

Patient complaints about communication in cancer care settings: Hidden between the lines

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ABSTRACT

Objectives: To investigate patient complaints in cancer care settings reported to patient advisory committees (PACs) and describe the frequency and content of communication failures across all reports.

Methods: Content analysis, with a summative approach, was applied to cancer care complaints (2016–2020) by 692 patients to PACs in one Swedish healthcare region.

Results: More than half the patients reported communication failures. Patients reported not receiving proper information, not being listened to, and being treated disrespectfully or impersonally. Communication failures occurred in different stages of the patients' cancer care, from diagnostic workup to end-of-life. Compared with the results of the PACs, communication failures were underreported, and were often combined with complaints in other categories.

Conclusions: Communication failures are hidden “between the lines” and do not appear clearly in existing reporting systems. Healthcare must utilize the knowledge conveyed by patient complaints and create conditions and environments that support healthcare providers in delivering person-centered care.

Practice Implication: A summary picture of patients' complaints in Swedish cancer care is provided. These results could be used to further improve the patient complaint system. Above all, the results could serve as a “wake-up call” about the importance of communication and a valuable resource in improving cancer care.

1. Introduction

Cancer is a serious health problem, and WHO reports that one in five people globally will face a cancer diagnosis at some time [1]. The incidences are higher in developed countries, but rates are also rising in lower-income countries [2]. Cancer in the general population has been described as a vicious, unpredictable, and indestructible enemy, evoking fears of the personal and social effects of the disease and of dying from it [3]. Patients suffering from cancer need high-quality, comprehensible, and timely information about the illness, treatments, and how to best manage their symptoms [4]. Healthcare providers (HCPs) need to support their patients and ensure that they have access to information about what they can expect during the course of the disease. However, patients often feel unsure about whom to approach with questions and when to do so [4].

In 2009, a government report, *A National Cancer Strategy for the Future* [5], stated that Swedish cancer care usually achieves good medical outcomes, but that it generally lacks an individual patient focus.

This problem is not unique to cancer care, but it may be particularly important in this case as the disease often follows a prolonged course and involves many disciplines [5]. The *Cancer Strategy* [5] resulted in the establishment of regional cancer centers (RCCs) in each of Sweden's six healthcare regions [6] to increase healthcare quality, improve care results, and achieve good health on equal terms for all [6]. The Patient Act [7], introduced in 2015, protects patients' rights and interests, including their rights to information, participation, and consent [7]. The *Cancer Strategy* [5] and Patient Act [7] have significantly promoted the improvement of cancer care in Sweden [6], although not all the intended impacts of the Patient Act have been realized [8,9]. Swedish cancer care is today paying more attention to patients' psychosocial factors, quality of life, and person-centeredness [6].

Communication is vital to establishing a trusting patient–provider relationship [10]—the core of person-centered care [10,11]—in which the patient is seen as a resourceful individual who should be informed, respected, and considered equal to the other parties in the healthcare team [12]. Communications that include the patient as an equal member

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of the healthcare team reportedly make the difference between adequate and missed care [13]. Contextual factors can affect clinical outcomes positively or negatively [14–17]. Person-centered communication positively influences patient–provider interactions, and can improve patient satisfaction, trust, and empowerment as well as reduce stress and anxiety [14]. Time constraints are barriers to effective communication in cancer care. HCP behaviors, such as arrogance, blunt delivery of bad news, and not responding to patient objections, could also impede high-quality interactions [18].

Complaints about healthcare illustrate patients' experiences of having their individual needs disregarded by healthcare professionals [19] and illuminate problems in healthcare not always identified by reporting systems (e.g., incident reports) [20]. An impartial patient advisory committee (PAC) to help patients and relatives with questions and complaints about healthcare has long been part of every Swedish county council. These complaints are a valuable resource for healthcare improvement. Patient complaints and needs have been described for specific cancers [21,22], settings [23,24], parts of the care chain [21, 22], and genders [25,26]. However, less is known about patient complaints in cancer care in general.

