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ORIGINAL ARTICLE

Cancer patients' evaluation of communication: a report from the population-based study 'The Cancer Patient's World'

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Abstract
Purpose The aims of this study were to assess how communication with health care staff is perceived by Danish cancer patients and to characterise those patients who report problems in communication.
Methods In a cross-sectional survey, a nationally representative sample of 2,202 cancer patients who had been in contact with a hospital department during the past year was invited to respond to a questionnaire. Communication with doctors and nurses was assessed separately as were their abilities as listeners, doctors' use of an understandable language, timing of the information, duration of consultations, and whether doctors criticised other doctors.
Results A total of 1,490 cancer patients responded to the questionnaire. Of these, 24 % reported one or more problems with the areas of communication measured. The problem most frequently reported (by 12 %) was not having sufficient time for consultations. More patients reported problems with doctors' communication and abilities as listeners than with nurses' skills in these areas. There was a general pattern that younger patients and those sampled in Copenhagen reported the highest degree of dissatisfaction with the communication. Those exposed to a high number of different treatment modalities were at especially high risk of experiencing problems.
Conclusions A high proportion of patients reported one or more problems in the communication. However, the number reporting each of the specific problems was remarkably low. Special focus should be given to patients exposed to several treatment modalities and their communicative needs.

Keywords Communication · Cancer · Patient perspective · Population-based

Introduction

Communication is not merely an information flow between people but also involves support and concern [1–4], and effective doctor–patient communication has been linked to compliance and better health outcomes for a range of diseases [2,5–7] including cancer [8–15]. In particular, communication where the patient is involved in decision-making seems related to successful outcomes [13,16]. Also, the impression of being heard by the medical staff is important [17,18]. A Danish study of cancer patients showed that the doctors' attentiveness was rated as more important than empathy by the patients although both aspects were associated with satisfaction with the contact and with improvement in self-efficacy [19]. According to statements from the American National Institutes of Health and the American Society of Clinical Oncology, improvements in survival and quality of life require effective communication between clinicians, patients and family members in a health care system that foster continuous healing relationships and care that is customised to meet patients' needs [20,21]. Most studies so far have focused on patients with specific types of cancer, especially breast cancer, and fewer studies have

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involved patients who have cancers with a poorer prognosis. Most studies have focused on doctors of one specialty and few have investigated nurses' communication [17,20,22].

The Danish Cancer Society financially supported a large population-based study to investigate the nature and occurrence of needs of cancer patients in Denmark [23]. First, information was gathered during focus groups and individual interviews with professionals and volunteers working with patient support within the Danish Cancer Society, cancer patients and relatives, amounting to a total of 77 informants. Subsequently, a questionnaire was developed based on these interviews providing information about a range of aspects on the experience of having cancer. This included eight items elucidating key elements of the communication with health care staff (CPWQ-com). This article aims to investigate how a large, nationally representative sample of cancer patients evaluates the communication in the Danish health care system and to identify demographic and clinical characteristics of cancer patients reporting problems with communication.

Methods

Study population

As previously described [24], all hospital departments treating cancer patients in three Danish counties (Ringkoebing, Funen and Copenhagen) provided lists of patients that had (1) been in contact with that department within the past 12 months, (2) had a diagnosis of cancer, (3) were alive and (4) lived in the county of interest. At the two largest oncology departments, 16 % of patients were selected for the study and on all other departments 28 % of patients were selected. In the analyses, data were weighted to take the sampling into account (see section on analyses).

Lists of eligible patients were reviewed between February 2005 and January 2006 to determine whether the inclusion criteria were met (Fig. 1). This led to exclusion of 797 patients (specified in Fig. 1).

The vital status of all citizens in Denmark is recorded in the Central Person Register (CPR) along with the postal address. After linkage with the CPR, an additional 140 patients were excluded: 99 patients had died, 33 patients had moved to another county, 2 patients had emigrated, 4 patients had protected mailing address and 2 were excluded for unknown reasons. The resulting sample of 2,202 patients was mailed a letter of invitation along with a questionnaire.

