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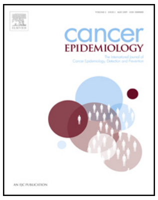

Risk factors for patient-reported errors during cancer follow-up: Results from a national survey in Denmark

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ABSTRACT

Due to an increased cancer survival, more cancer patients are referred to follow-up after primary treatment. Knowledge of patient safety during follow-up is sparse.
Objective: To examine patient-reported errors during cancer follow-up and identify factors associated with errors.
Design: A national survey on cancer patients' experiences of treatment and aftercare was conducted in 2012, about two years following cancer diagnosis (N = 6914). Associations between patient-reported errors during follow-up and covariates were examined using multiple logistic regression. Qualitative responses were analysed using text analysis.
Results: This study included 3731 patients, representing a response rate of 64%. Overall, 27.6% of patients reported at least one error during cancer follow-up. 11.7% reported that important information was missing at follow-up consultations; 9.8% were not called in for a follow-up as expected; 16.7% reported that the doctor/nurse handling the follow-up consultation were ill-prepared on their course of disease. Other errors were reported by 4.7%. Patients who reported errors in follow-up were more likely to report an error or complication during primary cancer treatment, not having one health professional with oversight and responsibility for their overall follow-up pathway, be younger, have a diagnosis of rare cancer, poorer self-rated health and high usage of healthcare services.
Conclusion: Workflows related to handling of test results, referrals, bookings and medical records have to be improved. Introduction of one particular healthcare professional responsible for the patients' follow-up may result in fewer patient-reported errors however interventions are needed to examine this. Patients prone to errors should be subject to particular attention.

1. Introduction

Every year 35,000 new cancer patients are diagnosed and currently nearly 267,500 persons are living with a cancer diagnosis in Denmark [1]. Due to an increased cancer survival, more cancer patients are followed-up after completing primary treatment. The follow-up usually involves outpatient consultations by specialists at the hospital with the aim to control for recurrence or metastasis, provide information and psychosocial support [2].

Cancer survivors are said to be lost in the transition from patient to survivor due to a fragmented and poorly coordinated cancer care system and the absence of a locus of responsibility for follow-up care [3].

Previous studies on safety and quality in cancer care show that due to the severity of cancer disease and the hazardous treatment, cancer patients are at particular risk of adverse events [4–8]. 11% of patients report being very concerned about their safety [9]. Studies on cancer patient safety have mainly focused on treatment. Thus, knowledge of patient safety during follow-up is sparse [10].

Follow-up care in Denmark involves multiple care providers and care settings, and patients rarely meet the same doctor at every appointment. This potentially increases the risk of errors as many errors are associated with inadequate care transitions and multiple contacts [4,8,11–13].

Usually, safety is assessed from a healthcare perspective and the patients' experiences of errors have only been explored to a limited extent. However, gathering information from various sources is necessary to improve the understanding of hazards [6,14,15].

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Patients are usually vigilant observers of the care they receive; they have a unique knowledge of their own cancer pathway and can provide information about experienced errors and safety-related processes [14,16]. Studies indicate that age [13,15,17,18], educational level [17,19], health status [13,17,19,20], clinical complexity [18] and comorbidity [18] are all associated with patients' reporting of errors during hospitalisation and ambulatory care.

2. Material and methods

To explore the patients' perspectives on the care and safety delivered during cancer treatment and follow-up, the Danish Cancer Society conducted a nationwide cross-sectional survey. Based on elements of the survey this study aims to examine patient-reported experience of errors during cancer follow-up and to identify patient-, organisational- and treatment related factors associated with errors. The definition of adverse events is unintended or unexpected incidents, which could have, or did harm the patient. The term *error* was chosen instead of e.g. 'adverse event' because the cognitive validation showed that patients understood the term error and used it to describe rather serious problems, whereas minor problems in general were not considered errors. Thus, we consider the patient-reported errors to be errors, even though some of the described errors mostly go beyond 'service complaints' or relates to expectations about quality that are not met.

2.1. Setting

The Danish healthcare system is primarily publicly funded with free access to diagnostics, treatment and follow-up for all citizens.

