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General practitioners' perceptions of their role in cancer follow-up care: A qualitative study in the Netherlands

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ABSTRACT

Background: In the last few decades there has been a considerable increase in the number of cancer survivors. Health policy makers would like to see cancer follow-up care moved from secondary to primary care. **Method:** Between 2008 and 2010, a qualitative study among primary health care professionals was performed to get more insight into the way they care for cancer survivors. Analysed was whether a coordinating role in cancer survivorship care would fit in with the practical logic underlying the way the general practitioners work. **Results:** In their everyday work, general practitioners are used to provide care in a reactive way. Based on this habitus, they classify their patients into 'not special' and 'special' ones. Since general practitioners label cancer survivors as 'not special,' they expect these patients to take the initiative to ask for help and present their complaints in a clear and complete way. Their habitus as a gatekeeper implies that they are reticent about referring patients to other primary health care professionals. In regard to 'not special' patients, such as cancer survivors, general practitioners appear to build on the patients' own strengths. **Conclusion:** The emphasis on a wait-and-see attitude in contemporary Dutch general practice, as well as the general practitioners' role as a gatekeeper are at odds with the proactive and holistic approach inherent to a coordinating role in cancer follow-up. Therefore, we assume that it will be difficult for general practitioners to shape a pivotal role in this care.

- The practical logic of the general practitioners' work is at odds with proactively exploring the needs of patients who are not perceived as 'special' patients.

- As cancer survivors are not considered 'special' patients, it can be questioned whether general practitioners are ready to fulfil a pivotal role in cancer survivorship care.

INTRODUCTION

The increase in successfully diagnosing and treating cancer has led to a steady rise in the number of patients who survive cancer as well as in cancer patients' life expectancy over the last few decades (2–5). Despite this positive development, research demonstrates that cancer survivors experience a decrease in their quality of life (6–7). Pain and fatigue symptoms or depression, as well as sexual problems, prevent many from regaining an acceptable quality of life after the initial treatment. The rise of the number of cancer survivors and awareness of the considerable impact of cancer treatment on patients' quality of life went hand-in-hand with the recognition of the 'chronic' nature of cancer. This is expressed in the growth of the number of professionals specialized in cancer survivorship care (especially paramedics, psychologists, social workers and specialized nurses).

In the Netherlands, policy makers have argued that—when aiming at optimal support for people in the 'stable, chronic phase'—after initial treatment only one health care professional should be responsible for care coordination. In 2007 the Dutch Health Council, in its report 'Follow-up care in oncology' (8), recommended handing over the coordinating role, which is currently often fulfilled by the medical specialist after initial treatment, to the general practitioner. The Health Council's advice was not only motivated by the necessity to reduce the pressure on secondary care, but was also based on the assumption that general practitioners are sufficiently skilled to detect symptoms of relapse and metastases in time and are also better equipped to keep more of an eye on the 'residual complaints' that impact cancer survivors' quality of life than medical specialists are. Moreover, it was expected that general practitioners can adequately refer cancer survivors to other professionals, such as paramedic professionals, psychologists, social workers and specialized nurses for additional aftercare, because of their short lines with these professionals.

Traditionally, the Netherlands has a strong primary care system, in which the general practitioner has always held a key position. In 1959, the position of the general practitioner was described as 'accepting responsibility for the continuous, integral and personal care of individuals and families entrusted to him' (9). This description has maintained its meaning. The definition from the 'Future Vision for General Practitioner Care 2012' (10) characterizes general practitioner care as 'generalistic and contextual health care, with its greatest strength in easy accessibility and provision of continuity of care for people in their own environment.' This position might offer an ideal opportunity for a more prominent role of general practitioners in cancer follow-up care. After simply following cancer patients in the period in which they are undergoing specialized treatments, general practitioners could actively resume and coordinate health care at any given moment after treatment. Then cancer follow-up care could easily be suited to the needs, not only of the individual cancer survivor but also of his or her family and social network. However, research among cancer survivors, in the Netherlands (6,11) as well as internationally (12–19), has

revealed that after cancer treatment patients have more faith in their medical oncologist. Doubts about presumed positive effects of the general practitioners' activities in cancer follow-up seem to be related to lack of confidence in the specific expertise of general practitioners to identify recurrences, as well as chronic fatigue following cancer treatments, or social problems, such as the struggles with returning to work and re- establishing family balance.