The questionnaire

The eight items (a–h) regarding communication (CPWQ-com) have been extensively validated, and it was shown that a sum scale of seven items (items a–g) performed well and had high reliability (Cronbach's alpha 0.89) [25]. The item that could not be included in the sum scale was about whether the patient had experienced that one doctor had criticised another doctor involved in his or her treatment (item h). The questions covered experiences from the full disease trajectory. The questionnaire was translated into English using the EORTC guidelines [26], and the wording of the English translation appears in Table 3.

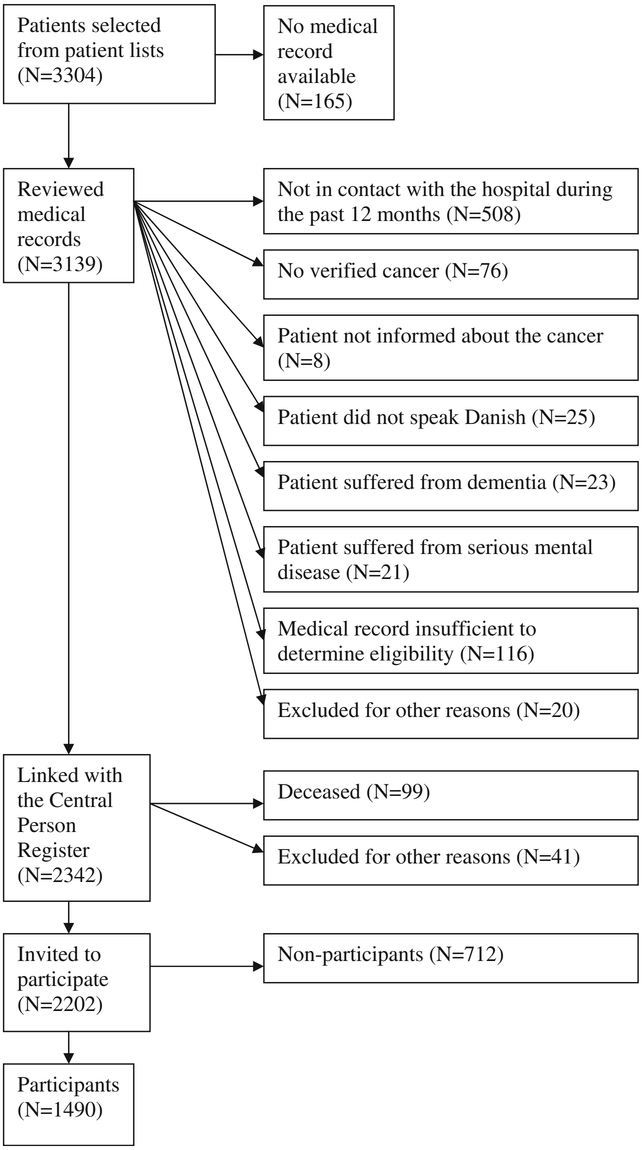

Fig. 1 Flow chart of the recruitment procedure in the 'Cancer Patient's World'

Analyses

Data were weighted to adjust for the unequal proportions of patients included from different departments using the PROC SURVEYFREQ procedure in the SAS statistical package v. 9.1. In this way, the results correspond to those that would have been obtained if equal proportions had been sampled from all departments. Likewise, all regression analyses were weighted using the PROC SURVEYLOGISTIC procedure.

Participants and non-participants were compared using ordinal logistic regression analysis not including the 'unknown' category. Those answering 'only sometimes' or 'rarely/never' in the first seven questions or 'yes' in the last question were considered to have experienced problems in the communication with health care staff.

The first seven items (a–g) were summed and transformed to a communication scale ranging from 0 (no communication problems) to 100 (maximum communication problems on all seven items). First, univariate analyses of the associations between background variables and the communication scale as well as all single aspects of communication were performed using ordinal logistic regression that did not include the unknown category. The background variables were gender, age, marital status, education, employment status, diagnosis, stage, disease/treatment phase (a variable taking stage, time since diagnosis and treatment into account), number of treatment modalities (i.e. surgery, radiation therapy chemotherapy and hormone therapy), county and type of hospital department.

