ORIGINAL ARTICLE

Does the organizational structure of health care systems influence care-seeking decisions? A qualitative analysis of Danish cancer patients' reflections on care-seeking

RIKKE SAND ANDERSEN¹, PETER VEDSTED¹, FREDE OLESEN¹, FLEMMING BRO¹ & JENS SØNDERGAARD²

¹The Research Unit for General Practice, Research Center for Cancer Diagnosis in Primary Care – CaP, Department of Public Health, University of Aarhus, Aarhus, Denmark, and ²Research Unit of General Practice, Department of Public Health, University of Southern Denmark, Odense, Denmark

Abstract

Objective. The absence of a more significant improvement in cancer survival in countries such as the UK and Denmark may be partly rooted in delayed care-seeking among cancer patients. Past research on patient delay has mainly focused on patient characteristics (e.g. sociodemographic and psychological factors and symptom recognition) as causes of delayed care-seeking, while few studies have examined how the organizational structure of health care systems may influence patients' reflections on seeking care. The aim of this study was to explore this relationship. **Design.** The analysis presented is based on semi-structured interviews with 30 cancer patients and their families. **Results.** The article raises two hypotheses on the relationship between structural elements of a health care system and people's reflections on seeking health care: (1) Gatekeeping introduces an asymmetrical relationship between the patient and the GP which potentially results in self-restricting care-seeking, (2) Continuity in the doctor–patient relationship may negatively influence patient reflections on access to health care, as the focus shifts from the medical issues of the consultation to reflections on how to properly interact with the GP and the system in which she/he is situated. **Conclusion.** It is concluded that these hypotheses form a sound basis for further primary care research on how the organizational structure of health care systems influences patient reflections on access to medical care.

Key Words: Cancer, care-seeking, health care systems, patient delay

Worldwide, Denmark has the highest incidence of cancer and compared with countries with similar health care expenditures it is doing poorly in relation to both survival and mortality [1,2]. A large study based on data from 1995 to 2007 concluded that Denmark, together with England, Northern Ireland and Wales, has persistently lower survival rates than countries such as Australia, Canada, Norway, and Sweden [3]. A number of studies have attempted to explain the reasons behind these inter-country differences in cancer survival and mortality, and differences in *time to diagnosis* have repeatedly been pointed to as one of the main culprits leading to poor survival rates [1,2,4]. Overall, it has been suggested that Danish cancer patients are at a later

stage in their cancer disease when diagnosed [5]. Research exploring *time to diagnosis* has traditionally been divided into studies on “patient delay” and “provider delay”, where provider delay refers to the waiting times for which health care systems can be made accountable. Patient delay refers to the period from the patient first experienced his/her cancer symptoms and until he/she sought care. While research on patient delay has mainly focused on patient characteristics (e.g. sociodemographic and psychological factors and symptom recognition) as causes of delayed care-seeking [6–8], a few studies have suggested that GP-related factors may be a barrier to care-seeking [9,10]. It has been shown that negative attitudes towards the GP potentially

Few studies have focused on the relation between care-seeking decisions and health care systems.

- Organizational aspects of health care systems, exemplified by the structuring principles of gatekeeping and the list system, provide a certain context for interaction between the GP and the patient, which influences patient reflections on access to health care.
- Merely focusing on the patient in order to understand care-seeking decisions draws attention away from issues such as power and social control in the clinic and from wider societal issues such as the economic and organizational aspects of health care.

influence the time of care-seeking [9], and a recent English study identified “worries about wasting the doctor’s time” as a main barrier to care-seeking [10]. While these studies indicate that care-seeking decisions are rooted in a complex interaction between patient, doctor, and system factors they reveal only sparse information on the wider context of interaction or how it may influence reflections on access to health care.

