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Patients' confidence in their GP before and after being diagnosed with cancer

Abstract

Background
General practice plays an important role in the cancer care pathway. The initial diagnostic phase may be crucial for the relationship between the patient and the GP.

Aim
The aim was to describe whether patients' confidence in their GP changed after a cancer diagnosis, and analyse whether the change in confidence was associated with doctor delay.

Design and setting
Population-based cohort study with 1892 questionnaires sent to patients and their GPs in general practices in the former Aarhus County, Denmark.

Method
Information on patients' confidence in their GP was obtained from the patient questionnaire. Information on doctor delay was obtained from the GPs and defined as a period of 14 days or more from the date of first symptom presentation to the GP until cancer-specific investigation was initiated.

Results
Before the cancer diagnosis, 88.4% of the patients had confidence in their GP, which decreased to 80.0% after the diagnosis ($P<0.001$); 15.8% of the patients who experienced no doctor delay reported a decrease in confidence after the cancer diagnosis, compared with 29.1% of the patients with a doctor delay ($P<0.001$). Patients presenting with alarm symptoms and experiencing doctor delay were 3.8 times more likely to lose confidence compared with those presenting with alarm symptoms who experienced no doctor delay ($P = 0.048$).

Conclusion
The majority of the patients had high levels of confidence in their GP before, as well as after, the cancer diagnosis. Nevertheless, a substantial amount had low confidence in the GP, especially when experiencing doctor delay in the initial phase of the pathway.

Keywords
early detection of cancer; general practice; trust.

INTRODUCTION

Approximately a third of a population gets cancer during a lifetime, and many more people will present at some point in their lives with signs that could be symptoms of cancer. The incidence and prevalence of cancer have increased in the Nordic countries during the last decades and will continue to do so in the years to come.[1] As such, early detection, treatment, follow-up, and rehabilitation of patients with cancer are major issues in both primary and secondary health care.[2]

In countries with a healthcare system based on comprehensive primary care and general practice as gatekeeper and first point of contact, the GP is often involved in the cancer diagnosis and in the post-treatment period. Hence, in Denmark, GPs are involved in the diagnosis of 85% of all patients with cancer,[3] and 90% of all patients with cancer visit their GP within 1 year of treatment.[4] Similar results are found in other countries;[5,6] this implies that the GP plays an important role in the entire cancer care pathway, from early symptoms through follow-up, survivorship, or palliation.[7,8]

An important prerequisite for GP involvement in the cancer care pathway is the patient's confidence in the GP's professional skills and clinical judgement. It is well known that dealing with cancer symptoms in general practice is complex, especially because of low positive predictive values and a high number of non-specific symptoms.[9] These challenges may extend the interval between the patient's first presentation of symptoms to the GP and the GP's initiation of a cancer-specific investigation — an interval that is also referred to as doctor delay. International findings indicate that factors such as the GP's knowledge of the patient and the GP–patient relationship are associated with the patient's confidence in the GP, and that problems with obtaining a referral to specialist care can undermine the patient's confidence in the GP.[10,11] However, it is not known whether doctor delay affects patients' trust in their GP.

The aim of this study was to describe whether cancer patients' confidence in their GP changed after a cancer diagnosis, and to analyse whether doctor delay was associated with the change in confidence.

METHOD

Study design

A population-based cohort study was carried out, based on questionnaires being sent to incident patients with cancer and their GPs (details are available from the authors). The study was set in the former Aarhus County, Denmark, which had 640 000 inhabitants and approximately 3000 new cancer cases per year.

Denmark's publicly funded healthcare system provides free access to general practice and hospital care. More than 98%

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How this fits in

The GP plays an important role in the early detection of cancer as well as the time after its diagnosis and treatment. The number of patients with potential symptoms of cancer in general practice is high and it may sometimes be difficult for the GP to refer the right patients as timely as possible. This may affect the doctor–patient relationship. An important prerequisite for GP involvement in the cancer care pathway is the patient's confidence in the GP's professional skills and clinical judgement. This article provides an insight into the change in patients' confidence in their GPs after a cancer diagnosis and how doctor delay may influence such a change.

of Danish citizens are registered with a GP, who acts as a gatekeeper to the rest of the healthcare system, and who carries out initial diagnostic investigations and refers patients to hospitals or outpatient clinics when necessary.[12] Danish GPs keep electronic medical records of their patients.