Second, for each of the nine outcomes (i.e. the communication sum scale and the eight aspects of communication), variables significantly associated with that particular outcome were entered in a multiple regression model in which backward stepwise logistic regression analysis was undertaken for model building. Only results from the multivariate analyses will be presented. A significance level of 0.05 was chosen.

Results

Characteristics of participants

A total of 1,490 patients (68 %) participated. Participation was lowest in the youngest and especially the oldest age groups, whereas there was a slight overrepresentation of patients diagnosed with breast cancer and stage three disease among participants (Table 1). A smaller proportion of patients treated at medical wards participated compared to patients treated elsewhere, and there was a high participation among those with locoregional disease receiving adjuvant treatment (Table 1). Of those participating, most were married (62 %), many had a long or short theoretical education (39 %), were old age pensioners (35 %) and had received one to three different treatment modalities (91 %) (Table 2).

Frequency of problems with communication

A total of 24 % of the sample reported problems in one or more of the eight aspects of the communication. In total, 8 % reported problems with the doctors' general communication, 4 % reported problems with the doctors' use of an understandable language, 8 % reported problems with the doctors' abilities as listeners, 5 % reported problems with the nurses' general communication and 5 % reported problems with the nurses' abilities as listeners (Table 3). Further, 6 % reported problems with the timing of information, 12 % reported problems in obtaining sufficient time for consultations and 5 % had experienced that a doctor criticised another doctor involved in his or her treatment (Table 3). When the first seven items (a–g) were summed and transformed to a communication scale ranging from 0 (no problems) to 100 (maximum problems), the mean value was 18 and the median value was 14 (range 0–86).

Multivariate analyses

The results of multivariate analyses are shown in Table 4. Those living in Copenhagen, the youngest, those receiving most different treatment modalities and those who were diagnosed 5–10 years ago were at the highest risk of reporting problems according to the communication scale.

Those living in Copenhagen reported more problems than patients in smaller towns and rural areas on five of the eight items: doctors' overall communication skills, doctors' and nurses' ability to listen to them, timing of the information and the availability of a sufficient amount of time for consultations. In addition, doctors at surgical and especially gynaecological departments were perceived as better communicators and listeners and using more understandable language than those at medical and oncology/haematology departments.

Gender was not associated with communication problems in the multivariate analyses. Younger age was associated with experiencing more problems with regard to the doctors' overall communication, doctors' use of an understandable language, doctors' and nurses' abilities as listeners and the timing of the information. Longer education was associated with having experienced that one doctor criticised another doctor involved in the treatment. The experience of not having sufficient time for consultations was reported mostly by patients on early retirement pension.

Patients diagnosed with urinary cancer, lung cancer, gastrointestinal cancer and lymphoma were those most frequently reporting problems with the timing of information. Stage of disease was not associated with communication problems in the multivariate analyses. Having received a high number of different treatment modalities was associated with the experience of problems with regard to the

Table 1 Characteristics obtained from medical records of the 2,202 invited patients and the 1,490 participants in the Cancer Patient's World