2.2. Study population

All patients registered with cancer for the first time in The Danish National Patient Register [21] from April 16th to September 15th 2010, alive by 4 June 2012 and aged $\geq$18 was sent a questionnaire including a prepaid envelope, two to 2,5 years following their cancer diagnosis (N = 6914). After three weeks, non-responders received a reminder. 4401 patients returned the questionnaire (response rate 64%).

This study is based on a subpopulation of the national survey, that is patients who reported being to at least one follow-up consultation and replied to at least one of the questions on errors in follow-up care listed in the questionnaire (n = 3731, 84.8% of responders). Thus, the patients reported the errors in their survivorship phase, not during active treatment.

2.3. Development of questionnaire

A review of the literature and six focus group interviews were conducted to identify important aspects of quality and safety during cancer treatment and survivorship. The questionnaire contained 121 items in total. It was validated through 14 cognitive interviews with patients [22].

2.4. Variables

Errors during follow-up were recorded by asking patients if they experienced one or more of the following situations in connection with their follow-up consultations (answer: No; Yes, a single time; Yes, more times; Don't know/not relevant):

- Important information about the course of my disease (e.g. records, letters or test results) was missing when I attended a follow-up consultation
- I was not called in for a follow-up consultation as expected
- The doctor/nurse handling my follow-up consultation were ill-prepared on my course of disease.

These three closed questions on errors were drafted based on previous patient safety studies [5,6]. They were posed to quantify 'known' types of error. Also patients were asked if they had experienced *"other errors"* than the ones stated (no/yes), and were given the opportunity to describe the error.

The analysis of factors associated with error-reporting included three areas:

- *The patient*: sex; age; education; cancer-type; comorbidity; self-rated health.
- *Organisational settings and care transitions*: setting for follow-up consultation; contacts to hospital; contacts to different health-care providers; one health professional with oversight and responsibility for the overall follow-up pathway.
- *Primary cancer treatment*: if the patient had experienced an error or complication during primary treatment.

Information on the patient's age, sex and cancer type were retrieved from The Danish National Patient Register. The remaining information were patient-reported.

Cancer types were grouped into three categories reflecting the incidences in Denmark (common, less common, rare). We defined comorbidity as the presence of one or more chronic diseases in addition to cancer. Patients reported self-rated health on a seven-point Likert scale.

High usage of healthcare services is a proxy of care transitions. Thus, this was analysed by number of contacts to hospital, and by creating a variable that combined contacts (yes/no) to nine different types of providers (e.g. hospital, GP, home nurse, pain clinic).

Patient-reported error or complication during primary treatment were combined in the analysis and considered an indicator of previous error. This variable comprised three questions on primary treatment at hospital: 1) complication(s) in surgery (e.g. infection, thrombosis) 2) important information about the course of disease was missing when attending a consultation/treatment, 3) not called in for a consultation/treatment as expected.

2.5. Data analyses

We estimated a multivariate logistic regression model for each of the three specific errors and one for 'all errors' which combined the three specific errors and the question on other errors. The outcome was error(s) during follow-up. For all models, a likelihood ratio test for significance testing was conducted; p-value $\leq$ 0.05 was considered statistically significant. To begin with, the models included all the covariates that had a p-value $\leq$ 0.1 in the univariate analyses. To get to the final models, covariates were withdrawn one by one starting with the ones least significant. We conducted a Test for trend across the values of certain covariates, e.g. age. The results presented are unadjusted and adjusted Odds Ratios (OR) with 95% confidence intervals (CI).

An analysis of non-responders was conducted to investigate whether non-responders on the four questions on errors were different from responders. Analyses of non-responders of the entire national survey has been published elsewhere [2]. Statistical analyses were performed using SAS 9.3.

The open-ended question on 'other errors' were analysed using systematic text condensation. Thus, we created categories of types of errors until no more categories emerged. All errors underwent a deductive coding according to the created categories. An expert in patient safety conducted the coding and analysis. Some of the 'other errors' described seemed to overlap with the three specific errors, but also included other facets and problems. This may be because patients felt that the wording of the error descriptions did not adequately cover what they had experienced. Thus, we analysed these as 'other errors'. The most frequent categories are presented.

3. Results

The analysis included 3731 patients. Most had breast-, prostate- or gastrointestinal cancer (Table 1). There was a predominance of women (54%). Average age was 64 years. 7% had one follow-up consultation, 27% two or three, and 66% had more than three consultations.