The study population included all newly diagnosed patients with cancer during a 1-year period from 1 September 2004 to 31 August 2005. Patients with a cancer recurrence, patients younger than 18 years, and patients with non-melanoma skin cancer were excluded.

Patients were identified from the county hospital discharge registry (HDR). For each hospital admission and outpatient visit, the HDR holds information on: the patient's unique civil registry number (CRN), dates of admission and discharge, and discharge diagnoses classified according to the International Classification of Diseases (ICD-10).[13] The CRN was used to link the HDR data to the county health service registry, in order to identify each patient's GP.[3]

Data collection

Once a month, questionnaires were sent to the GPs whose patients had been registered in the HDR with a cancer diagnosis. The GPs received remuneration for their participation. Two weeks after the GP questionnaires were sent out, questionnaires were sent to the patients. Non-responding GPs and patients received a reminder after 3 weeks.

The GP questionnaire requested a detailed description of the patient's diagnostic pathway. This included the date of the first cancer-related symptom presentation to the GP and the date of the GP's initiation of a cancer-specific investigation of the symptoms. Furthermore, the GP was requested to provide information on the patient's symptom presentation at the first consultation, and whether the GP regarded the symptoms as alarm symptoms of cancer, symptoms of serious illness, or vague symptoms.

The patient questionnaire requested information on the patient's confidence in the GP before and after the cancer diagnosis. Another item asked about the patient's confidence in the specialised healthcare system. Vocational education was used as a proxy for socioeconomic status.

Dependent variable

The dependent variable was the patients' confidence in their GP before and after the cancer diagnosis. This information was obtained retrospectively from the patient questionnaire using a five-point scale ranging from 'completely disagree' to 'completely agree', with 'neither disagree nor agree' as the middle value. The scale was divided into two categories for the purpose of evaluating the change in confidence after the cancer diagnosis: 'low confidence in GP' ('completely disagree', 'disagree', and 'neither disagree nor agree') and 'high confidence in GP' ('completely agree' and 'agree'). The change in confidence was divided into three categories: 'confidence in GP higher after diagnosis', 'confidence in GP lower after diagnosis', and 'no change in confidence after diagnosis'.

Independent variables

Doctor delay was defined as the interval between the date when the patient first presented to the GP with relevant symptom(s) and the date when the GP initiated cancer-specific investigation of the symptoms. Patients with an interval of <14 days were defined to have had no doctor delay, whereas patients with a doctor delay of ≥14 days experienced doctor delay. Although the cut-off point for doctor delay is

arbitrary, the use of 14 days is considered clinically appropriate, as watchful waiting may be part of a standard diagnostic investigation.[14]

Analyses

Patients were only included if the GP was involved in the diagnostic pathway. The change in confidence was analysed for all cancer types, for the five most frequent cancers (breast, colorectal, lung, prostate, and malignant melanoma), and for the three categories of symptom presentation (alarm, serious, and vague symptoms). The difference in patients' confidence in their GP after the cancer diagnosis was tested by McNemar's test.

The association between the patients' change in confidence in their GP and the doctor delay was estimated as prevalence ratios (PRs) using multinomial logistic regression. The PRs were chosen instead of odds ratios as odds ratios would tend to overestimate the association due to a high prevalence of change in confidence and delay.[15]

Symptom presentation was considered to influence doctor delay and, as such, analyses were made for each of the three symptom categories. Adjustment was made for the patients' age, sex, and vocational education. Patient clustering was accounted for using robust standard errors. Estimates were given with 95% confidence intervals (CIs) when relevant, and statistical significance was defined as a probability of ≤5% or less. Analyses were coducted using Stata 10.1 (Stata Corporation, Texas, US).