This study follows five years of complaints reported to PACs by patients suffering from cancer in one of Sweden's healthcare regions. Describing communication failures in all reports of patient complaints, regardless of other complaints, could clarify the extent and deepen our knowledge of communication failures experienced by patients with cancer.

The aims of this study were to investigate patient complaints in cancer care settings and to describe the frequency and content of communication failures in all reports.

2. Material and methods

2.1. Material

All reports to PACs in the four northernmost counties of Sweden (the Northern Health Care Region [NHCR]) concerning patients with presumed cancer during a five-year period (2016–2020) form the basis of this study.

2.2. Sample and setting

Context. NHCR is vast, covering about 52% of the area of Sweden, but is sparsely populated in parts and has less than 10% of the Swedish population. In one county, the university hospital provides tertiary and secondary care; the other three counties each have a county hospital providing secondary care. Together, all counties have eight more or less complete local hospitals also providing secondary care.

Complaints to local PACs are coded and filed in a national data system. Each report is supplied with one code consisting of one category and one subcategory (Table 1). The personnel assess the complaint coding based on the content and identified problems, often in dialogue with the complainant. The PAC reports received by the research team were unidentified and contained only the patients' gender and age, the role of the complainant (i.e., patient, relative, or another person), the addressed healthcare providers, the PAC coding, and a short summary of the event(s), sometimes with quotations from the complainant. Reports often lacked information on the type of cancer, prognosis, or how the complaints were communicated to the PAC. Throughout this article, the complaints are described as coming from patients, but individual complaints may have been made by a patient, a relative, another person, or an HCP.

2.3. Procedure

All reports by and about presumed cancer patients were scrutinized to identify and remove multiple reports in cases in which more than one

Table 1

The patient advisory committee manual (shortened version) for coding patients' complaints in categories and subcategories. Overview of number of patients with complaints in each category, and number of complaints in each category and subcategory.

Categories and subcategories	No. of patients	No. of complaints*
Care and treatment	454	510
Examination/assessment**		133
Diagnosis**		154
Treatment: ** <i>negative treatment effect (comments on the results not registered here)</i>		136
Pharmaceutical interventions: ** <i>side effects</i>		41
Nursing: <i>personal care, e.g., diet/nutrition, pressure ulcers, pain relief linked to nursing</i>		39
Second opinion: ** <i>dissatisfied with where/how it was obtained</i>		7
Results	69	69
Results: <i>unexpected, complications, damage; the patient is not satisfied with the result/feels injured despite information before the procedure</i>		69
Communication	354	443
Information: <i>about health conditions, treatment, examinations, aftercare, etc., has not been sufficient/given at the wrong time/been difficult to understand/not given in writing or not including relatives if necessary; cultural/linguistic barriers</i>		162
Participation: <i>the care has not been designed or implemented in dialogue with the patient; the patient's participation in care or treatment has not been based on the patient's wishes or individual conditions; the patient has not been listened to</i>		146
Consent: <i>the patient's right to self-determination and integrity have not been respected; treatment/examination has been given without the patient's consent; abuse</i>		2
Interactions: <i>matters not included in Patient Act; lack of empathy or unprofessional interaction are registered here</i>		133
Patient's record and secrecy	23	23
Documentation in the record: <i>documentation has violated the integrity of the patient; documentation is missing, incomplete, or incorrect; denied or delayed change of text in record</i>		21
Breach or hacking: <i>health service has violated secrecy and confidentiality, oral or written</i>		2
Economic aspects	35	35
Patient fees: <i>cost of drugs, etc.; general comments on fees</i>		8
Claims for compensation/guarantees: <i>cost proposals have not been realized; lost property; no compensation when surgery is canceled</i>		27
Access to healthcare	108	110
Access to care: <i>difficult to contact healthcare/HCP; contact not following agreement; difficulties getting to care facility</i>		47
Waiting time in care: <i>the promised time to care has not been realized; follow-up has not been fulfilled according to medical assessment; long waiting time for appointment /in waiting room</i>		63
Responsibilities of healthcare and organization	168	185
Right to choose care freely: <i>not given the opportunity to choose treatment options, providers, or aids</i>		2
Permanent care contact/individual care plan: <i>the patient's needs for safety, continuity, and security have not been met; care planning/discharge planning not done appropriately or at all</i>		69
Care processes: <i>lack of cooperation between different care units, care providers, and principals such as hospital care and primary care/municipalities; comorbidity, i.e., mental illness with concomitant somatic illness, with lack of coordination between providers</i>		82
Lack of resources/canceled interventions: <i>different priorities, lacks of staff and accommodation/hospital beds, outsourced care, aides not provided</i>		28
Hygiene/environment: <i>e.g., deficiencies in cleaning</i>		4