		Invited	Participants	Proportion participating (%)	Odds ratio[a] (OR)	95 % confidence interval
All		2,202	1,490	68		
Gender	Female	1,390	952	68		
	Male	812	538	66		
Age*	18–39 years	154	91	59	0.43	(0.30–0.64)
	40–49 years	193	146	76	0.90	(0.60–1.33)
	50–59 years	435	329	76	0.92	(0.68–1.24)
	60–69 years	568	436	77	1.00	–
	70–79 years	546	348	64	0.52	(0.40–0.68)
	80+	306	140	46	0.26	(0.19–0.35)
Diagnosis**	Head and neck	113	70	62	0.56	(0.36–0.86)
	Gastrointestinal	223	160	72	0.88	(0.62–1.25)
	Lung	105	73	70	0.80	(0.51–1.28)
	Gynaecological	226	156	69	0.83	(0.59–1.16)
	Prostate	184	114	62	0.59	(0.41–0.83)
	Urinary	82	52	63	0.65	(0.40–1.05)
	Breast	670	490	73	1.00	–
	Lymphoma	189	120	63	0.62	(0.44–0.88)
	Leukaemia	159	102	64	0.64	(0.44–0.93)
	Other	243	150	62	0.57	(0.41–0.78)
	Unknown	8	3	38	–	–
Stage**	1	611	439	72	1.00	–
	2	485	335	69	0.94	(0.72–1.23)
	3	325	239	74	1.11	(0.81–1.52)
	4	364	229	63	0.66	(0.50–0.88)
	Unknown	417	248	59	–	–
Time since diagnosis	<6 months	132	82	62		
	6–12 months	337	233	69		
	1–2 years	426	289	68		
	2–5 years	622	430	69		
	5–10 years	365	243	67		
	>10 years	149	101	68		
	Unknown	171	112	66		
Department**	Surgery	793	543	68	0.96	(0.79–1.17)
	Medicine	146	78	53	0.51	(0.36–0.72)
	Oncology/Haematology	1,105	761	69	1.00	–
	Gynaecology	158	108	68	0.96	(0.67–1.37)
County**	Ringkoebing	263	182	69	1.21	(0.91–1.63)
	Funen	882	624	71	1.37	(1.12–1.67)
	Copenhagen	1,057	684	65	1.00	–
Treatment phase*	Locoreg., year 1, no treatment	142	90	63	0.77	(0.52–1.13)
	Locoreg., year 1, treatment	87	80	92	5.36	(2.38–12.10)
	Locoreg., year 1+, control	582	406	70	1.00	–
	Locoreg., year 1+, treatment	215	150	70	1.08	(0.76–1.54)
	Advanced, control	380	253	67	0.87	(0.65–1.16)
	Advanced, treatment	309	212	69	0.97	(0.71–1.32)
	Unknown	487	299	61	–	–

Locoreg local/locoregional stage 1 and 2, *advanced* stage 3 and 4

*$p<0.001$; **$0.01>p\geq 0.001$ (in the ordinal logistic regression analysis not including the unknown category)

[a] Odds for participation is analysed using ordinal logistic regression analysis

Table 2 Self-reported characteristics of the 1,490 participants in the Cancer Patient's World

Variable		Number	(Pct.)
Marital status	Married/cohabiting	929	(62)
	Divorced/separated	188	(13)
	Unmarried	113	(8)
	Widow/widower	209	(14)
	Non-response	51	(3)
Education	No education	224	(15)
	Semi-skilled worker/short education (<1 year)	147	(10)
	Skilled worker	115	(8)
	Short theoretical education (1–3 years)	244	(16)
	Long theoretical education (>3 years)	341	(23)
	University education	129	(9)
	Non-response	290	(19)
Employment status	Full time	365	(24)
	Part time	120	(7)
	Unemployed	43	(3)
	Old age pension	520	(35)
	Early retirement pension	251	(17)
	Non-response	191	(13)
No. of treatment modalities[a]	0	59	(4)
	1	626	(42)
	2	447	(30)
	3	276	(19)
	4	80	(5)
	Non-response	2	(0)

[a] A combination of treatment modalities mentioned in the medical record and by the patient

doctors' overall communication, timing of the information, not having sufficient time for consultations and having experienced that a doctor criticised another doctor involved in the treatment. Longer time since the diagnosis of cancer was associated with problems with the nurses' overall communication and their abilities as listeners but was unrelated to the doctors' communication (Table 4).

Discussion

Our study showed that 24 % of cancer patients reported problems in one or more aspects of the communication with health care staff. Although nurses are previously found to employ some of the same inappropriate communicative behaviours as doctors [27–29], more patients reported problems with the doctors' general communication and their abilities as listeners than with the nurses' abilities in these areas. Only 4 % of the patients in the present study had experienced that the doctor only 'rarely' or 'only sometimes' used an understandable language. One explanation for this relatively low number could be that the general Danish anti-authoritarian style facilitates clarifying questions from the patients whenever there is something they do not understand. Reports from other Western countries have shown that as many as half of cancer patients were not confident about common medical terms or felt that the information received was unclear [9,10,30,31]. The aspect where the largest proportion of patients had experienced problems was in obtaining sufficient time for consultations. A study of 240 women newly diagnosed with breast cancer showed that longer consultation time was associated with the perception that the discussion with the surgeon was 'extremely helpful' [32], whereas a smaller study (*N*=36) found that duration of the outpatient visit was not associated with the patients' satisfaction with the doctor [33].

