in parts of the interview. GPs did not know the reason for the patient's visit nor the progress of the decision-making process, which may have caused them to initially express more hesitance when discussing their contribution to SDM. Moreover, despite data saturation, the research might have benefited from the inclusion of a more diverse range of GPs. For example, most GPs were employed in urban areas and indicated having strong affinity with palliative care, which may have affected their views.

Comparison with existing literature

In line with our findings, other literature reports that GPs' involvement in caring for people with advanced cancer is common (31-34) and perceived as valuable (23, 27, 37). Descriptions of involvement include practices that may support SDM, for example by clarifying diagnoses and adverse treatment effects and acting as an intermediary between patients and medical specialists (25, 35, 41). However, many such descriptions were not put in the context of SDM nor explicitly identified as supporting SDM. This study adds an in-depth description of Dutch GPs' perspectives regarding their role in the treatment decision-making process of advanced cancer patients. Moreover, our findings identified an additional type of GP involvement: checking the quality of a treatment decision. This seems to be an important intervention to discover patients' hesitations and/or needs and it puts GPs in a monitoring role. The conceptualisation of GPs' role in SDM helps understanding how SDM is carried on through, first, relationship-based care and, second, interprofessional collaboration.

GPs mentioned that a continuous longstanding relationship with patients enables them to support their patients in decision-making after a cancer diagnosis. In terms of Haggerty et al.'s (26) categorisation of continuity, GPs mentioned the importance of elements of so-called relational continuity, i.e. the "ongoing therapeutic relationship between a patient and one or more providers", as well as informational continuity, i.e. the "use of information on past events and personal circumstances to make current care appropriate for each individual", and management continuity, i.e. the "consistent and coherent approach to the management of a health condition that is responsive to a patient's changing needs". All types of continuity of care present in family medicine seem to facilitate a supporting role on SDM about cancer treatment.

The results also show that GPs make an important contribution to interprofessional SDM. Although oncologists have decisional responsibility, GPs may help identify patients' decisional needs and ensure that these are responded to. Previously, we interviewed hospital nurses about their role in SDM about life-prolonging treatment and extracted similar categorisations of SDM support (40). Although the role of nurses and GPs is not identical, their role may be regarded as a 'decision coach' (42): "the health professional who is trained to support the patient's involvement in healthcare decision-making but who does not make the decision" (22). The importance of cooperating healthcare professionals for reaching high quality decisions is stressed by Légaré et al. (22, 43), who proposed an interprofessional model of SDM in which multiple healthcare professionals, among whom a decision coach, are involved in the SDM-process. Our findings in both the hospital nurses and GPs study show that already involved healthcare professionals may take on the role of decision coach without the need for involving extra healthcare professionals.

GPs did seem to struggle with interprofessional boundaries: who is responsible for and should be involved in which part of the collaborative SDM-process. This may possibly explain some of the preconditions mentioned, such as good collaboration with oncologists and having adequate information about the disease and its treatment. In addition, it may explain the experienced discomfort with 'meddling' in the decision-making as GPs need to negotiate the tension between ensuring the quality of decisions, while at the same time preventing unnecessary doubts and confusion. The importance of collaboration between healthcare professionals was confirmed in a study evaluating the effect of actively facilitating GP-patient conversations about the treatment decision. These conversations were often realised only after the decision in the hospital had already been made, and – possibly as a consequence – decreased rather than raised patient-perceived SDM (44).

Implications for research and/or practice

There is a growing body of evidence on the GPs' role in cancer patients' care and on interprofessional collaboration. In order to adopt an interprofessional model of SDM in advanced cancer care and stimulate its implementation, future research should explore the perspectives of oncologists, patients and caregivers on the supporting role of GPs in SDM. For investigating the generalisability of the current study findings on GPs decision support, it would be valuable to examine if these also apply to decisions in non-oncological and non-palliative care settings, as well as to other geographical areas and other healthcare systems, with no universal coverage and/or gatekeeper system (45).

The proposed conceptualisation of how GPs can support SDM helps understanding how SDM could be administered through relationship-based care and interprofessional collaboration. In order to improve this collaboration and facilitate GPs' involvement, 'time out conversations' (TOCs), i.e. proactively organised patient-GP conversations about cancer treatment decisions, show promising results (30, 44, 46). Besides, training GPs effectively in SDM support may increase insight in and awareness of GPs' contribution to the decision-making process. This may render their involvement more conscious and hence more effective, thereby safeguarding high quality, i.e. conscious, informed and appropriate, treatment decisions for patients with incurable cancer.

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ETHICAL APPROVAL

In line with the Medical Research Involving Human Subjects Act, the Medical Ethical Committee of Amsterdam UMC, location AMC provided written exemption for the study from the requirement to seek formal approval (reference number W18_268 # 18.312).