(continued on next page)

Table 1 (continued)

Categories and subcategories	No. of patients	No. of complaints*
Administration	60	61
Deficiencies in handling: <i>notifications of care, referrals, tests, test results; prescriptions not sent or reported to the patient, or not sent to the relevant care provider/care unit; matters not connected to medical assessment</i>		54
Certificate: <i>incorrect, substandard, delayed, absent/denied</i>		7
In addition	0	0
Other: <i>when no other category fits, for example, transportation to healthcare; when viewpoint is not valuable from an analytical perspective; should be used sparingly</i>		0

* A patient could have one or more complaints within the same category, as well as having complaints in more than one category. Also note that 15 patients had complaints within the two categories “Care and treatment” and “Results.”
 ** Denied, delayed, incorrect, absent/missed

discipline was involved in the same negative event or chain of care. If any of these reports contained new data, all information was compiled to give a concise picture. All specialties were noted, but for primary care the specific health centre was not reported.

2.4. Data analysis

All data were imported into Excel. Data were analyzed using content analysis [27] with a summative approach [28], using the PAC coding system as predetermined categories and subcategories (Table 1). The analysis was performed in several steps, beginning with repeated individual reading by the first and second authors (AH and EL). All complaints were independently coded by the authors. Unlike PAC, however, the authors chose up to three codes per report with no preference for one over another. Additionally, less prominent complaints were also registered. If the two authors disagreed, they discussed the report until they reached consensus. To validate the authors’ assessments, a comparison with PAC coding was performed for the two largest groups of complaints: *care and treatment, including results and communication.*

When all complaints in each category and subcategory were identified, the authors focused on describing the frequency and content of communication failures across all reports. The first author (AH) performed an additional reading of the reports containing communication complaints (information, participation, consent, and interactions) to identify the communication complaints related to complaints in other categories. Finally, a short summary of the content in each category and any related communication failures was added. Four of the authors (AH, EL, CF, and EJ) met on several occasions and discussed the coding and the results.

2.5. Ethical considerations

The research was approved by the Swedish Ethics Review Authority (No 2020–05680), according to the ethics standards and principles outlined in the ethics recommendations of the Swedish Research Council (Codex 2018), following the ethics principles of the Declaration of Helsinki [29].

3. Results

The results initially describe demographic data of the material. Thereafter, the communication complaints are presented, followed by an overview of the findings and communication failures across all reports.

3.1. Sample characteristics

For the 692 patients, 1436 complaints were identified. The process of establishing the present material on cancer complaints, representing 5% of all reports to PACs, is described in Fig. 1. For demographic data on patients and complainants, see Table 2.

The type of malignant disease was often missing in the reports. For 26% of the patients, the diagnosis was cancer of undefined type. The largest groups of malignancies specifically defined were cancers of the breast (11%), prostatic gland (9%), and colorectal cancer (9%) (data not shown).

3.2. Data on complaints

Most of the patients (73%) had more than one complaint (see Table 2). The option of more than three complaints was discussed for only 7% of the patients. For the numbers of complaints in each category and subcategory, see Table 1.