Those included at surgical and gynaecological departments rated the doctors as better communicators and listeners and using more understandable language than those from medical and oncology/haematology departments. This finding contrasts a smaller study of patients with advanced cancer where the patients rated the surgeon more negatively than non-surgical specialists and general practitioners in bad-news consultations [34].

As previously shown [35], gender was not associated with any of the measured aspects of communication.

Table 3 Frequencies (in percent) of answers to items regarding communication by the 1,490 participants in the Cancer Patient's World

	Always	Most of the time	Only sometimes	Rarely/ never	Don't know/ not relevant
a. Have the doctors been good at communicating?	41	48	7	1	3
b. Have the doctors used an understandable language?	53	42	3	1	1
c. Have the doctors been good at listening to you?	51	40	7	1	2
d. Have the nurses been good at communicating?	57	35	4	1	3
e. Have the nurses been good at listening to you?	60	32	4	1	4
f. Has information been provided at the appropriate time (has the timing been right)?	43	45	5	1	6
g. Has the staff allowed enough time for consultations?	44	40	8	4	5
h. Have you experienced that one doctor criticised another doctor involved in your treatment?	No, 93		Yes, 5		2

The response categories for items a–g were: always, most of the time, only sometimes, rarely/never and don't know/not relevant. The response categories for item h were: yes, no and don't know/not relevant

Younger patients reported more problems than older patients on several aspects of communication. Other studies have also shown that older patients were more satisfied with their doctor [36] and with the communication [37] than younger patients and younger patients reported more communication needs [38]. However, in a Swedish study, younger patients expressed higher satisfaction with 'doctors' interpersonal skills' than older patients [8]. Higher education was associated with experiencing that one doctor criticised another doctor. However, the doctor's disclosure of his or her opinion on the treatment given so far may be seen as a sign of confidence between patient and doctor and we do not have information indicating whether this is seen as problematic or not by the patient. This limitation was revealed in the validation of the scale [25]. It has previously been shown that less thorough information is disclosed to cancer patients who are elderly or have less education [39], and low-income patients have been shown to have low confidence in their health care providers [40]. Among breast cancer patients, those with higher income have reported more need for health information than those with low income [38]. We have no 'objective' assessment of the communication or assessments of expectations and therefore we cannot determine whether the reporting of communicative problems in younger and more educated groups and those living in the capital could be interpreted as an expression of higher expectations in these groups of patients.

The stage of disease was not associated with any of the measured aspects of communication. Likewise, in a study of breast cancer patients, stage was unrelated to the 'helpfulness' of a discussion with the surgeon [32]. In contrast, a smaller study showed that women with small tumours of the breast were more satisfied with the communication than those with larger tumours [37]. In the present study, patients with gastrointestinal, lung and urinary cancer reported most problems, and patients with breast and prostate cancer reported fewest problems with the timing of information. One could speculate that more discouraging information regarding prognosis may be perceived as untimely.

Patients receiving several different treatment modalities will need more information from doctors than patients receiving only one or a few treatment modalities. The former patient group reported more problems with the communication with doctors, the timing of the needed information, the time allowed for the consultations and doctors criticising other doctors. It is therefore important to have special focus on patients exposed to several kinds of treatment and their communicative needs.

Longer time since treatment has been associated with less satisfaction with the communication with doctors [41]. In our study, time since diagnosis was not associated with doctors' communication but patients diagnosed most recently were more satisfied with nurses' communication and their abilities as listeners. This might indicate changes of internal standards (response shift), that the increasing focus on efficient communication during the past years has improved the communicative skills of nurses, or that a lengthy contact with the health care system increases the risk of accumulation of unsatisfactory experiences.