COMPETING INTERESTS

None.

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References

1. Epstein RM, Street RL. Patient-centered communication in cancer care. US Department of Health and Human Services; 2007.
2. Elwyn G, Frosch D, Rollnick S. Dual equipoise shared decision making: definitions for decision and behaviour support interventions. *Implement Sci.* 2009;4:75.
3. Legare F, Witteman HO. Shared decision making: examining key elements and barriers to adoption into routine clinical practice. *Health Aff (Millwood)*. 2013;32(2):276-84.
4. Charles C, Gafni A, Whelan T. Shared decision making in the medical encounter: What does it mean? (Or it takes at least two to tango). *Social Science & Medicine*. 1997;44(5):681-92.
5. Stiggelbout AM, Pieterse AH, De Haes JC. Shared decision making: Concepts, evidence, and practice. *Patient Educ Couns.* 2015;98(10):1172-9.
6. Gulbrandsen P, Clayman ML, Beach MC, et al. Shared decision-making as an existential journey: Aiming for restored autonomous capacity. *Patient Educ Couns.* 2016;99(9):1505-10.
7. Hack TF, Degner LF, Watson P, Sinha L. Do patients benefit from participating in medical decision making? Longitudinal follow-up of women with breast cancer. *Psychooncology*. 2006;15(1):9-19.
8. Weeks JC, Cook EF, O'Day SJ, et al. Relationship between cancer patients predictions of prognosis and their treatment preferences. *JAMA*. 1998;279(21):1709-14.
9. Shay LA, Lafata JE. Where is the evidence? A systematic review of shared decision making and patient outcomes. *Med Decis Making*. 2015;35(1):114-31.
10. Brown R, Butow P, Wilson-Genderson M, et al. Meeting the Decision-Making Preferences of Patients With Breast Cancer in Oncology Consultations: Impact on Decision-Related Outcomes. *Journal of Clinical Oncology*. 2012;30(8):857-62.
11. Kane HL, Halpern MT, Squiers LB, et al. Implementing and evaluating shared decision making in oncology practice. *CA: A Cancer Journal for Clinicians*. 2014;64(6):377-88.
12. Kehl KL, Landrum MB, Arora NK, et al. Association of Actual and Preferred Decision Roles With Patient-Reported Quality of Care: Shared Decision Making in Cancer Care. *JAMA Oncol*. 2015;1(1):50-8.
13. Austin CA, Mohottige D, Sudore RL, et al. Tools to Promote Shared Decision Making in Serious Illness: A Systematic Review. *JAMA Intern Med*. 2015;175(7):1213-21.
14. NFK. Samen belissen over de kankerbehandeling: Hoe ervaren patiënten dat? Utrecht: Nederlandse Federatie van Kankerpatiëntenorganisaties; 2018.
15. Brom L, Pasman HR, Widdershoven GA, et al. Patients' preferences for participation in treatment decision-making at the end of life: qualitative interviews with advanced cancer patients. *PLoS One*. 2014;9(6):e100435.
16. Belanger E, Rodriguez C, Groleau D. Shared decision-making in palliative care: a systematic mixed studies review using narrative synthesis. *Palliat Med*. 2011;25(3):242-61.
17. Henselmans I, Van Laarhoven HW, Van der Vloodt J, et al. Shared decision making about palliative chemotherapy: A qualitative observation of talk about patients' preferences. *Palliat Med*. 2017;31(7):625-33.
18. Brom L, De Snoo-Trimp JC, Onwuteaka-Philipsen BD, et al. Challenges in shared decision making in advanced cancer care: a qualitative longitudinal observational and interview study. *Health Expect*. 2017;20(1):69-84.
19. Koedoot CG, de Haan RJ, Stiggelbout AM, et al. Palliative chemotherapy or best supportive care? A prospective study explaining patients' treatment preference and choice. *British Journal of Cancer*. 2003;89(12):2219-26.
20. Koedoot CG, Oort FJ, de Haan RJ, et al. The content and amount of information given by medical oncologists when telling patients with advanced cancer what their treatment options are. palliative chemotherapy and watchful-waiting. *Eur J Cancer*. 2004;40(2):225-35.