RESULTS

A total of 2212 out of 2663 GPs completed the questionnaire (83.1%). In 1892 (85.5%) cases, the GP was part of the diagnostic pathway. The patient questionnaire was completed by 904 (47.8%) of these patients. There was complete information on doctor delay and on the patient's confidence in the GP for 766 patients (40.5%; Figure 1).

There were no statistically significant differences in sex and vocational education between included and excluded patients (including non-responders). Included patients were statistically significantly younger and more often presented with alarm symptoms than non-participants. Most patients who participated had breast cancer; lung cancer affected the smallest number of participants (Table 1).

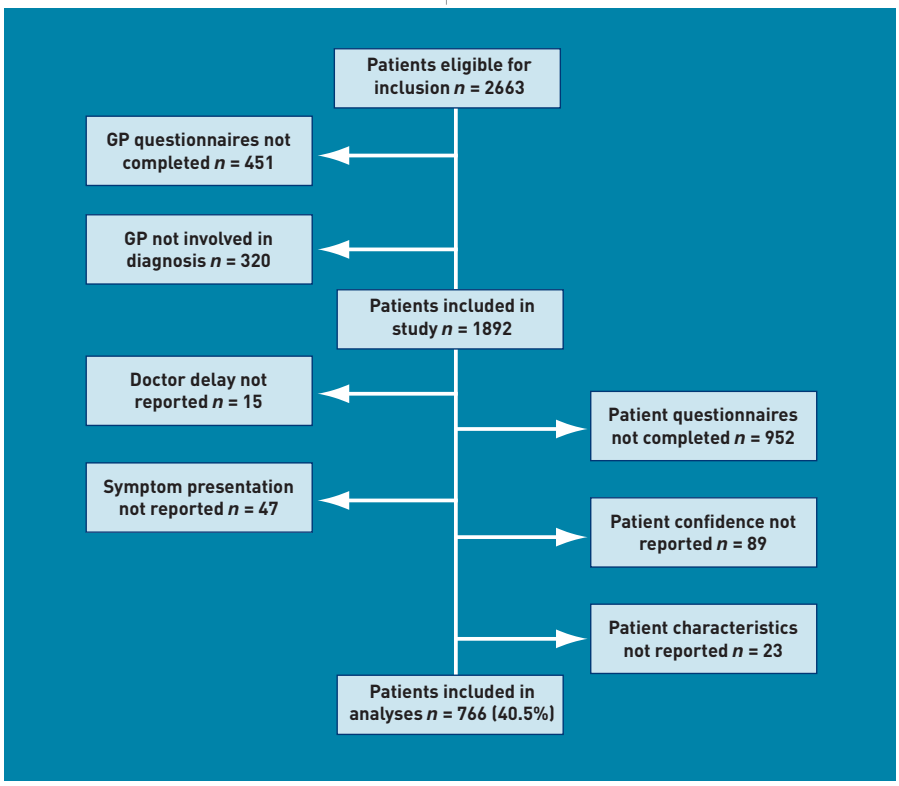

Figure 1. Patients included in the analyses.

Table 1. Analyses of differences between participants and non-participants (including non-responders)

	Participants, *n* = 766 (%)	Non-participants, *n* = 1126 (%)	Test of no difference
Sex			*P* = 0.239
Female	417 (54.4)	582 (51.7)	
Male	349 (45.6)	544 (48.3)	
Age, years			*P*<0.001
18–49	149 (19.5)	107 (9.5)	
50–69	360 (47.0)	436 (38.7)	
≥70	257 (33.6)	583 (51.8)	
Cancer diagnosis			
Breast	171 (22.3)	120 (10.7)	*P*<0.001
Colorectal	114 (14.9)	140 (12.4)	*P* = 0.125
Lung	68 (8.9)	185 (16.4)	*P*<0.001
Prostate	99 (12.9)	91 (8.1)	*P* = 0.001
Melanoma	70 (9.1)	52 (4.6)	*P*<0.001
Other	244 (31.9)	538 (47.8)	*P*<0.001
Symptom presentation		***n* = 1078**	*P*<0.001
Alarm symptoms	431 (56.3)	476 (44.2)	
Serious symptoms	135 (17.6)	300 (27.8)	
Vague symptoms	200 (26.1)	302 (28.0)	
Vocational education		***n* = 110**	*P* = 0.480
None	196 (25.6)	32 (29.1)	
Skilled worker	341 (44.5)	51 (46.4)	
Higher education (>3 years)	229 (29.9)	27 (24.6)	