We know from disciplines such as anthropology and sociology that health care systems form a basis for the development of specific practices and cultural assumptions in relation to care-seeking [11–13]. That is, the organizational structures of health care systems influence social practices and cultural assumptions (“what can be said and done”) and to some extent define the fields of possible action (e.g. care-seeking decisions). Moreover, while large amounts of research have documented positive effects of strong front-line care systems, such as e.g. the Danish gatekeeper system [14–16], a recent study showed that gatekeeper systems have a significantly lower one-year cancer survival than health care systems without such functions (Vedsted et al., *In Press*). The UK, and Denmark which both have comprehensive gatekeeper and list systems, demonstrate significantly poorer performance on cancer than countries such as Sweden or Canada, which have adopted less stringent gatekeeper and list systems. So far, it can only be hypothesized how such structures influence care-seeking decisions. However, in order to further lay the ground for future research on the context-based mechanisms governing care-seeking decisions the aim of this article is to do just that. In the following we present two hypotheses on the relationship between health care organizations and care-seeking decisions

Material and methods

Our study is based on semi-structured interviews with 30 cancer patients and their families. In order to obtain a wide range of information and perspectives, we selected informants according to gender, age, and cancer diagnosis. Recruitment was done through relevant hospital oncological departments. Here, potential informants received written information concerning the study immediately after they had been informed of their cancer diagnosis and gave verbal permission that we could contact them by phone, provide further information, and invite them to participate in an interview. To give the patients time to discuss potential interview participation with a spouse or another relevant family member and for ethical reasons, we waited two to three days before calling to make the final invitation. The interviews took place in the informants’ homes and were carried out according to ethnographic principles for open-ended questions, meaning that informants were encouraged to speak freely and to raise issues of importance to them, or also if the issues went beyond the themes in the topic guide [17]. The interviews were conducted by anthropologist RSA according to a guide in which we attempted to assess aspects of the informant’s wider social situation, and obtain detailed descriptions of symptom experiences and former illness experiences. In addition informants were asked in detail about their relationship with their general practitioner, and how the decision to consult a health professional had finally been made.

We followed ethnographic principles of analysis, meaning that the analytic process was not a confined process undertaken separately from reviewing literature, interviewing, coding, interpreting, and writing; that is, both inductive and deductive approaches were used [17,18]. A variety of organizational aspects influencing how patients perceive access to health care could be distinguished [19]. As the aim of this article is to raise a number of hypotheses and make suggestions for future research, however, we focused our analysis on the issues of gatekeeping and the list system, as they were both key categories in our data material, and are central structuring principles of the Danish health care system. Moreover, the interview excerpts presented in the article are based on patients’ statements only. The overall assumptions driving the analytical presentation are, however, based on all our material, including interview statements from family members.

Setting

The Danish health care system is a gatekeeper system with a comprehensive list system. GPs are self-employed on a contract basis with the Regions, and

all Danes [98%] are registered with a particular practice. As gatekeepers, the GPs are responsible for initial assessment and referral of patients to hospital or outpatient clinics for work-up and treatment when medically relevant [20].

Results

Hypothesis one: Gatekeeping

Our material suggests that the power structure introduced by the principle of gatekeeping in the clinic influences how patients reflect on access to health care. It has been pointed out that, in order to understand how power works in social organizations, we must acknowledge that power is an aspect of all relations [21]. Because of their role as gatekeepers the GPs are the most powerful in the doctor–patient relationship. They possess access to knowledge and medical technology, which means that the patient participates in an asymmetrical relationship, which is potentially restricting. This is obvious in the experiences of Brad, a 61-year-old man who had been diagnosed with malignant melanoma. Asked to reflect on care-seeking decisions related to his malignant melanoma, he said:

I have always known that I was at risk of this. I have bright skin and red hair, and as a kid I often got sunburnt. Already in the 1970s I talked to my GP about it, and he did once refer me to a specialist. But then, well, then I stopped talking to him [the GP] about it, because, I must admit, I got the feeling that it was stupid of me. I think he thought I was just plain silly. Instead of referring me he once gave me a brochure showing me what to look for. "You have many 'seeds'", he said. What the hell are seeds, I thought? I never found out.