In the study presented here (1,20), the aim is to answer the question whether the suggested proactive and holistic approach in cancer survivorship care would fit in with the everyday practice of the general practitioners. To that end, general practitioners were interviewed, as well as other primary health care professionals to see how they would assess the general practitioners' appropriateness for such a pivotal role. To interpret and understand professionals' perceptions of cancer survivorship care, Bourdieu's concepts of 'practical logic' and 'habitus' were used. Bourdieu (21) introduced the concept of the logic of practice to emphasize that acting is not a matter of rational decision-making or pursuing conscious goals, but a product of automatic behaviours. He argued that implicit assumptions structure the way in which action takes place. His notion of habitus refers to a system of taken-for-granted beliefs, which form the ultimate source of professionals' values. As habitus is a product of history and earlier experiences, it functions as 'the strategy-generating principle enabling agents to cope with unforeseen and ever-changing situations (22, p. 72).' Different researchers have already shown how medical professionals are led by the mechanism of 'practical logic' (23,24). It has been argued that in performing their daily tasks, professionals act upon a perception of the world as it were a matter-of-fact. Their habitus generates a kind of implicit, but 'common sense' behaviour that determines the way they perceive, value, think and act. Insight in the way professionals define problems, their ideas about solving the problems that spring from these definitions, and the implicit perceptions regarding their tasks and responsibilities sheds light on whether or how specific care or care for specific patients would fit in with their habitus.

In this study is analysed how care for cancer survivors would fit in with the 'habitus,' the everyday work of general practitioners.

Method

The research, a qualitative empirical study among primary care professionals, was conducted between September 2008 and April 2010. A qualitative approach was deemed the most suitable since the goal was to identify perceptions, assumptions and experiences that constitute the professional habitus, to assess whether this habitus would leave room for the required work with cancer survivors (25,26). The participants' own perspective using their own words and concepts were studied.

Selection of participants

In total, 53 primary care professionals participated in this study. In-depth interviews were conducted with 35 primary care professionals (of whom 11 general

practitioners); 18 others (of whom four general practitioners) participated in an online focus group discussion. In addition, other primary health care professionals (paramedics, psychologists, social workers, and specialized nurses) were involved in the study to explore their perception on professional responsibilities in cancer survivorship care and on a potential key position of general practitioners within that care.

Participants were recruited via contacts at the Integrated Cancer Centres (ICCs) and via websites of professional associations. They were informed about the research in advance, by telephone and in writing. Professionals from all parts of the Netherlands and with different backgrounds participated to get a wide and varied picture: male and female professionals of various ages, early career and more experienced professionals, professionals working in cities and rural areas, and professionals working in small and large health care practices and organisations. Professionals especially trained for cancer follow-up care or with a special interest in this group of patients were interviewed, as well as professionals without this special expertise or interest.

Data collection

Interviews. The first author (EG) together with one other member of the research group conducted the interviews. The in-depth interviews were semi-structured; all participating professionals were presented with comparable questions. To learn more about their practical logic, we first asked them to talk about how they practised their profession. By allowing them to speak about their daily practice, we were able to detect the conventional 'rules' of their profession, their implicit expectations for their patients, their professional values, their perceptions of their tasks and responsibilities as professionals, and their ideas about cooperating with other professionals. Second, we spoke with them about cancer survivors and cancer survivorship care and about how they defined 'good' or 'ideal' care in this context, and what challenges they experienced in their current care for cancer survivors. (We deliberately did not focus on the general practitioners' care for patients in the initial phase of cancer, nor for those in the palliative phase; 'good' or 'ideal' care might be defined differently in these contexts.) The other primary health care professionals were explicitly asked to reflect on the practical logic of the general practitioners: did they confirm the ideas of the general practitioners and recognize their way of providing care to cancer survivors? There were many opportunities during the interviews for the individual participants to elaborate on specific experiences and circumstances and give examples from their own practice. The interviews lasted 60–90 min on average. Audio recordings were made, which were then transcribed verbatim.

Focus groups. In the online focus group, 18 participants were asked to reflect on the preliminary results of the research and explicitly embarked on a discussion with one another in response to questions and statements. The responses of this group confirmed the findings from the in-depth interviews. All respondents are quoted anonymously in the following description of the results.

Data analysis

After a process of reading and rereading the interview transcripts and verification with the literature, the following concepts, relevant to primary health care and cancer follow-up care, arose:

- images of patients/cancer survivors,
- professional responsibilities towards patients/ cancer survivors,
- communication with patients/cancer survivors and other professionals,
- organization of care,
- perceptions regarding 'good' care, and
- perceptions regarding the needs of patients/ cancer survivors.

The first two authors (EG and AK) independently identified the patterns and themes of the interviews. In conversations with the last author (MvdA), the initial analysis was refined and further developed. Together, similarities and differences in the professionals' perspectives were looked for, within as well as between the professions involved.