3.1. Non-responders

300 responders skipped the questions on errors during follow-up. The non-responders were more likely to be ≥70 years, be comorbid, have a lower educational level and not reporting their health as excellent. These covariates were all statistically significant ($p > 0.0001$).

3.2. Patient-reported errors

Overall, 1029 (27.6%) of patients reported one or more errors during cancer follow-up (Table 2). 11.7% reported that important information (e.g. records, letters or test results) was missing at follow-up consultations; 9.8% were not called in for a follow-up as expected; 16.7% reported that the doctor/nurse handling the

Table 1
Characteristics of responders, (N = 3731).[a]

Variable	Responders, N (%)	
Sex		
Male	1700	(45.6)
Female	2031	(54.4)
Age, yrs		
18–49	447	(12.0)
50–59	742	(19.9)
60–69	1424	(38.2)
≥70	1118	(30.0)
Education		
Elementary/intermediate school	971	(26.0)
School leaving/Higher preparatory exam or skilled tradesman	1389	(37.2)
Medium cycle higher exam or more	1225	(32.8)
Cancer type[b]		
Common cancers (breast, prostate, gastrointestinal, melanoma, and lung)	2684	(71.9)
Less common cancers (lymphoma and blood, urinary tract, gynaecological, head and neck)	822	(22.0)
Rare cancers (e.g. penis and brain)	225	(6.0)
Comorbidity		
Yes	1442	(38.7)
No	2059	(55.2)
Self-rated health		
Excellent (six-seven)	2017	(54.1)
Fair to good (three-five)	1430	(38.3)
Poor (one-two)	108	(2.9)
Setting for follow-up consultations		
At hospital by doctor	2910	(78.0)
At hospital by nurse	136	(3.7)
At hospital by a nurse and a doctor	383	(10.3)
Other or more places	272	(7.3)
Number of contacts to hospital within the past six months[c]		
0-2 contacts	3359	(90.0)
≥3 contacts	269	(7.2)
Contact to different types of providers (e.g. hospital, GP, community nurse) within the past six months		
1–2 types of providers	1045	(28.0)
≥3 types of providers	239	(6.4)
Experience of one health professional with oversight and responsibility for your overall follow-up pathway		
Yes	2015	(54.0)
No	1161	(31.1)
Error or complication during primary cancer treatment		
Yes	1451	(38.9)
No	2085	(55.9)

[a] Sex, age and cancer type was retrieved from The Danish National Patient Register. The remaining variables were patient-reported.
[b] Non-melanoma skin cancer is not included in the study.
[c] The sum of the percentages is less than 100% because of missing values.

consultation were ill-prepared on my course of disease (Table 3). Other errors during follow-up were reported by 177 (4.7%) of which 109 (61.6%) provided a free text comment. Errors related to:

- Poor/incorrect/lack of communication and information to the patient (n = 15/13.8%).
- Test or examination orders had not been made (n = 13/11.9%).
- Lack of coordination between hospital departments, e.g. diagnostic tests were not taken in proper order before consultation (n = 12/11.0%).
- Tests were incorrect or destroyed and had to be re-ordered (n = 10/9.2%).
- Delay or waiting time – either delay or an experience that waiting time between consultations was too long (n = 9/8.3%).
- A mix up of patients (n = 9/8.3%).
- Other: patients described e.g. a clinical complication, medication-event or misdiagnosis (n = 41/37.6%).

Table 2

Factors associated with patient-reported errors during follow-up. Univariate and multivariate analysis of 'all errors' (the three specific errors and 'other errors' combined). N = 3731.