Confidence in the GP before and after the cancer diagnosis

Overall, 88.4% of the patients had high confidence in their GP before the cancer diagnosis; this decreased to 80.0% after the cancer was diagnosed. Of the patients with low confidence in their GP before the diagnosis, 20.2% (absolute 2.3%) changed to high confidence after the diagnosis. Of the patients with high confidence before the diagnosis, 12.1% (absolute 10.7%) changed to low confidence (Table 2).

In comparison, 77.4% of the patients reported high confidence in the rest of the healthcare system before the diagnosis, and 79.6% after the diagnosis (*P* = 0.148). Regarding confidence in the rest of the healthcare system, 41.8% of the patients (absolute 9.4%) changed from low to high confidence, and 9.4% (absolute 7.3%) changed from high to low confidence. Before the diagnosis, statistically significantly more patients had high confidence in the GP than in the rest of the healthcare system (*P*<0.001). After the diagnosis, there were no statistically

Table 2. Cancer patients' confidence in their GP before and after the cancer diagnosis.

		Before I received my cancer diagnosis, I had complete confidence in my GP's professional skills and judgement, *n* [%]		
		High confidence	Low confidence	All
After I received my cancer diagnosis, I had complete confidence in my GP's professional skills and judgement, *n* (%)	**High confidence**	595 (97.1) [87.9]	18 (2.9) [20.2]	613 (100) [80.0]
	Low confidence[a]	82 (53.6) [12.1]	71 (46.4) [79.8]	153 (100) [20.0]
	All	677 (88.4) [100]	89 (11.6) [100]	766 (100) [100]

Patient answers were dichotomised into 'low confidence' ('completely disagree', 'disagree' and 'neither disagree nor agree') and 'high confidence' ('agree' and 'completely agree'). [a]A statistically significantly higher proportion with low confidence was observed after the diagnosis (McNemar, P<0.001).

Table 3. Changes in the proportion of patients with confidence[a] in their GP before and after the cancer diagnosis.

All cancers (*n* = 766)	Before diagnosis, *n* (%)	After diagnosis, *n* (%)	Difference within groups, % (95% CI)	% (95% CI)
All	677 (88.4)	613 (80.0)	−8.4% (−11.0 to −5.7) *P*<0.001	
Sex				
Female	365 (87.5)	333 (79.9)	−7.7% (−11.2 to −4.1) *P*<0.001	Reference
Male	312 (89.4)	280 (80.2)	−9.2% (−13.2 to −5.1) *P*<0.001	1.5% (−2.4 to5.4) *P* = 0.448
Age, years				
18–49	127 (85.2)	112 (75.2)	−10.1% (−16.8 to −3.3) *P* = 0.003	Reference
50–69	323 (89.7)	293 (81.4)	−8.3% (−12.4 to −4.3) *P*<0.001	−1.7% (−6.3 to2.9) *P* = 0.460
≥70	227 (88.3)	208 (80.9)	−7.4% (−11.6 to −3.1) *P*<0.001	−2.7% (−7.3 to2.0) *P* = 0.259
Symptom presentation				
Alarm	386 (89.6)	367 (85.2)	−4.4% (−7.6 to −12.2) *P*<0.005	Reference
Serious	122 (90.4)	110 (81.5)	−8.9% (−15.6 to −2.2) *P* = 0.008	4.5% (0.1 to 8.9) *P* = 0.046
Vague	169 (84.5)	136 (68.0)	−16.5% (−22.7 to −10.3) *P*<0.001	12.1% (7.8 to 16.4) *P*<0.001
Diagnosis				
Breast cancer (*n* = 171)	151 (88.3)	143 (83.6)	−4.7% (−10.3 to .01) *P* = 0.115	Reference
Colorectal cancer (*n* = 114)	102 (89.5)	93 (81.6)	−7.9% (−15.3 to −.01) *P* = 0.035	3.2% (−1.8 to 8.3) *P* = 0.212
Lung cancer (*n* = 68)	57 (83.8)	46 (67.7)	−16.2% (−26.4 to −6.0) *P*<0.001	11.5% (5.9 to 17.1) *P*<0.001
Prostate cancer (*n* = 99)	84 (84.9)	78 (79.0)	−6.1% (−13.8 to 1.7) *P* = 0.146	1.4% (−3.7 to 6.5) *P* = 0.597
Melanoma (*n* = 70)	66 (94.3)	56 (80.0)	−14.3% (−24.8 to −3.8) *P* = 0.006	9.6% (4.5 to 14.7) *P* = 0.001