In this article, only results of the analysis of interviews with the general practitioners are presented. The analysis of interviews with other primary care professionals confirmed these results; therefore, the results of interviews with the other primary care professionals are not presented separately.

Results

When talking about their everyday work with the general practitioners, their wait-and-see attitude and demand-driven approach was the first thing that struck us. In their work, they not only seemed to expect their patients to ask for help themselves, but to give a complete and clear presentation of their complaints as well. Another aspect of the general practitioners' practical logic we became aware of during the interviews, was the reticence to refer patients to paramedics, psychologists, social workers, and specialized nurses. In their care for cancer survivors, the general practitioners seemed to build on the patients' own strength.

Assuming cancer survivors' initiative to ask for help

The general practitioners justified the approach of 'functioning as a service desk' (GP A) by referring to the low threshold, which characterizes standard general practitioner care in the Netherlands. As this general practitioner said:

In our practice we have a low threshold, and we do see people coming when things are not going well. (GP A).

This basic logic of waiting for patients to approach them, seemed to be linked to a distinction they made between 'not special' patients, from whom they reasonably expected that they would ask for care themselves when something was wrong, and

'special' patients, who, according to them, would need more systematic proactive attention. Although the general practitioners defined cancer as a disease that can have long-term effects and make a great impact on people's quality of lives and that of their next of kin, they did not deem cancer survivors to be special enough to warrant proactive attention as soon as they were declared 'cancer-free' after treatment. This did not mean that the general practitioners denied that patients still have a long way to go after a cancer treatment and that they live with 'the sword of Damocles having over them' (GP J); they especially emphasized that:

there are so many important diseases that cancer no longer receives a particularly significant label. (GP J)

Illustrative for their approach of cancer survivors was the low number of 'social visits' the general practitioners said they paid to these patients. While it had previously been common to visit regularly someone who had gone through cancer treatment, in current practice this seemed to be no longer the case:

When after curative treatment all tumour cells have been removed and a patient has had radiation treatment, I think "in principle everything is okay." I read the letter of the medical specialist, but I do not contact these persons. (GP D)

Most general practitioners we spoke to did not express concerns that their reactive approach might fall short of their patients' needs. Some of them seemed to doubt whether they always could assume that 'no news' meant 'good news' and whether cancer survivors were really 'not special' patients. These general practitioners now and then called these patients by telephone, or, just 'coincidentally,' visited them at home unannounced:

I tried to visit someone today, I was in the neighbourhood, and I thought "I have not seen her in a while." Then, I went and had a look, but she was not at home. (...) that is not structured; it is more of a coincidence. (GP B)

One of the general practitioners, however, really showed feelings of discomfort about the way she provided care for patients, such as for instance cancer survivors, who had faced a difficult period. She explained how she 'resolved' her struggles:

I always say that they should call if they need me, and then I will come, something like that. Well, that is of course very vague, I have noticed that it is no longer sufficient. (...) So I have to discuss it much more explicitly, in terms of, what do you need from me, and what can I offer you, and make compromises. (GP K)

This 'solution,' however, also shows the power of the general practitioner's habitus: the fact that her patients had to say themselves when and how they wanted care implies that 'good' care relied on the initiative of the patient and on the need the patient indicated.

Despite of these doubts about a reactive approach of cancer survivors, none of these general practitioners seemed to see any reason to change the way of giving care to

cancer survivors. First, they wondered whether proactive, systematic cancer follow-up care would meet patients' needs, as a general practitioner said:

I think people are not waiting for such regular visits, they will experience it as patronising to have to present themselves at specific times. After treatment most cancer patients have had enough of visiting doctors. (GP F)

Second, the general practitioners argued that the huge variety of the trajectories cancer survivors may go through would make it impossible to organize standardized proactive cancer follow-up care in the way it is done for patients with other chronic diseases, such as diabetes mellitus, COPD, and heart failure, for which special consultations or care programmes exist. A general practitioner explained this as follows:

There are great differences in the course of the different types of cancer and follow-ups, yes, really depend on the type of cancer (...) to be honest, you can't talk about one specific, sharply defined group of patients; that makes it much more complicated than for instance diabetes follow-up care. (GP D)

Third, low efficiency was seen as a disadvantage of systematic cancer follow-up care, by among others, this general practitioner:

I think you can come up with many issues where the general practitioner could be more proactive, but you need to weigh up the profits against the time it would cost; time that is no longer available for issues that need more attention. I do not have high expectations of organized control, and prefer to leave it up to the patients as to how they would like to receive care. (GP J)

In their struggles about how to provide cancer survivors with 'ideal' care, some of the general practitioners came up with an alternative to proactive cancer follow-up care organized by themselves. They suggested appointing a specialized oncology nurse employed between secondary and primary care, or a nurse practitioner in their own general practice. They, however, immediately gave a comment on these suggestions: a nurse could never cover all aspects of care. According to the general practitioners, medical care, whether offered reactively or in the form of a systematic cancer follow-up, must always be provided under the responsibility of a doctor.