	Number of patients reporting errors (%)	OR, univariate, unadjusted (95% CI)	OR, multivariate, adjusted[a] (95% CI)
Total	1029 (27.6)[b]	–	–
Sex		p-value = 0.243	–
Male	453 (26.7)	0.92 (0.79–1.06)	Not included
Female	576 (28.4)	[1] (ref)	
Age, yrs		p-value ≤ 0.000	p-value ≤ 0.000
18–49	191 (42.7)	2.01 (1.61–2.50)	1.31 (1.01–1.71)
50–59	223 (30.1)	1.16 (0.95–1.41)	0.82 (0.66–1.03)
60–69	386 (27.1)	[1] (ref)	[1] (ref)
≥70	229 (20.5)	0.69 (0.57–0.83)	0.71 (0.58–0.88)
Education		p-value ≤ 0.000	–
Elementary/intermediate school	211 (21.7)	[1] (ref)	Not included
Higher preparatory exam or school or skilled tradesman	372 (26.8)	1.32 (1.09–1.60)	
Medium cycle higher exam or more	408 (33.1)	1.80 (1.48–2.18)	
Cancer type		p-value ≤ 0.000	p-value = 0.016
Common cancers	722 (26.9)	[1] (ref)	[1] (ref)
Less common cancers	213 (25.9)	0.95 (0.80–1.14)	1.02 (0.83–1.24)
Rare cancers	94 (41.8)	1.95 (1.48–2.58)	1.60 (1.16–2.21)
Comorbidity		p-value = 0.007	–
Yes	439 (30.4)	1.27 (1.10–1.48)	Not included
No	527 (25.6)	[1] (ref)	
Self-rated health		p-value ≤ 0.000	p-value = 0.002
1 + 2 (Poor)	48 (44.4)	2.60 (1.75–3.85)	1.93 (1.22–3.04)
3–5 (Fair or good)	466 (32.6)	1.57 (1.35–1.83)	1.32 (1.11–1.57)
6–7 (Excellent)	475 (23.6)	[1] (ref)	[1] (ref)
Setting for follow-up consultations		p-value = 0.777	–
At hospital by doctor	811 (27.9)	[1] (ref)	Not included
At hospital by nurse	35 (25.7)	0.90 (0.61–1.33)	
At hospital by a nurse and a doctor	107 (27.9)	1.00 (0.79–1.27)	
Other or more places	70 (25.7)	0.90 (0.68–1.19)	
Number of contacts to hospital within the past six months		p-value ≤ 0.000	p-value ≤ 0.000
0-2 contacts	723 (25.2)	[1] (ref)	[1] (ref)
≥3 contacts	171 (40.1)	1.98 (1.66–2.37)	1.38 (1.11–1.71)
Number of contacts to different types of providers (e.g. hospital, GP, community nurse) within the past six months		p-value ≤ 0.000	p-value = 0.042
1–2 types of providers	286 (27.4)	[1] (ref)	[1] (ref)
≥3 types of providers	122 (51.1)	2.77 (2.08–3.69)	1.51 (1.07–2.12)
Experience of one health professional with oversight and responsibility for your overall follow-up pathway		p-value ≤ 0.000	p-value ≤ 0.000
Yes	395 (19.6)	[1] (ref)	[1] (ref)
No	518 (44.6)	3.30 (2.82–3.88)	2.88 (2.41–3.45)
Error or complication during primary cancer treatment		p-value ≤ 0.000	p-value ≤ 0.000
Yes	705 (48.6)	6.14 (5.22–7.23)	5.41 (4.57–6.42)
No	278 (13.3)	[1] (ref)	[1] (ref)
Missing information[c]	46 (23.6)	2.01 (1.41–2.86)	2.51 (1.73–3.64)

CI = Confidence interval; ref = reference group.

[a] All covariates with a p-value ≤ 0.1 in the univariate analyses are included in the multivariate analysis. The results shown from the multivariate analysis only includes the covariates with a p-value ≤ 0.05.

[b] The sum of all patient-reported errors will be less than the sum of the individual errors (in Table 3), as the responders can report more than one error.

[c] Missing information is included in the table as the OR was found significant.

Table 3
Factors associated with patient-reported errors during follow-up. Univariate and multivariate analysis of each of the three specific errors. N = 3731.