Patients addressing complaints to only one medical specialty dominated (87%), see Table 2. For the reported authorities and medical specialties, see Fig. 2. In total, 23% of the patients addressed primary care, 63% secondary care, and 7% both primary and secondary care. Only 3% of the patients addressed tertiary care in their complaints.

A high level of agreement between the PACs’ and the authors’ coding was found in complaints about care and treatment, including results (94%), and about communication (86%). However, this study identified 216 additional patients who complained about communication failures than did the PACs’ coding of the reports.

3.3. Communication complaints

A total of 354 patients (51%) reported communication failures, present from diagnostic workup to end-of-life. The number of communication complaints did not differ between the different years of the study period (data not shown; Chi-square test).

Patients reported not receiving information about their diagnosis or test results, even when they had clearly asked for it. They reported HCPs being in such a rush that they had no time to listen to patients or answer questions. Sensitive information was given to patients by letter, over the telephone, when patients were in public surroundings, at night, or when no relative or friend was present. Patients also reported mixed messages from HCP, resulting in confusion and frustration. Patients reported not being listened to and feeling that their symptoms and worries were trivialized or not taken seriously. Patients felt misunderstood, doubted, discriminated against, and opposed, and they did not feel part of the decisions about their care. Patients described impersonal, unfeeling, condescending, offensive, unpleasant, and insensitive interactions with HCPs, who were sometimes felt to be unprofessional to the point that it was unforgivable. Patients reported being laughed at, met with irony, or

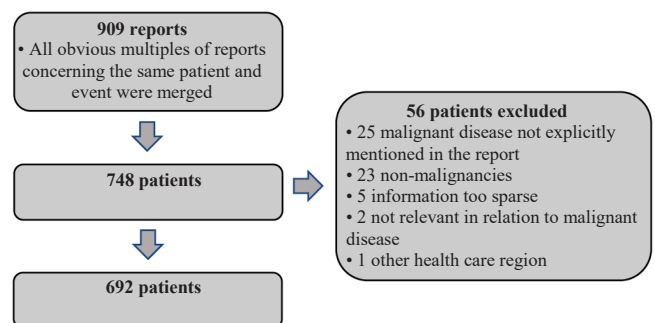


Fig. 1. Flow-chart describing review of the material from all reports to patients included in the study material.

Table 2
Demographic data on patients, information on informants, numbers of patients reporting one or more complaints, and numbers of patients addressing one or more medical specialties.

Data on patients, n = 692	
Mean age (range) years*	64 (4–97)
Median age, years	67 (IQ range 55; 74)
Women	391 (57%)
Men	301 (43%)
Died before report	96 (14%)
Died during reporting process	4 (0.6%)
Reports to PAC** from	
Patients	426 (62%)
Relatives	241 (35%)
Both patient/relatives	16 (2%)
Other person/personnel	9 (1%)
Number of patients reporting complaints	
One complaint	186 (27%)
Two complaints	268 (39%)
Three complaints	238 (34%)
Number of patients addressing medical specialties	
One medical specialty	603 (87%)
Two medical specialties	60 (9%)
Three medical specialties	19 (3%)
Four to six medical specialties	10 (1%)

* For 27 patients (4%), information on age was missing.

** PAC = patient advisory committee

made to feel that they were being difficult.

3.4. Overview of findings and communication failures across all reports

The content of communication failures across all reports is presented in the following categories and in Table 3a. Quotations illustrating the findings are presented in Table 3b.