[a]Patients answered 'agree' or 'completely agree' regarding having confidence in their GP.

significant differences between the proportion of patients with confidence in the GP and the proportion of patients with confidence in the rest of the healthcare system (*P* = 0.938) (data not shown).

The decrease in confidence in the GP was seen for all patient groups, with the exception of patients with breast cancer and those with prostate cancer. Patients presenting with vague symptoms had a statistically significantly larger decrease in confidence compared with patients presenting with alarm symptoms. There were no statistically significant differences in the change in confidence between men and women or between younger and older patients. Compared with breast cancer patients, the decrease in confidence was especially high for patients with lung cancer and malignant melanoma (Table 3).

Change in confidence in the GP and doctor delay in the diagnosis of cancer

Of the patients with cancer with no doctor delay, 15.8% reported less confidence in the GP after the cancer diagnosis compared

Table 4. The association between decrease in confidence and doctor delay. Doctor delay and symptom presentation were reported by the GP and confidence was reported by the patient.

				Decrease in confidence			
	Doctor delay, days	*n* (% of all)	*n* (% of *n*)[a]	Crude PR (95% CI)	*P*-value	Adjusted[b] PR (95% CI)	*P*-value
All (*n* = 766)	<14	663 (86.6)	105 (15.8)	2.2 (1.4 to 3.5)	0.001	2.3 (1.4 to 3.7)	0.001
	≥14	103 (13.4)	30 (29.1)				
Symptom presentation							
Alarm (*n* = 431)	<14	419 (97.2)	53 (12.7)	3.5 (0.6 to 12.6)	0.060	3.8 (1.0 to 14.0)	0.048
	≥14	12 (2.8)	4 (33.3)				
Serious (*n* = 135)	<14	111 (82.2)	15 (13.5)	2.6 (0.9 to 7.4)	0.067	3.0 (1.0 to 8.9)	0.054
	≥14	24 (17.8)	7 (29.2)				
Vague (*n* = 200)	<14	133 (66.5)	37 (27.8)	1.0 (0.6 to 1.9)	0.933	1.2 (0.6 to 2.3)	0.616
	≥14	67 (33.5)	19 (28.4)				

[a]Decrease in confidence (with relative % in brackets) was defined as a patient scoring lower on having confidence in the GP's professional skills and judgement after the diagnosis compared with before. [b]Adjusted for the patient's sex, age, and vocational education. PR = prevalence ratio.

with 29.1% of the patients with a doctor delay (Table 4); thus, the probability of losing confidence in the GP doubled for patients with cancer who experienced doctor delay. This was especially the case for patients presenting with alarm or serious symptoms, but not for patients presenting with vague symptoms.