21. Rapley T. Distributed decision making: the anatomy of decisions-in-action. *Sociol Health Illn.* 2008;30(3):429-44.
22. Legare F, Stacey D, Pouliot S, et al. Interprofessionalism and shared decision-making in primary care: a stepwise approach towards a new model. *J Interprof Care.* 2011;25(1):18-25.
23. NHG. NHG-standpunt oncologische zorg in de huisartsenpraktijk. Utrecht: Nederlands Huisartsen Genootschap; 2014.
24. de Wit NJ. A "time out consultation" in primary care for elderly patients with cancer: Better treatment decisions by structural involvement of the general practitioner. *Eur J Cancer Care (Engl).* 2017;26(3).
25. Dahlhaus A, Vanneman N, Guethlin C, et al. German general practitioners' views on their involvement and role in cancer care: a qualitative study. *Fam Pract.* 2014;31(2):209-14.
26. Haggerty JL, Reid RJ, Freeman GK, et al. Continuity of care: A multidisciplinary review. *BMJ.* 2003(327):1219-21.
27. Noteboom EA, Perfors IAA, May AM, et al. GP involvement after a cancer diagnosis; patients' call to improve decision support. *BJGP Open.* 2020.
28. Wallner LP, Abrahamse P, Uppal JK, et al. Involvement of Primary Care Physicians in the Decision Making and Care of Patients With Breast Cancer. *J Clin Oncol.* 2016;34(33):3969-75.
29. O'Toole E, Step MM, Engelhardt K, et al. The role of primary care physicians in advanced cancer care: perspectives of older patients and their oncologists. *J Am Geriatr Soc.* 2009;57 Suppl 2:S265-8.
30. Wieldraaijer T, de Meij M, Zwaard S, et al. Introducing a time out consultation with the general practitioner between diagnosis and start of colorectal cancer treatment: Patient-reported outcomes. *Eur J Cancer Care (Engl).* 2019;28(6):e13141.
31. Mitchell GK, Burrige LH, Colquist SP, Love A. General Practitioners' perceptions of their role in cancer care and factors which influence this role. *Health Soc Care Community.* 2012;20(6):607-16.
32. Jiwa M, McManus A, Dadich A. The impact of knowledge, attitudes and beliefs on the engagement of primary and community-based healthcare professionals in cancer care: a literature review. *Curr Med Res Opin.* 2013;29(11):1475-82.
33. Campbell NC, MacLeod U, Weller D. Primary care oncology: Essential if high quality cancer care is to be achieved for all. *Family Practice.* 2002;19(6):577-8.
34. Demagny L, Holtedahl K, Bachimont J, et al. General practitioners' role in cancer care: a French-Norwegian study. *BMC Res Notes.* 2009;2:200.
35. Beernaert K, Van den Block L, Van Thienen K, et al. Family physicians' role in palliative care throughout the care continuum: stakeholder perspectives. *Fam Pract.* 2015;32(6):694-700.
36. Green E, Knight S, Gott M, et al. Patients' and carers' perspectives of palliative care in general practice: A systematic review with narrative synthesis. *Palliat Med.* 2018;32(4):838-50.
37. Wind J, Nugteren IC, van Laarhoven HWM, et al. Who should provide care for patients receiving palliative chemotherapy? A qualitative study among Dutch general practitioners and oncologists. *Scand J Prim Health Care.* 2018;36(4):437-45.
38. O'Brien BC, Harris IB, Beckman TJ, et al. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med.* 2014;89(9):1245-51.
39. Braun V, Clarke V. Thematic analysis. *APA handbook of research methods in psychology, Vol 2: Research designs: Quantitative, qualitative, neuropsychological, and biological* 2012. p. 57-71.
40. Bos-van den Hoek DW, Thodé M, Jongerden IP, et al. The role of hospital nurses in shared decision-making about life-prolonging treatment. A qualitative interview study. *Journal of Advanced Nursing.* 2020.
41. Halkett GK, Jiwa M, Lobb EA. Patients' perspectives on the role of their general practitioner after receiving an advanced cancer diagnosis. *Eur J Cancer Care (Engl).* 2015;24(5):662-72.
42. Stacey D, Murray MA, Legare F, et al. Decision Coaching to Support Shared Decision Making: A Framework, Evidence, and Implications for Nursing Practice, Education, and Policy. *Worldviews on Evidence-Based Nursing.* 2008;5(1):25-35.

43. Stacey D, Legare F, Pouliot S, et al. Shared decision making models to inform an interprofessional perspective on decision making: a theory analysis. *Patient Educ Couns*. 2010;80(2):164-72.
44. Perfors IAA, Noteboom EA, de Wit NJ, et al. Effects of a time out consultation with the general practitioner on cancer treatment decision-making: a randomised controlled trial: Time out with the general practitioner and cancer treatment decision. *Psychooncology*. 2020.
45. Faber MJ, Burgers JS, Westert GP. A sustainable primary care system: lessons from the Netherlands. *J Ambul Care Manage*. 2012;35(3):174-81.
46. Noteboom EA, de Wit NJ, van Asseldonk I, et al. Off to a good start after a cancer diagnosis: implementation of a time out consultation in primary care before cancer treatment decision. *J Cancer Surviv*. 2020;14(1):9-13.