Strengths and limitations of the method

A major strength of this study is that it included an almost representative, national sample of cancer patients and gives a picture of how various aspects of communication are perceived by Danish cancer patients as a whole. This is important because communication problems as encountered by cancer patients are often discussed, both in the public media and by health care professionals who are dissatisfied with their ability to dedicate sufficient time to patients [21]. Furthermore, we were able to assess associations between a range of sociodemographic and disease-related characteristics

Table 4 Multivariate analyses of the effect of sociodemographic and disease-related variables on patients' satisfaction with the communication with health care staff among the 1,490 participants in the Cancer Patient's World

	Communication scale[a]		Doctors' communication		Doctors' language		Doctors as listeners		Nurses' communication		Nurses as listeners		Timing of information		Sufficient time for consultations		Doctor criticising another doctor	
	OR	(95 % CI)	OR	(95 % CI)	OR	95 % CI	OR	95 % CI	OR	95 % CI	OR	95 % CI	OR	95 % CI	OR	95 % CI	OR	95 % CI
County	$p=0.021$		$p=0.0011$				$p<0.0001$				$p=0.0055$		$p=0.0043$		$p<0.0001$			
Ringkoebing	0.83	(0.59–1.17)	0.75	(0.53–1.05)	–	–	0.71	(0.50–1.00)	–	–	0.67	(0.45–1.02)	0.69	(0.48–0.98)	0.55	(0.39–0.78)	–	–
Funen	0.72	(0.57–0.91)	0.64	(0.51–0.82)	–	–	0.59	(0.46–0.74)	–	–	0.68	(0.53–0.87)	0.68	(0.53–0.87)	0.53	(0.41–0.67)	–	–
Copenhagen	1.00	–	1.00	–	–	–	1.00	–	–	–	1.00	–	1.00	–	1.00	–	–	–
Type of department			$p=0.0019$		$p=0.0091$		$p=0.0017$											
Surgery	–	–	0.74	(0.58–0.94)	0.76	(0.60–0.95)	0.79	(0.63–1.00)	–	–	–	–	–	–	–	–	–	–
Medicine	–	–	1.27	(0.76–2.10)	1.17	(0.70–1.95)	1.18	(0.72–1.95)	–	–	–	–	–	–	–	–	–	–
Oncology/ Haematology	–	–	1.00	–	1.00	–	1.00	–	–	–	–	–	–	–	–	–	–	–
Gynaecology	–	–	0.48	(0.30–0.77)	0.56	(0.36–0.87)	0.46	(0.30–0.71)	–	–	–	–	–	–	–	–	–	–
Age	$p<0.0001$		$p<0.0001$		$p<0.0001$		$p<0.0001$		$p=0.044$				$p<0.0001$					
18–39 years	2.63	(1.66–4.16)	2.61	(1.60–4.28)	2.69	(1.66–4.34)	1.85	(1.12–3.07)	1.64	(1.02–2.64)	–	–	2.08	(1.26–3.44)	–	–	–	–
40–49 years	1.82	(1.25–2.64)	1.78	(1.22–2.62)	1.52	(1.04–2.22)	1.72	(1.19–2.48)	1.17	(0.78–1.76)	–	–	2.19	(1.46–3.27)	–	–	–	–
50–59 years	1.49	(1.10–2.01)	1.66	(1.22–2.24)	1.31	(0.98–1.76)	1.73	(1.29–2.32)	1.02	(0.74–1.41)	–	–	1.43	(1.05–1.95)	–	–	–	–
60–69 years	1.00	–	1.00	–	1.00	–	1.00	–	1.00	–	–	–	1.00	–	–	–	–	–
70–79 years	0.78	(0.58–1.06)	0.7	(0.54–0.99)	0.74	(0.55–1.01)	0.68	(0.51–0.92)	0.75	(0.54–1.03)	–	–	0.88	(0.64–1.21)	–	–	–	–
80+	0.80	(0.50–1.27)	1.01	(0.65–1.56)	0.73	(0.49–1.11)	0.99	(0.66–1.47)	1.02	(0.64–1.61)	–	–	0.68	(0.43–1.09)	–	–	–	–
Education																	$p=0.0009$	
No education	–	–	–	–	–	–	–	–	–	–	–	–	–	–	–	–	0.63	(0.27–1.46)
Semi-skilled worker/short (<1 year)	–	–	–	–	–	–	–	–	–	–	–	–	–	–	–	–	0.72	(0.28–1.81)
Skilled worker	–	–	–	–	–	–	–	–	–	–	–	–	–	–	–	–	0.65	(0.23–1.87)
Short theoretical (1–3 years)	–	–	–	–	–	–	–	–	–	–	–	–	–	–	–	–	0.69	(0.32–1.51)
Long theoretical (>3 years)	–		–		–	–	–	–	–	–	–	–	–	–	–	–	1.00	–
University	–	–	–	–	–	–	–	–	–	–	–	–	–	–	–	–	2.87	(1.41–5.84)
Employment status															$p=0.0098$			
Full time	–	–	–	–	–	–	–	–	–	–	–	–	–	–	1.17	(0.88–1.57)	–	–
Part time	–	–	–	–	–	–	–	–	–	–	–	–	–	–	1.40	(0.94–2.08)	–	–
Unemployed	–	–	–	–	–	–	–	–	–	–	–	–	–	–	1.10	(0.61–1.99)	–	–
Old age pension	–	–	–	–	–	–	–	–	–	–	–	–	–	–	1.00	–	–	–
Early retirement pension	–	–	–	–	–	–	–	–	–	–	–	–	–	–	1.74	(1.28–2.37)	–	–