The power of the GP lies in the fact that most patients feel bound to accept the judgement of the GP. Based on the information obtained from Brad, it is difficult to say whether he should have been referred for further investigations at an earlier stage. The point, however, is not normative in the means of exploring whether what the GP did was "right or wrong". Rather, the case is presented in order to illustrate that the GP *qua* his position as a gatekeeper is bound to balance between medical judgements, economic constraints, and the needs expressed by patients [22,23]. The role of the gatekeeper is to select those who will enter and those who will not. As illustrated in the case of Brad, this is a position that potentially brings the GP into a situation in which he risks eroding the patient's trust in the health care system. This is equally illustrated in the case of Paul, a 68-year-old heavy smoker who had been diagnosed with lung cancer.

When I first showed up, I was coughing up mucus – it was so bad, I tell you. Then he started giving me all these pills and stuff. "No", I said to him, "you need to send me to the hospital, this is no good". Instead he [the GP] just told me to quit the cigarettes, and said that he could not hear anything when listening to my chest. That was no good. I figure that when you go to the doctor, he can help you. But I lost trust in him. I thought he knew what he was doing.

Both Brad and Paul thus expressed reluctance to seek care due to the restrictions they experienced regarding the referral practices of their GPs. As stated by Brad:

I really would have liked it if my GP had just said that I should have them [the moles] properly checked every two years or so. But that was never an issue. Instead I got the feeling that one should not go to the doctor all the time.

Hypothesis two: The list system

Similar to other studies, we observed a recurring issue of "not wanting to fuss over small things" and "not wanting to disturb the doctor" [9]. This, we will argue, may be due to the fact that when reflecting on seeking care, patients are also in a process of managing relationships with their GPs. In this manner, we suggest that continuity, as established through the list system, influences patients' reflections on care-seeking. This is illustrated in the case of Sue, a 45-year-old woman with malignant melanoma:

I always think that I do not want to fuss over small things, and then, you know, I do not want to bother the GP with unnecessary stuff. Sometimes when I leave the clinic, knowing that there was nothing wrong it makes me feel a bit silly for taking up his time. I think this really influences how I think about calling and making an appointment.

Like other informants, Sue reported that she was very pleased with her doctor, but concerned about how to legitimize her visit without compromising his time or his professional judgement of her. Informants continually stated that "one should not go to disturb the doctor for just anything" and they always presented a line of arguments in defence of their decisions to consult. A young woman, Hanne, aged 33 and diagnosed with malignant melanoma stated that:

Well, I really like her – she was the one who actually told me to have my melanoma checked. She was quick. But sometimes she is too busy. Sometimes when I show up with my child, maybe

she has been crying all night, and her ears hurt. Then I get a little remark on that – “that it is nothing”. I know that she is not mad at me, but at all the others that come for nothing. But still, it makes you think of when to go and when not to go. And I do not want to go for just any little thing.

When considering issues such as time, and whether they are misusing the time of their GPs, patients are to some extent managing relations with their GP. Thus it could be argued that continuity in the doctor–patient relationship (as primarily established through the list system) potentially influences patient reflections on access to health care, as the focus shifts from the medical issues legitimizing care-seeking to reflections on how to properly interact with the GP and the system in which he/she is situated.

Overall, the cases illustrate that the meeting between the doctor and the patient is framed by a set of structural elements. Referral practices as they are established by the gatekeeping system and continuity as established by the list system create a particular form of interaction, potentially affecting any participant in the system, whether health care professional or patient, and which therefore feeds into patients’ reflections on care-seeking.

Discussion

Two hypotheses are raised: (1) Gatekeeping introduces an asymmetrical relationship between the patient and the GP which potentially results in self-restricting care-seeking; (2) Continuity in the doctor–patient relationship (as primarily established through the list system) influences patient reflections on access to health care as the focus potentially shifts from the medical issues of legitimizing care-seeking to reflections on how to properly interact with the GP and the system in which she/he is situated. Patients’ reflections on care-seeking thus happen in a complementary role structure with GPs as well as with the wider structure of health care system.