Specific Error Types	Important information (e.g. records, letters or test results) was missing (n = 3604)			I was not called in for a follow-up consultation as expected (n = 3394)			The doctor/nurse handling my follow-up consultation were ill-prepared on my course of disease (n = 3379)		
	Number of patients reporting errors (%)	OR, univariate, unadjusted (95% CI)	OR, multivariate, adjusted[a] (95% CI)	Number of patients reporting errors (%)	OR, univariate, unadjusted (95% CI)	OR, multivariate, adjusted[a] (95% CI)	Number of patients reporting errors (%)	OR, univariate, unadjusted (95% CI)	OR, multivariate, adjusted[a] (95% CI)
Total	423 (11.7)	–	–	332 (9.8)	–	–	565 (16.7)	–	–
Sex		p-value = 0.351	–	–	p-value = 0.542	–	–	p-value = 0.101	–
Male	201 (12.3)	1.10 (0.90–1.35)	Not included	145 (9.4)	0.93 (0.74–1.17)	Not included	240 (15.6)	0.86 (0.72–1.03)	Not included
Female	222 (11.3)	[1] (ref)		187 (10.1)	[1] (ref)		325 (17.7)	[1] (ref)	
Age, yrs		p-value ≤ 0.000	–	–	p-value = 0.002	–	–	p-value ≤ 0.000	p-value = 0.028
18–49	71 (16.2)	1.44 (1.06–1.94)	Not included	64 (14.6)	1.93 (1.39–2.68)	Not included	114 (26.4)	1.86 (1.43–2.41)	1.10 (0.81–1.48)
50–59	98 (13.5)	1.16 (0.89–1.52)		73 (10.2)	1.28 (0.93–1.75)		128 (18.2)	1.15 (0.91–1.47)	0.78 (0.59–1.02)
60–69	164 (11.8)	[1] (ref)		107 (8.2)	[1] (ref)		213 (16.2)	[1] (ref)	[1] (ref)
≥70	90 (8.5)	0.70 (0.53–0.91)		88 (9.5)	1.18 (0.88–1.59)		110 (11.9)	0.70 (0.55–0.90)	0.74 (0.57–0.97)
Education		p-value = 0.003	–	–	p-value = 0.559	–	–	p-value ≤ 0.000	–
Elementary/ intermediateschool	82 (8.9)	[1] (ref)	Not included	77 (9.3)	[1] (ref)	Not included	92 (11.1)	[1] (ref)	Not included
Higher preparatory exam or school or skilled tradesman	161 (11.9)	1.37 (1.04–1.82)		117 (9.2)	0.98 (0.72–1.32)		206 (16.1)	1.54 (1.18–2.00)	
Medium cycle higher exam or more	167 (14.1)	1.67 (1.26–2.21)		127 (10.8)	1.17 (0.87–1.58)		247 (21.4)	2.17 (1.68–2.81)	
Cancer type		p-value ≤ 0.000	p-value = 0.002	–	p-value ≤ 0.013	p-value = 0.054	–	p-value = 0.002	–
Frequent occurring cancers	278 (10.7)	[1] (ref)	[1] (ref)	230 (9.5)	[1] (ref)	[1] (ref)	409 (16.9)	[1] (ref)	Not included
Less common cancers	98 (12.3)	1.17 (0.91–1.49)	1.24 (0.95–1.62)	68 (9.0)	0.94 (0.71–1.25)	1.00 (0.74–1.35)	105 (13.9)	0.79 (0.63–1.00)	
Rare cancers	47 (21.3)	2.24 (1.59–3.17)	1.97 (1.34–2.90)	34 (16.0)	1.81 (1.22–2.68)	1.69 (1.12–2.56)	51 (24.4)	1.58 (1.13–2.21)	
Comorbidity		p-value = 0.004	–	–	p-value = 0.165	–	–	p-value = 0.005	–
Yes	188 (13.5)	1.38 (1.12–1.71)	Not included	142 (11.0)	1.24 (0.98–1.56)	Not included	248 (19.2)	1.36 (1.12–1.64)	Not included
No	203 (10.2)	1		174 (9.1)	[1] (ref)		282 (14.9)	1	
Self-rated health		p-value ≤ 0.000	–	–	p-value ≤ 0.000	p-value ≤ 0.004	–	p-value ≤ 0.000	p-value = 0.001
1 + 2 (Poor)	20 (19.6)	2.30 (1.38–3.84)	Not included	22 (22.9)	3.03 (1.79–5.12)	2.64 (1.55–4.51)	28 (29.5)	2.35 (1.46–3.77)	1.81 (1.06–3.10)
3–5 (Fair or good)	33 (15.1)	1.61 (1.30–1.99)		134 (10.4)	1.83 (1.18–2.84)	1.02 (0.79–1.31)	46 (22.7)	1.64 (1.13–2.39)	1.50 (1.21–1.85)
6–7 (Excellent)	113 (11.0)	[1] (ref)		160 (8.6)	[1] (ref)	[1] (ref)	147 (15.1)	[1] (ref)	[1] (ref)
Setting for follow-up consultations		p-value = 0.365	–	–	p-value = 0.083	–	–	p-value = 0.621	–
At hospital by doctor	325 (11.5)	[1] (ref)	Not included	259 (9.7)	[1] (ref)	Not included	455 (17.1)	[1] (ref)	Not included
At hospital by nurse	11 (8.4)	0.70 (0.38–1.32)		20 (17.4)	1.96 (1.19–3.24)		17 (15.7)	0.91 (0.54–1.54)	
At hospital by a nurse and a doctor	48 (12.9)	1.14 (0.82–1.57)		30 (8.6)	0.87 (0.59–1.30)		58 (16.8)	0.98 (0.73–1.32)	
Other or more places	37 (14.5)	1.30 (0.90–1.87)		22 (9.7)	1.01 (0.64–1.59)		31 (13.2)	0.74 (0.50–1.09)	
Number of contacts to hospital within the past six months		p-value ≤ 0.000	p-value = 0.003	–	p-value = 0.003	–	–	p-value ≤ 0.000	p-value = 0.007
0-2 contacts	276 (10.0)	[1] (ref)	[1] (ref)	238 (9.1)	[1] (ref)	Not included	375 (14.5)	[1] (ref)	[1] (ref)
≥3 contacts	131 (20.8)	2.37 (1.89–2.98)	1.57 (1.21–2.05)	82 (13.6)	1.57 (1.20–2.05)		165 (27.2)	2.21 (1.80–2.73)	1.49 (1.16–1.92)
				–		–	–		