Table 4 (continued)

	Communication scale[a]		Doctors' communication		Doctors' language		Doctors as listeners		Nurses' communication		Nurses as listeners		Timing of information		Sufficient time for consultations		Doctor criticising another doctor	
	OR	(95% CI)	OR	(95% CI)	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Diagnosis													p=0.0042					
Head and neck	–	–	–	–	–	–	–	–	–	–	–	–	1.38	(0.78–2.43)	–	–	–	–
Gastrointestinal	–	–	–	–	–	–	–	–	–	–	–	–	1.89	(1.24–2.88)	–	–	–	–
Lung	–	–	–	–	–	–	–	–	–	–	–	–	2.22	(1.23–3.99)	–	–	–	–
Gynaecological	–	–	–	–	–	–	–	–	–	–	–	–	1.39	(0.89–2.16)	–	–	–	–
Prostate	–	–	–	–	–	–	–	–	–	–	–	–	0.99	(0.59–1.68)	–	–	–	–
Urinary	–	–	–	–	–	–	–	–	–	–	–	–	3.16	(1.48–6.77)	–	–	–	–
Breast	–	–	–	–	–	–	–	–	–	–	–	–	1.00	–	–	–	–	–
Lymphoma	–	–	–	–	–	–	–	–	–	–	–	–	1.62	(1.06–2.49)	–	–	–	–
Leukaemia	–	–	–	–	–	–	–	–	–	–	–	–	1.18	(0.68–2.05)	–	–	–	–
Other	–	–	–	–	–	–	–	–	–	–	–	–	1.91	(1.20–3.05)	–	–	–	–
No. of treatment modalities	p=0.0067		p=0.0002										p=0.0001		p=0.0011		p<0.0001	
0	0.82	(0.41–1.66)	0.57	(0.29–1.11)	–	–	–	–	–	–	–	–	1.16	(0.56–2.40)	0.31	(0.15–0.67)	–	–
1	1.00	–	1.00	–	–	–	–	–	–	–	–	–	1.00	–	1.00	–	1.00	–
2	1.44	(1.11–1.86)	1.58	(1.22–2.05)	–	–	–	–	–	–	–	–	1.63	(1.22–2.17)	1.18	(0.90–1.55)	1.90	(1.03–3.51)
3	1.24	(0.92–1.68)	1.27	(0.93–1.74)	–	–	–	–	–	–	–	–	1.89	(1.31–2.73)	1.21	(0.89–1.64)	1.09	(0.50–2.36)
4	1.98	(1.27–3.07)	2.15	(1.30–3.56)	–	–	–	–	–	–	–	–	3.40	(1.95–5.94)	1.84	(1.16–2.93)	4.24	(1.86–9.69)
Time since diagnosis	p=0.029								p=0.0084		p=0.0033							
<6 months	0.68	(0.42–1.10)	–	–	–	–	–	–	0.75	(0.44–1.29)	0.96	(0.57–1.64)	–	–	–	–	–	–
6–12 months	1.13	(0.81–1.57)	–	–	–	–	–	–	1.15	(0.81–1.61)	1.20	(0.84–1.70)	–	–	–	–	–	–
1–2 years	0.80	(0.60–1.08)	–	–	–	–	–	–	0.78	(0.56–1.09)	0.90	(0.65–1.26)	–	–	–	–	–	–
2–5 years	1.00	–	–	–	–	–	–	–	1.00	–	1.00	–	–	–	–	–	–	–
5–10 years	1.35	(0.98–1.86)	–	–	–	–	–	–	1.50	(1.07–2.08)	1.80	(1.28–2.52)	–	–	–	–	–	–
>10 years	0.91	(0.57–1.46)	–	–	–	–	–	–	1.38	(0.85–2.24)	1.44	(0.89–2.34)	–	–	–	–	–	–