Health care systems based on gatekeeping and list systems like the Danish one were established in past times when access to health care was simpler and more linear in its structure. Public procurement of health technologies was more limited than it is today, and private health insurance had not yet challenged the public monopoly on health care delivery. This, combined with the fact that health care systems in general have been influenced by a market and an individual rights discourse, has paved the way for a changing patient role [24]. The modern patient is often described as being less authoritative and more consumer-oriented, and as one who feels obliged to

be active in seeking care, asking questions, and collaborating in the care process [24]. Such changes condition how patients and health care systems interact, and how patients come to perceive access to health care. The necessity of gatekeeper systems with comprehensive list systems is often underscored by three arguments: a need to ensure that patients receive appropriate care, a need for demand management and cost control, and a need for justice in distributing health care [22,25]. Our material, however, indicates that there might be a gap between how patients define appropriate care and how they think of the GP’s role in managing and distributing equal health care. Such a gap may result in various forms of self-restricting care-seeking and loss of trust and confidence in the system. As illustrated in the cases presented, this meant that some patients initiated negotiations with their GP on access to further investigations and some decided to see the GP less. As well as influencing care-seeking decisions, gatekeeper and list systems may thus enhance inequality in health care [22], potentially feeding into larger discussions on social inequality in health care delivery.

Moreover, comprehensive list systems such as the Danish one support continuity as a central component of general practice, placing focus on the importance of the doctor–patient relationship in the diagnostic process [26,27]. This coincides with more ideological aspects of general practice, where doctors are viewed as being committed to persons more than to diseases and where proper treatment is ideally based on long-term relationships integrating social as well as psychological aspects into the diagnostic process [28,29]. In general, continuity has proved positive in many aspects [30,31]. It has been argued that continuity overall improves the chances of a positive outcome of GP–patient consultations and improves patient satisfaction [15]. Moreover, a recent Danish study illustrated that patients have a need to feel attached to their GP [32]. As illustrated, continuity as established by the list system may, however, have unintended side effects in relation to care-seeking decisions, as some patients worry if their decision to seek care is legitimate. As illustrated in the above, and in other studies [9], not wanting the GP to think of them as “hypochondriacs” is a potential barrier to care-seeking. This, we will argue, indicates that when deciding to seek care people are not only influenced by considerations of potential illness but are also in a process of managing the relationship with their GP.

Are continuity and gatekeeping, then, mixed blessings? Large amounts of research have documented positive effects of strong front-line care systems [14,15], and the arguments brought forward here are

not placed in order to denigrate such findings. It is probably possible to identify both beneficial and adverse effects of all kinds of health care organizations. Moreover, the examples presented in this article naturally simplify what determines care-seeking decisions and interaction in general practice. The point is, however, that merely focusing on the patient in order to understand care-seeking decisions draws attention away from issues such as power and social control in the clinic, but also wider societal issues such as the economic and organizational aspects of health care. Moreover, the traditional conceptualization of “patient” and “provider delay” attributes responsibility at the level of the individual, neglecting the fact that the actions of patients and providers are intermittingly related – an aspect which has only briefly been touched upon in the “delay literature” [33]. In order to further improve our understanding of care-seeking decisions and what causes “delay”, it could therefore be argued that we need to integrate a wider range of contextual elements in our analysis.

Patient interviews, which formed the basis of our analysis, pose a line of limitations when approaching organizational analysis. Patient interviews are representations of patient experiences and they do not fully allow us to go beyond the individual perspective and to take account of the implications that the wider organisational structure has for care-seeking decisions [34]. Moreover, a study of care-seeking decisions is a study of meaning-making and practice, which further adds to the limitations of the interview method. First of all, the story of “what really happened” might not easily be elicited in an interview. As particularly noticed by Bourdieu a good deal of informants’ behaviour is accomplished unthinkingly and unknowingly, because the logic of social life is implicit and often taken for granted [35]. In interviews we only access the verbalized, retrospective stories of what happened. Second, the stories about and the meanings of certain events are potentially established in the interview situation, as being asked to reflect on what happened naturally brings forth connections and interrelatedness which might not have been there at the time of action [36]. Having been given a cancer diagnosis may, in other words, restructure how people in retrospect experienced interaction with the GPs. In order to learn more of how health care systems structure care-seeking, it would be fruitful to conduct prospective ethnographic field studies; observing GP–patient interactions, interaction and information-sharing between primary and secondary care, and interviewing GPs and other staff. A more prospective approach inspired by organizational theories would help us to explore the organizational logics or the culturally preferred patterns guiding interaction and influencing how patients perceive access to health care.