3.4.1. Care and treatment

In this category, patients' complaints addressed denied or lacking as well as insufficient examinations, and symptoms that were misinterpreted or incorrectly investigated. Patients reported cancer diagnoses that were missed, inaccurate, or delayed. They also reported discovering, during retrospective reviews of x-rays and when "benign" tumors later metastasized, that their malignancies could have been found earlier. Patients complained about incorrect or delayed treatments and that tumors grew during the waiting time. Incorrect pharmaceutical dosages and prescriptions not distributed as agreed or prescribed despite serious allergies were also reported. In complaints related to nursing, patients reported HCPs to be inattentive, lacking in hygiene, and denying fundamental care (e.g., help with toileting). Communication failures related to care and treatment included information, participation, and interactions. Complaints included patients not receiving proper information, not being listened to, and

Addressed authorities and medical specialties

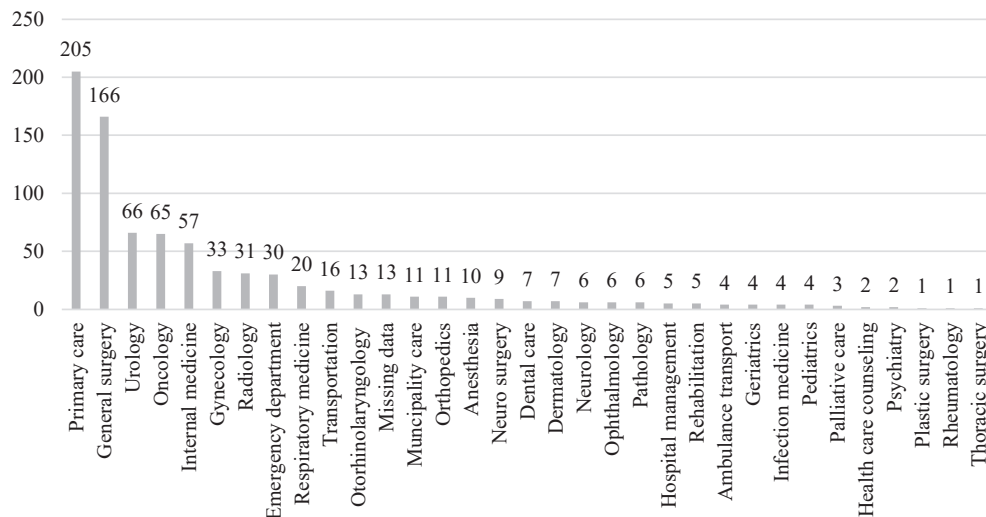


Fig. 2. Authorities and medical specialties addressed in reports to local Patient advisory committees. Radiology includes clinical physiology; transportation is that provided by healthcare.

Table 3a
Number of patients reporting communication complaints (information, participation, consent, and interaction) in other categories.

Category	No. of patients	No. of communication complaints in each subcategory				Total no. of communication complaints
		Information	Participation	Consent	Interaction	
Care and treatment	199	73	96	-	75	244
Results	15	7	3	-	5	15
Patient's record and secrecy	2	-	1	1	-	2
Economic aspects	0	-	-	-	-	-
Access to health care	12	6	3	-	4	13
Responsibilities of healthcare and organization	46	23	23	1	11	58
Administration	5	4	-	-	2	6

If two other categories were related to a communication complaint (n = 82), only the most accurately related is disclosed in the table. If more than one communication complaint was identified for one other category (n = 59), both communication complaints are disclosed.

Table 3b
Quotations illustrating the findings of communication failures across all reports.