Assuming cancer survivors' initiative to raise problems of a sensitive nature

With respect to achieving ideal care for the whole person—'integral, holistic care'—it is noticeable that the general practitioners' habitus was to address cancer survivors' own initiative, as well. From the interviews, it became clear that for instance, although it was no news to general practitioners that partner relationships can be strongly affected when one of the two has had cancer as it takes its toll on sexual relations (especially after mastectomy, after treatment for cervical cancer, or for people with a stoma), most of them would not explicitly ask cancer survivors about these issues. As an alternative, some general practitioners, offered those patients

whom they suspected of suffering from psychological or social problems, the opportunity to talk about those problems at the end of the consultation.

It is taken up in your routine communication: "and how are you doing in general, are there things that you would like to ask or say?" There is a standard sentence to conclude each consultation, just to check that we covered everything. That gives the patient an explicit opportunity to mention things. If there is something, then that is also dealt with. Look, if I literally ask them and they do not say anything, then I can do no more. (GP J)

This quote demonstrates the doctors' strive for the ideal of integral, holistic care and the willingness to help his patients with the challenges that they were facing. However, as a general practitioner being able to help truly, patients, cancer survivors included, will have to present all aspects of their complaints themselves. For cancer survivors, this means that attention for sexual, as well as psychological or social problems succeeds or fails depending on their own willingness and options to present their problems clearly.

Building on cancer survivors' own strengths

As 'gatekeepers of health care,' general practitioners self-evidently felt responsible to 'keep patients away from some of the 'nonsense'' (GP E). When discussing their attitude of non-referring for specialized aftercare, it became clear that the general practitioners' habitus to practice a wait-and-see policy in case of 'non-special' patients, generated a strong belief that for cancer survivors outside the professional medical circuit, a lot could be gained. When cancer survivors consulted them, next to physical examination, eventually complemented by specific tests to exclude relapses or metastases, general practitioners particularly encouraged them to live a 'normal' life as much as possible. They considered recovery after cancer as a process, which patients have to go through themselves. Assuming that 'it is good when people can stand on their own two feet' (GP E), and that, 'as a doctor, one cannot solve all patients' problems' (GP I), general practitioners implicitly built on the strength of patients to take responsibility for their own recovery. Illustrative for this was the general practitioners' strong belief that, instead of promoting the physical exercise programmes defined by physical therapists, 'doing sports, walking, singing, or playing the trumpet could do a lot of good' (GP E). In the same vein, a dietician was seen as unnecessary, as long as 'people eat "responsibly," or, to regulate their weight, just eat more or eat less' (GP E).

In line with the articulated feelings of uneasiness about their reactive approach towards cancer survivors described in the preceding paragraph, some of the general practitioners reported that they felt uncomfortable about their poor referrals to other professionals for cancer aftercare. They struggled with the question whether they could expect that all cancer survivors, just like the many other 'not special' patients they saw, were able to put their lives back on the tracks without specialized treatment. However, their 'no-nonsense' approach was legitimized by stating that after the busy and heavy period of cancer operations, chemotherapy, and radiation, people would prefer not to be cared for, for a while. Next to this assumption, general

practitioners supposed that also cancer survivors' partners had to be protected as their whole life had revolved around cancer as well:

That man said, "we have no life; we do nothing else than go to the hospital or drive to group therapy. We have been doing that for years, I cannot even hear the word cancer anymore". I think people become so psychologically attached to cancer. (GP G)

From the point of view that general practitioners assumed cancer survivors' own responsibility, it is not strange that many of them lacked the knowledge of various specific possibilities that other professionals can offer to improve the lives of these patients and help them to regain their strength faster. In line with their habitus as a gatekeeper, they do not see the need exploring these specific possibilities.

DISCUSSION

Main findings

The analysis in this study makes clear that the implicit matter-of-factness of the wait-and-see (reactive) attitude and demand-driven (service-desk-oriented) working method of general practitioners inspires, which patients they see as 'not special,' and which as 'special'. The general practitioners—against the background of a great number of chronic patients in their practice—do not consider patients who have been able to tolerate cancer treatment as 'special.' On the contrary, they emphasize that these patients are 'normal' (chronic) patients; therefore, they should offer them 'normal,' thus reactive, care. 'Not special' patients have to 'work' to get good care: they have to come forward themselves and articulate their problems as completely and clearly as possible. The enterprising patient, therefore, not only has a strong advantage, but also fulfils the necessary condition for receiving truly 'good' care.