Ethics

According to the Central Denmark Region Committees on Biomedical Research Ethics, the Act on a Biomedical Research Ethics Committee System and the Processing of Biomedical Research Projects does not apply to this project, as the project does not involve the use of human biological materials (jr.nr:73/2007).

Funding

The study is funded by the Novo Nordisk Foundation and performed at the Danish Cancer Society and Novo Nordisk Foundation’s Centre for Research in Cancer Diagnosis in Primary Care.

Conflict of interests

The authors declare no conflict of interests.

References

- [1] Storm HH, Engholm G, Hakulinen T, Tryggvadottir L, Klint A, Gislum M, et al. Survival of patients diagnosed with cancer in the Nordic countries up to 1999–2003 followed to the end of 2006: A critical overview of the results. *Acta Oncol* 2010;49:532–44.
- [2] Olesen F, Hansen RP, Vedsted P. Delay in diagnosis: The experience in Denmark. *Br J Cancer* 2009;101:S5–S8.
- [3] Coleman M, Forman D, Bryant H, Butler J, Rachet B, Maringe C, et al. Cancer survival in Australia, Canada, Denmark, Norway, Sweden, and the UK, 1995–2007 (the International Cancer Benchmarking Partnership): An analysis of population-based cancer registry data. *Lancet* 2010;377:127–38.
- [4] Berrino F, Verdecchia A, Lutz JM, Lombardo C, Micheli A, Capocaccia R. Comparative cancer survival information in Europe. *Eur J Cancer* 2009;45:901–8.
- [5] Storm HH, Dickman PW, Engeland A, Haldorsen T, Hakulinen T. Do morphology and stage explain the inferior lung cancer survival in Denmark? *Eur Respir J* 1999;13:430–5.
- [6] Macleod U, Mitchell ED, Burgess C, Macdonald S, Ramirez AJ. Risk factors for delayed presentation and referral of symptomatic cancer: Evidence for common cancers. *Br J Cancer* 2009;101:S92–S101.
- [7] Hansen RP, Olesen F, Sorensen HT, Sokolowski I, Sondergaard J. Socioeconomic patient characteristics predict delay in cancer diagnosis: A Danish cohort study. *BMC Health Serv Res* 2008;8:49.
- [8] Tromp DM, Brouha XD, de L, Jr., Hordijk GJ, Winnubst JA. Psychological factors and patient delay in patients with head and neck cancer. *Eur J Cancer* 2004;40:1509–16.
- [9] Scott SE, Grunfeld EA, Auyeung V, McGurk M. Barriers and triggers to seeking help for potentially malignant oral symptoms: Implications for interventions. *J Public Health Dent* 2009;69:34–40.
- [10] Robb K, Stubbings S, Ramirez A, Macleod U, Austoker J, Waller J, et al. Public awareness of cancer in Britain: A population-based survey of adults. *Br J Cancer* 2009;101:S18–23.
- [11] Pappas G. Some implications for the study of the doctor–patient interaction: Power, structure, and agency in the works of Howard Waitzkin and Arthur Kleinman. *Soc Sci Med* 1990;30:199–204.