Category	Short summary and quotation
Care and treatment	A man sought care on several occasions for recurrent stomach pain. After two years, the patient was referred for an X-ray revealing a tumor. Chemotherapy treatment was started and after eight weeks it turned out that it had no effect on the tumor as the treatment did not comply with the biopsy results. <i>"The patient experiences deficiencies in information both about the further examinations and about how the care mediated the results of, for example, test results and further treatment efforts. ... The patient questions how such powerful treatment was started based on preliminary results and why no information was given about the results being preliminary. The patient feels that he himself had to run his care chain."</i> (Male, in his fifties)
Results	A man who had a stoma due to bowel cancer several years ago had experienced troublesome fecal leakage since the operation and had to use diapers. <i>"This situation severely impairs his quality of life. He has always thought that maybe this would go away, but was informed yesterday that during the operation "a seam burst" that is causing this. He wants help to find out why he was not informed about this."</i> (Male, in his seventies)
Patient's record and secrecy	A man had been bothered by abdominal pain for a long time and experienced that his pain problem was not taken seriously as part of his underlying disease. <i>"The man feels offended by the doctor's wording in the medical record, that he was only looking for a prescription renewal."</i> (Male, in his twenties)
Economic aspects	This category had no related communication complaints
Access to healthcare	Relatives reported not receiving feedback. <i>"At the time of death, they had questions about the treatment with blood transfusions where the doctor promised to return to the matter, which did not happen."</i> (Female, in her nineties)
Responsibilities of healthcare and organization	A patient had nutritional problems due to her cancer. <i>"The patient explains that in secondary care, there are always new doctors so there is no continuity and the patient feels insecure and does not know who is responsible. She also feels that she is met in a derisive manner, which makes it difficult for her to feel trust."</i> (Female, in her thirties)
Administration	A woman was contacted after a missed examination. <i>"The nurse who called the patient announced that she had an appointment the day before, whereupon the patient explained that she had not received the notification. She was of course very worried about the conversation and reacted saying that the tone was not pleasant but accusatory."</i> (Female, in her fifties)

unprofessional or unempathetic interactions in care situations.

3.4.2. Results

The complaints in this category addressed serious complications due to surgery, radiation, and pharmaceutical treatment (including chemotherapy). Related communication complaints concerned not receiving enough information about complications and not being listened to about symptoms after interventions went wrong. Patients reported unprofessional interactions such as nonchalant or derisive encounters, and they felt that HCPs avoided interacting with them after interventions failed.

3.4.3. Patient's record and secrecy

Patients reported complaints about their records and breaches of integrity, such as inaccurate information in their medical records or

delays in receiving requested copies. Confidentiality was not always ensured, as HCPs discussed patients with doors open. Related communication complaints regarded participation and consent, such as slanderous comments in records and patients' integrity not respected in social media.

3.4.4. Economic aspects

Complaints about economic aspects concerned questioned patient fees and compensation claims for treatments and travel. No related communication complaints were identified.

3.4.5. Access to healthcare

In complaints related to access to healthcare, patients reported problems contacting healthcare and that they were, in turn, not contacted as promised. They experienced long waiting times for examinations, consultations, assessments, and treatments. These delays led to worries and uncertainty, and in some cases to the cancer no longer being treatable. Patients lacked information about follow-up or waited for an appointment but were not contacted as promised. When patients contacted healthcare, they did not get information, were not listened to, or had unprofessional and unpleasant interactions.

3.4.6. Responsibilities of healthcare and organization

Patients complained about a lack of coordination between different hospitals, medical specialties, and care units, as well as between HCPs. Patients reported that they did not have any designated contact person, and that plans for patient care and discharge were either not made or not followed. They also reported cancelled operations and other treatments, multiple changes of care units, and receiving care in units belonging to another medical specialty. Lack of coordination between units and/or medical specialties led to loss of information, patients feeling not listened to, or patients being dealt with unprofessionally regarding their care and discharge plans.

3.4.7. Administration

In this category, the complaints were related to laboratory and test results not sent to patients, and tests and referrals lost. Patients lacked information about administrative errors and were dealt with unprofessionally when addressing the errors.

4. Discussion and conclusion

4.1. Discussion

This study investigated a large number of patient complaints in cancer care settings in Sweden to clarify the nature and extent of communication failures for patients with cancer. More than half the patients reported communication failures, often combined with other complaints. Communication failures occurred in different stages of the patients' cancer care, from diagnostic workup to end-of-life. Complaints about communication were stable over the five-year period. Complaints about one medical specialty dominated. As single speciality, primary care was most often addressed in the reports. However, secondary care out-numbered both primary and tertiary care in terms of complaints, when the different specialties in secondary care were aggregated. Compared with the results of the PACs, Sweden's most comprehensive reporting system in healthcare, communication failures were under-reported, and were often combined with complaints in other categories, excluding economic aspects.