DISCUSSION

Summary

It was found that 88.4% of the patients had high confidence in their GP before the cancer diagnosis. After the diagnosis, one in 10 reported that they had changed from high to low confidence. In comparison, nearly 80% had high confidence in the rest of the healthcare system both before and after diagnosis. Of the patients with low confidence before the diagnosis, relatively more gained confidence in the rest of the healthcare system than the GP after the diagnosis. This may be explained by the increased contact with the hospital and an unexpected positive experience during treatment.

Patients presenting with vague symptoms had the highest probability of changing to low confidence after the diagnosis. However, relating changing to low confidence with symptom presentation showed a strong association between presenting with alarm or serious symptoms and losing confidence in the GP when patients experienced doctor delay. This means that although patients most often lose confidence in the GP when they present with vague symptoms, delay becomes very important for GP confidence when patients present with alarm or serious symptoms that are not acted upon by the GP.

Strengths and limitations

The study included an entire population of patients with cancer, and eligible patients were selected based on valid registers and GP questionnaires. The latter might have induced selection bias if non-responding GPs had more patients with doctor delay than those who responded; as such, the study might have underestimated the association between doctor delay and loss of confidence in the GP. However, the high response rate among GPs (83.1%) reduces the magnitude of this selection bias. The relatively low response rate among patients (47.8%) might introduce selection bias, as non-responders were mainly older patients who may have died or have more serious illnesses (for example, lung cancer). It is not possible to precisely estimate the direction or extent of this selection bias.

Recall bias is inherent in the retrospective design, and patients already diagnosed with cancer may answer differently than they would have answered before the diagnosis. However, asking patients before a possible cancer diagnosis would require a prospective and much larger study. The effect of recall bias on doctor delay was minimised by choosing GP-reported dates, since the GPs had electronic records to support the answers.

There might be residual confounding due to patient and GP characteristics. If patients' confidence in their GP is not simply associated with the quality of medical care, but also with other variables, the study might have underestimated the association between doctor delay and confidence. Furthermore, it did not control for patients' comorbidity, which might be associated with delay and confidence. It has not been possible to determine the direction of this confounding.

The population-based approach and the homogeneous structure of general practice make the results generalisable to the rest of Denmark and other settings where GPs act as gatekeepers.

Comparison with existing literature

It is known that patients with cancer in general evaluate their GP very well, especially with regard to factors related to the doctor–patient relationship.[16,17] To the authors' knowledge, there are no studies on patients' confidence in their GP, and how this might be influenced by doctor delay. However, Grumbach *et al* found an association between patients experiencing difficulties with getting a referral to specialist care and loss of confidence in the GP, which may be related to doctor delay.[10]

It has long been recognised that patient confidence is a core element of the doctor–patient relationship. However, confidence is a complicated multidimensional construct, and empirical research is limited. Confidence has been defined and measured in various ways for various purposes. However, there seems to be agreement on confidence as a multidimensional construct that requires a

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Ethical approval

According to the Committees on Biomedical Research Ethics in the Central Denmark Region, the Act on a Biomedical Research Ethics Committee System and the Processing of Biomedical Research Projects does not apply to this project. The study was approved by the Danish Data Protection Agency and the Danish National Board of Health.

Competing interests

The authors have declared no competing interests.

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validated instrument of measurement.[18–20] The study questions may be too simple to capture the construct of trust. Further research is needed to clarify this.

Implications for practice and research

The majority of patients with cancer had high confidence in their GP before and after the cancer diagnosis. Loss of confidence was most frequent among patients with lung cancer and malignant melanoma and when patients presented with vague symptoms. Doctor delay was only associated with losing confidence in the GP if the patient presented with an alarm symptom of cancer or a symptom of serious illness.

Future research should investigate factors that may damage the patients' confidence in their GP. It should also test whether confidence may be preserved if GPs are aware of patients presenting with vague symptoms that may complicate the diagnostic pathway. Furthermore, attention must be paid to how the patient can regain confidence in the GP when presenting with alarm or serious symptoms and experiencing delay. This study indicates a need for appropriate follow-up after a difficult diagnostic process in order to restore confidence in the doctor–patient relationship if the GP is going to be involved in the later stages of the cancer care pathway.

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