Table 3 (*Continued*)

Specific Error Types	Important information (e.g. records, letters or test results) was missing (n = 3604)			I was not called in for a follow-up consultation as expected (n = 3394)			The doctor/nurse handling my follow-up consultation were ill-prepared on my course of disease (n = 3379)		
	Number of patients reporting errors (%)	OR, univariate, unadjusted (95% CI)	OR, multivariate, adjusted[a] (95% CI)	Number of patients reporting errors (%)	OR, univariate, unadjusted (95% CI)	OR, multivariate, adjusted[a] (95% CI)	Number of patients reporting errors (%)	OR, univariate, unadjusted (95% CI)	OR, multivariate, adjusted[a] (95% CI)
Number of contacts to different types of providers (e.g. hospital, GP, community nurse) within the past six months		p-value ≤ 0.000	p-value $= 0.000$		p-value ≤ 0.000			p-value ≤ 0.000	p-value $= 0.001$
0-2 types of providers	103 (10.2)	[1] (ref)	[1] (ref)	89 (8.9)	[1] (ref)	Not included	154 (15.7)	[1] (ref)	[1] (ref)
≥3 types of providers	69 (30.3)	3.82 (2.69–5.41)	2.18 (1.47–3.24)	41 (17.8)	2.23 (1.49–3.33)		87 (38.3)	3.35 (2.44–4.60)	2.03 (1.39–2.96)
Experience of one health professional with oversight and responsibility for your overall follow-up pathway		p-value ≤ 0.000	p-value ≤ 0.000	–	p-value ≤ 0.000	p-value ≤ 0.000	–	p-value ≤ 0.000	p-value ≤ 0.000
Yes	181 (9.2)	[1] (ref)	[1] (ref)	129 (7.1)	[1] (ref)	[1] (ref)	158 (8.6)	[1] (ref)	[1] (ref)
No	201 (17.8)	2.13 (1.72–2.62)	1.62 (1.28–2.06)	159 (14.6)	2.25 (1.76–2.88)	1.86 (1.44–2.41)	355 (33.2)	5.30 (4.31–6.52)	4.89 (3.92–6.10)
Error or complication during primary cancer treatment		p-value ≤ 0.000	p-value ≤ 0.000	–	p-value ≤ 0.000	p-value ≤ 0.000	–	p-value ≤ 0.000	p-value ≤ 0.000
Yes	354 (25.5)	13,4 (9.87–18.1)	11.77 (8.66–15.99)	250 (18.8)	6.79 (5.10–9.02)	6.28 (4.71–8.38)	378 (28.8)	4.26 (3.49–5.19)	3.37 (2.73–4.16)
No	51 (2.5)	[1] (ref)	[1] (ref)	64 (3.3)	[1] (ref)	[1] (ref)	168 (8.7)	[1] (ref)	[1] (ref)
Missing information[b]	18 (10.5)	4.57 (2.60–8.01)	4.74 (2.67–8.39)	18 (14.5)	4.98 (2.85–8.70)	5.00 (2.83–8.87)	19 (14.2)	1.74 (1.04–2.89)	2.09 (1.22–3.60)