- [12] Strong PM. The ceremonial order of the clinic: Parents, doctors and medical bureaucracies. London, Boston and Henley: Routledge & Kegan Paul; 1979.
- [13] Shilling C. Culture, the "sick role" and the consumption of health. *Br J Sociol* 2002;53:621–38.
- [14] Freeman GK, Olesen F, Hjortdahl P. Continuity of care: An essential element of modern general practice? *Fam Pract* 2003;20:623–7.
- [15] Hjortdahl P, Laerum E. Continuity of care in general practice: Effect on patient satisfaction. *BMJ* 1992;304:1287–90.
- [16] Starfield B. Is primary care essential? *Lancet* 1994;344:1129–33.
- [17] Emerson RM, Fretz RL, Shaw LL. Writing ethnographic fieldnotes. Chicago: University of Chicago Press; 1995.
- [18] Hammersley M, Atkinson P. Ethnography: Principles in practice. London: Tavistock Publications; 1983.
- [19] Ahmed A, Fincham JE. Physician office vs retail clinic: Patient preferences in care seeking for minor illnesses. *Ann Fam Med* 2010;8:117–23.
- [20] Vedsted P, Olesen F, Hollnagel H, Bro F, Kamper-Jørgensen F. *Almen lægepraksis i Danmark* [in Danish] [Danish General Practice]. 1st ed. København: Tidsskrift for Praktisk Lægegerning; 2005.
- [21] Hayward C, Lukes S. Nobody to shoot? Power, structure, and agency. A dialogue. *Journal of Power* 2008;1:5–20.
- [22] Willems DL. Balancing rationalities: Gatekeeping in health-care. *J Med Ethics* 2001;27:25–9.
- [23] Grumbach K, Selby JV, Damberg C, Bindman AB, Quesenberry CJ, Truman A, et al. Resolving the gatekeeper conundrum: What patients value in primary care and referrals to specialists. *JAMA* 1999;282:261–6.
- [24] Nordgren L. The performativity of the service management discourse: "Value creating customers" in healthcare. *J Health Organ Manag* 2008;22:510–28.
- [25] Halm EA, Causino N, Blumenthal D. Is gatekeeping better than traditional care? A survey of physicians' attitudes. *JAMA* 1997;278:1677–81.
- [26] Guthrie B, Wyke S. Personal continuity and access in UK general practice: A qualitative study of general practitioners' and patients' perceptions of when and how they matter. *BMC Fam Pract* 2006;7:11.
- [27] Hjortdahl P. General practice and continuity of care: Organizational aspects. *Fam Pract* 1989;6:292–8.
- [28] Levenstein JH, Mccracken EC, McWhinney IR, Stewart MA, Brown JB. The patient-centred clinical method, 1: A model for the doctor–patient interaction in family medicine. *Fam Pract* 1986;3:24–30.
- [29] Olesen F, Vedsted P. Family medicine should redefine its essential attributes: Affirmative position. In: Buetow S, Kenealy T, editors. *Ideological debates in family medicine*. 1st ed. Hauppauge, NY: Nova Science Publishers; 2007. p 13–23.
- [30] Turner D, Tarrant C, Windridge K, Bryan S, Boulton M, Freeman G, et al. Do patients value continuity of care in general practice? An investigation using stated preference discrete choice experiments. *J Health Serv Res Policy* 2007;12:132–7.
- [31] Freeman G. Continuity of care in general practice: A review and critique. *Fam Pract* 1984;1:245–52.
- [32] Frederiksen HB, Kragstrup J, Dehlholm-Lambertsen B. Attachment in the doctor–patient relationship in general practice: A qualitative study. *Scand J Prim Healthcare* 2010;28:185–90.
- [33] Facione NC. Delay versus help seeking for breast cancer symptoms: A critical review of the literature on patient and provider delay. *Soc Sci Med* 1993;36:1521–34.
- [34] Stein HF. The role of some nonbiomedical parameters in clinical decision making: An ethnographic approach. *Qual Health Res* 1991;1:6–26.
- [35] Bourdieu P. *The logic of practice*. Cambridge: Polity Press; 1980.
- [36] Kvale S. *The qualitative research interview: A phenomenological and a hermeneutical mode of understanding*. *J Phenomenological Psychology* 1993;171–96.