In addition, the analysis shows that the general practitioners' habitus of gatekeeper generates an attitude to keep health care in their own hands as much as possible. Emphasizing the cancer patient's own strengths and their preference to stay away from professional health care for a while, agrees with the image that the general practitioners have of these patients, namely that of 'not special' patients, who do not need special attention or specialized aftercare.

Not all general practitioners were really satisfied about the way they offered care for cancer survivors. Some, for example, struggled with the question whether the problems that these patients are often faced with, physically, as well as psychologically or socially, are sufficiently addressed in the consultation room. Others doubted if their reticent attitude of referring to other professionals could be seen as 'optimal' care for cancer survivors. The practical logic of their work, however, made it difficult for them to explore proactively, which additional care someone needs. This implies that general practitioners consider cancer survivors' own initiative and own responsibility as core characteristics.

Based on interviews with the professionals involved in this study, concluded is that the practical logic of the current general practitioner working method does not fit well with the expected habitus of the cancer follow-up coordinator as formulated by the Dutch Health Council.

Comparison with existing literature

Doubt about the pivotal role of general practitioners in cancer survivorship care is confirmed by existing international studies in countries that also aimed to place general practitioners in key positions for cancer follow-up care, such as Norway, Great Britain, Canada and the United States. Research among general practitioners has shown that there may be a willingness to take on more responsibility in cancer survivorship care but that the conditions necessary for this are considered far from optimal (27–33). From these studies, it has emerged that continuation of secondary cancer care to primary cancer survivorship care raises problems due to general practitioners' lack of knowledge about the unique problems of the different types of cancer, the chronic effects of pain, and about the psychosocial aspects of cancer in the phase in which patients are 'cancer free.' While in many of these studies, it is suggested to arrange education for general practitioners, and make care plans in which their responsibilities in the cancer follow-up are formalized, following our conclusions, we would state that these solutions will not be sufficient for general practitioners having a key position in cancer survivorship care. We consider that such a position would require a transformation of the general practitioners' habitus.

Strengths and limitations

The research was conducted on a small scale. This drawback was overcome by ensuring a great variety of backgrounds of the participating general practitioners. This has resulted in a varied picture of perspectives and experiences of general practitioners. Despite the relatively small number, the point of saturation was reached. That is to say, at a certain moment, no new findings were extracted from the interviews, and we can assume that justice is done to the perceptions, assumptions and experiences of general practitioners regarding cancer survivors and cancer survivorship care. Qualitative research does not aim to generalize, but rather to generate new insights.

Lacking in this study was the habitus of the cancer survivors. It might have been interesting to analyse the tensions between the habitus of these patients and of the general practitioners; it would have sharpened the conclusions. Including cancer survivors, however, went beyond the context of this project.

Reflecting on the relationship between theory, method and analysis, it would have been appropriate to use participatory observations as part of the method. Observations, however, would have been too cumbersome. In the analysis, therefore, the professionals' practical logic was deduced from their accounts of their 'normal' way of working, of cancer survivors and the way they cared for these patients.

Implications for the organization of primary care

Traditionally, general practitioners fulfil a pivotal role in health care. They are the first point of contact for patients with questions or problems about their health, and they know their patients' histories like no other. Retention of this identity, even when it concerns cancer follow-up care, demands a change in the health care system. Current developments in Dutch general practitioner care in the direction of the demand-driven approach imply an increasing reactive attitude of general practitioners, and that is at odds with the coordinating role of general practitioners for cancer follow-up care. That role demands actively maintaining relations with patients, taking the initiative to discuss problems openly and organize help. Moreover, a good 'pivot' must maintain active relations with other professionals to know where to send their patients for further care. Good coordination should occur according to what the philosopher Mol calls the 'logic of care' (34). Mol has criticized the ideal of the active patient making his or her own personal choice that dominates current health care practices in The Netherlands. Instead of leaving the initiative up to the patients, she has argued, physicians should enter into a dialogue with their patients. Just by exchanging stories, patients' needs, experiences and ideas can be explored and 'good' care be started up. What that 'good' care is, is not given, but the result of the search for it together with the patients.

Conclusion

The analysis in this study suggests that the practical logic of the current general practitioner working method of the demand-driven approach, as well as the gatekeeper habitus of general practitioners, will make it difficult to fulfil a pivotal role in cancer follow-up care. The question remains if this can be solved within the current organization of the general practitioner practice. It will be a challenge to design systematic follow-up within primary care in the future.

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