CI = Confidence interval; ref = reference group.

[a] All covariates with a p-value ≤ 0.1 in the univariate analyses are included in the multivariate analysis. The results shown from the multivariate analysis only includes the covariates with a p-value < 0.05.

[b] Missing information is included in the table as the OR was found significant.

3.3. Factors associated with patient-reported errors

The results from the multivariate logistic analyses on the combined analysis of all errors (Table 2) are commented in the following. Table 3 show results from analysis of the three specific error types separately.

3.3.1. Patient related factors

Younger cancer patients (<50 years), patients with rare cancers and lower self-rated health were more likely to report errors. Sex, education and comorbidity were not associated with reporting of all errors.

3.3.2. Organisational settings and care transitions

Patients' that did not experience one particular health professional with oversight and responsibility for their overall follow-up pathway had an almost three times higher risk of reporting error compared to those that did experience one particular health professional. High usage of healthcare services (≥3 contacts) within the past six months increased the risk of reporting errors. The setting for the follow-up consultations, and whether it was a doctor or nurse handling the follow-up, was not associated with reporting of all errors.

3.3.3. Primary cancer treatment

Patients' that reported an error or complication during primary cancer treatment were more than five times as likely to report an error during follow-up compared to those that did not report an error or complication.

4. Discussion

To our knowledge, this is the only study addressing patient-reported experience of errors during cancer follow-up. 27.6% of patients reported at least one error during follow-up. Compared to studies on patient-reported errors during cancer treatment or hospitalisation the percentages of errors are on a par [5,7,9,15,23]. The frequencies of patient-reported errors are high compared to health professional estimates of errors [15,24]. The differing results may be due to patients and healthcare professionals having different perspectives on errors [6,25]. Further, many patient-identified errors are not captured by incident reporting systems, nor recorded in the medical record, including serious events [15,25,26]. The potential for patient involvement in detection of errors is increasingly acknowledged internationally [14,16,26].

4.1. Patient related factors associated with errors

It is well described that patient characteristics such as health status [13,17,19,20,27–29] and age [8,13,15,17,27–29] are related to experiences and responses to surveys. Patients with poor health status are more critical, maybe due to their frequent use of healthcare and the increased opportunity to experience errors [17]. These results support our findings. Older patients (defined as >60 years in some studies) generally give more positive evaluations of healthcare. It is shown that young adults diagnosed with cancer meet challenges that are different from those experienced by older patients [30]. This could explain why younger patients in our study were more likely to report errors, and not necessarily because they have a higher risk of errors.

We found that patients with rare cancers were more likely to report an error compared to patients with other more frequent cancer types. Not all patients with rare cancer are in a standardised follow-up care program and thus maybe more prone to errors. This indicates that the healthcare system and healthcare professionals are observant and responsive to common cancer types compared to rare cancers.

4.2. Organisational settings and care transitions associated with errors

Experience of poor coordination of care and contact to three or more different doctors is associated with experience of error [13]. The patient-reported errors in care transitions is often ascribed to lack of information continuity in transitions, especially when travelling between different healthcare units [8]. This supports our findings that patients with high usage of healthcare and patients that did not experience one particular health professional with oversight and responsibility for the overall follow-up pathway reported more errors. The latter is a modifiable factor with potential to reduce patient-reported errors however, we cannot conclude on the causality of the association.