For patients' satisfaction, OR was calculated as the risk of having a problem, i.e., answering 'only sometimes' or 'rarely/never' in the first seven questions or 'yes' in the last question

OR odds ratio—a higher odds ratio indicates more problematic communication, *CI* confidence interval

[a] The communication scale consists of the first seven items

of cancer patients and their satisfaction with key elements of the communication with health care professionals. These key elements were defined by patients themselves during initial focus group interviews ensuring that we assessed those elements of communication that were most relevant to the patients.

There are three associated weaknesses. First, not all patients participated and this may affect results probably by underestimation of the problems. The youngest patients and those living in Copenhagen participated least and these groups were those who reported most problems on five out of eight items. Also, patients recruited from medical departments were least likely to participate and were those who reported most problems with of doctors' communication. Second, as the aim of this study was to study the overall levels of satisfaction with communication among cancer patients, a cross-sectional design was chosen, and the patients had to summarise their experiences through their full disease trajectory. Third, the fact that we included patients irrespective of diagnoses, stages, treatments, etc. means that our ability of subdividing patients in clinically well-characterised subgroups is much lower than what could be done if a highly selected subgroup of patients was included. These three weaknesses are unavoidable with the design we selected and we find it important to supplement large, national surveys like this study (which give the overall picture and allow, e.g. comparisons between diagnoses, departments, hospitals and regions as well as studies of trends over time and comparisons between countries) with longitudinal studies of subgroups of patients.

Conclusion

Our study showed that 24 % of cancer patients reported problems in one or more aspects of the communication with health care professionals with the general pattern of younger patients and those sampled in Copenhagen reporting the highest degree of dissatisfaction with the communication. It is impossible to judge whether any of these associations are caused by higher expectations among the younger group and those living in the capital or whether they reflect a higher prevalence of communication problems in these groups, e.g. communicative flaws due to 'burn-out' of the health care staff, high workload or other management circumstances [42]. However, this survey was undertaken as an attempt to hear 'the patient's voice' and not to perform an objective assessment of the communication. As long as the patient is not satisfied with the communication, there is room for improvement, as effective communication should be tailored to the needs of the individual patient [14]. The literature suggests that communication outcomes are enhanced when the patients' emotional needs are attended to [43]. Several communication training programmes have been tested, and these suggest that the best results are to be expected from training programmes carried out over a longer period of time where participants identify problem areas from their own practice experience [44]. In the present study, the global nature of the ratings provide insufficient detail for feedback that can guide improvement and learning [4]. Particularly comments about useful or appreciated communication would have been useful.

On the other hand, the percentages of negative ratings of each type of problem were remarkably low. These ratings showed that more patients reported problems with doctors' communication and abilities as listeners than with nurses' skills in these areas and that those exposed to a high number of different treatment modalities were at especially high risk of experiencing problems with communication.

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