Figure 1. Three strategies for supporting shared decision-making (SDM)

Note: this Figure represents the three strategies that general practitioners (GPs) may deploy to reach high quality decisions. That is, a decision that is 1) conscious, i.e. the decision is made consciously, the patient is aware of the choice, 2) informed, i.e. the decision is made fully informed, the patient is knows the various possibilities and their pros and cons, and 3) appropriate, i.e. the decision aligns with patients' values and preferences (1, 2). The strategies for supporting shared decision-making (SDM) include 1) checking the quality of a decision, i.e. asking questions to check if there are any hesitations or deficiencies for making a high quality decision, 2) complementing SDM, i.e. adding to the SDM-process by for example introducing the choice, clarifying information and supporting preference construction, and 3) enabling SDM, i.e. organizing additional activities to ensure that the SDM-process will continue beyond GPs' direct involvement.

References

1. Elwyn G, O'Connor A, Stacey D, et al. Developing a quality criteria framework for patient decision aids: online international Delphi consensus process. *Bmj*. 2006;333(7565):417-0.
2. Stacey D, Murray MA, Legare F, et al. Decision Coaching to Support Shared Decision Making: A Framework, Evidence, and Implications for Nursing Practice, Education, and Policy. *Worldviews on Evidence-Based Nursing*. 2008;5(1):25-35.

Table 1. Topic guide

A. Short introduction to the interview	
	Introducing interviewer and research
	Explaining confidentiality and anonymity
	Signing informed consent
	Asking permission for audio taping
B. Substantive part of the interview	
	<p>Presentation of a case of an incurable cancer patient who had to decide on treatment with a life-prolonging intent:</p> <p><i>“Pieter de Vries, aged 74, is single, has two daughters and one grandson. He lives on an outside farm. His wife died a few years ago. He has been dizzy for some time and has little appetite. He also lost a lot of weight. After two visits to the GP, he was referred to the hospital and received bad news last week. He has stomach cancer, with metastases to the bones. The same week he had a conversation with the medical oncologist about treatment. He is eligible for palliative chemotherapy (CapOx). The median survival without chemotherapy is 6 months; with chemotherapy 11 months. Chemotherapy has side effects, including nausea or vomiting, fatigue, diarrhoea, tingling or numbness of the fingers and feet, hand-foot syndrome (redness, chapping).”</i></p>
	Current role and ideal role for involvement in treatment decision-making
	Current and desired role
	Position with respect to other health professionals
	Goals in conversations with patients
	Steps or actions to reach these goals
	Involvement in four steps of SDM (i.e., 1) informing about decision, 2) explaining options with pros and cons, 3) discussing preferences and supporting deliberation, 4) making decision (5)).
	Added value of conversation with GP
	Moments for conversation
	Stimulating and restraining factors for fulfilling role
	Needs for fulfilling role
C. Conclusion of the interview	
	Issues that were not addressed

Table 2. Layout of the categories resulting from the thematic analysis

Involvement of GPs in the SDM-process	Involvement during patients' treatment in the hospital	
	Moment for conversation with patient about treatment decision	
	Initiative for the GP-patient conversation	
Added value of GPs in the SDM-process	Unique position of GP in healthcare system	
	Additional and different conversations about treatment	
	Building a close relationship in anticipation of the terminal stage	
Supporting role of GPs in the SDM-process	Checking the quality of a decision (high quality decision: conscious, informed and appropriate)	Checking choice awareness
		Checking if decision is informed
		Checking if decision is aligned with patient's values
	Complementing SDM (adding to the decision-making process to reach a high quality decision)	Raising choice awareness
		Clarifying and adding information
		Exploring values and supporting preference construction
	Facilitating SDM (organizing activities to ensure reaching a high quality decision)	Acting as a patient advocate
		Preparing upcoming conversations with the oncologist
Preconditions and needs for fulfilling a role in the SDM-process	Cooperation with oncologist	
	Insight into conversation between patient and oncologist	
	Knowledge and experience with cancer and treatment options	
	Relationship with patient	
	Time	
	Communication with patient	

Table 3. Participants' characteristics

	(n=15)
Years of experience (mean*, range)	17.4 (4-30)
<10 years	4
10-20 years	4
>20 years	7
Gender	
Male	6
Female	9
Patient population	
Origin	
Mixed	11
Mostly native-born	2
Mostly foreign-born	2
Age group	
Younger than average	5
Average	5
Older than average	5
Type of practice**	
Type	
Solo	3
Duo	8
Group	4
Location	
Rural	2
Suburban	8
Urban	5
Affinity with palliative care***	
High	8
Average	6
Low	1

* Mean age of the study participants.

** GPs worked in fourteen different practices; two GPs worked at the same practice.

*** Combined score of received training on palliative care (yes/no) and indicated affection with palliative care (yes/no); indicating having both was scored as high affinity, having either one was scored as average affinity and having none was scored as low affinity with palliative care.