Administrative processes are not always visible to patients. However, 11.7% of patients in our study report on errors involving e.g. missing referrals, test results or records. Equally, studies found that 8–21% of patients reported that test results, medical records or radiograms were unavailable when needed [20,26,31]. A Danish study of adverse events in cancer aftercare reported by health professionals showed that 50% of the adverse events were related to care transitions which very often led to delay in referral, treatment or diagnosis of recurrence or new cancer [4]. Other studies on patient-reported experiences demonstrate similar types of events: poor communication and lack of information to the patient, poor coordination of care, waits and delay [5,7,31–33]. A fragmented healthcare system has an inherent risk of these administrative errors going unnoticed and patients may play a vital role in bridging the gaps [5]. However, the responsibility for this should never be the patients'.

4.3. The role of past errors or complications

We found that the strongest factor associated with patient-reported experience of errors during follow-up was if the patient had experienced an error or complication during primary cancer treatment. Beside the possible explanation that patients who experienced an error may simply become more vigilant and critical in the future, the association can be understood in terms of error cascades, describing that one error initiates other errors like a chain of errors [34,35]. One study documents a chain of errors in 77% of incidents, comprising two to four errors. Most errors were initiated by errors in communication [36]. Error cascades can evolve entirely within a single healthcare location or across organisational boundaries [34,35]. Thus, errors can occur during follow-up as a result of errors during primary treatment because the patients' course will then be off track and prone to future errors. The analysis of error cascades indicates that the aetiology of error is complex [34,35].

4.4. Strengths and limitations of the study

A major strength of the study was its size, which ensures high statistical power. Furthermore, the population was well-defined and representative for Danish residents. Finally, selection bias was minimised as we identified the patients in the National Patient Register, including 98% of all cancer patients in Denmark. Most responders had breast-, prostate- or colon cancer. This distribution is anticipated and reflects – in addition to differences in incidence – the relatively higher survival, especially for the first two cancers.

Patient-experiences are highly subjective and the responses can be influenced by a variety of factors [27,29], e.g. recall bias and expectations. Expectations are an important determinant of patient-experienced quality [8,27,29]. Thus, some of the observed differences in patient-reported errors between groups are probably not due to differences in delivered care, but should rather be interpreted as differences in patient expectations between groups of e.g. different age, self-rated health and healthcare usage [29]. Finally, high healthcare usage and poor health status are risk factors for experiencing errors but they are also likely to affect ability and willingness to report.

The specific error types presented in the survey cover a relatively narrow range of events, e.g. they do not include medication or injuries during invasive procedures. Thus, this framing of questions may affect the broadness of events mentioned in the open-ended question on 'other errors'. However, this would probably just lead to underestimates of 'other errors'. Finally, our findings indicate that patients have a broader perspective on errors compared to health professionals'.

Patients were not invited to describe the consequences of the experienced errors. Thus, the impact of the errors cannot be estimated.

5. Conclusion

The results of this study indicate that patient-reported errors during cancer follow-up are similar to those experienced during cancer treatment. Potential implications in relation to patient safety are:

- Workflows related to test results, referrals, bookings and medical records have to be improved.
- Introduction of one particular healthcare professional with oversight and responsibility for the overall follow-up pathway may increase continuity and result in fewer patient-reported errors. However interventions are needed to examine this hypothesis.
- Patient reported outcome measures (PROM) can be used to identify patients vulnerable to experience errors (e.g. patients with poor self-rated health) so that special attention can be paid to them.
- Specific attention should be paid to patients with rare cancers and to the design of system interventions to enhance safety for this group of patients.
- As error during primary cancer treatment may lead to future errors, implementations of specific interventions targeting upstream errors are desirable.

Conflicts of interest

None.

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Authors Contribution

All of the four authors meet the ICMJE Recommendations for authorship credit.

Christiansen, AH has contributed substantial to the conception and design of the work, analysis and interpretation of data, and drafting the work.

Lipczak, H has contributed substantial to the conception and design of the work, the acquisition and interpretation of data, and revising the work critically for intellectual content.

Knudsen, JL has contributed substantial to the conception and design of the work and the acquisition and interpretation of data, and revising the work critically for intellectual content.

Kejs, AMT has contributed substantial to the design of the work, the analysis and interpretation of data, and revising the work critically for intellectual content.

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