Congruent with previous national and international studies of patient complaints nonspecific to cancer care, the largest groups of complaints concerned care and treatment, communication, and responsibilities of health care and organization [30,31], although the international study used different terms. In this study, patients reported situations during their cancer care when they did not receive proper information, were not listened to, and were treated disrespectfully or

impersonally. These complaints concern needs previously expressed by patients with cancer [4], and similar findings are also described in other studies of patient complaints nonspecific to cancer care [30,32]. Despite extensive structural improvements as a result of the Patient Act [7] and RCC [6] work in Swedish cancer care, challenges with communications and patient–provider relationships remain in cancer care, as in healthcare in general. The results clarify that a vulnerable group of patients, i. e., those diagnosed with cancer, report communication failures in various stages of cancer care. These patients have made a conscious decision to report uncaring relationships with HCPs. Communication failures are probably far more prevalent than this study reports, as not all patients file complaints about experienced failures. The filed complaints constitute an important voice for other patients as well.

The number of communication failures found in this study implies that this is not only a matter of individual HCP errors, but also a structural and perhaps even cultural problem within these organizations. In Sweden we continue to report about the same communication failures across the years [32,33], although we know that communication is crucial for patient safety and to achieve person-centered care [10,11]. How are we to move forward within healthcare organization? We could argue that healthcare leaders need to act urgently and focus on creating a system that helps HCPs to use their skills and full potential, developing trusting relationships with those being cared for, including their families [10]. Still, we all need to remind ourselves, and each other—as recently stated by Heath and Montori [34]—that care happens in the space between people, in unhurried encounters, and only humans in interactions can care.

The results highlight the complexity and challenges of cancer care, as well as one weakness of the national reporting system using single-issue coding. Most patients had at least two complaints about the same event or chain of care, so a single identified complaint could be inadequate to describe a patient’s experience. Communication failures may affect how other events are perceived [35], or may be important for patients and relatives to report in light of other errors. A systematic review noticed a difference in the distribution of complaints between studies using single-issue coding and those coding for multiple issues, with the former reporting fewer problems in communication [30]. By addressing more categories of complaints within the same report, this study identified more than twice as many communication complaints as were reported by the PACs.

A limitation of this study is that the reports are summaries written by the PACs and do not always include the patients’ original correspondence or words, especially as many complaints are reported by phone. Also, the reports contain no information about socioeconomic factors, education levels, or ethnicity. The study’s strengths include the breadth of the reports from patients suffering from all cancers, not just one specific cancer diagnosis, about communication failures throughout the care chain and concerning many medical specialties. The large sample, the thorough reading of all reports independently by two authors with different professional backgrounds (i. e., registered nurse and physician), and the repeated whole-group discussions of the coding of the research also strengthened the results.

4.2. Conclusion

Communication failures are underreported and a common cause of dissatisfaction in patient complaints. These communication failures are hidden “between the lines” and do not appear clearly in existing reporting systems. Despite great structural improvements in Swedish cancer care, patients’ communication needs are not always met. Healthcare must utilize the knowledge conveyed by patient complaints and create conditions and environments that support healthcare providers in delivering person-centered care.

4.3. Practice implications

A summary picture of patients’ complaints in cancer care is provided. These results could be used to further improve the patient complaint system and make it a reliable quality monitoring system coding for multiple issues within a single report. Above all, the results could serve as a “wake-up call” about the importance of communication and a valuable resource in improving cancer care and moving it toward the goal of person-centered care.

We confirm that all personal identifiers have been removed or disguised so that the persons described cannot be identified through the details reported here.

CRediT authorship contribution statement

Anna Hult: Formal analysis, Funding acquisition, Investigation, Writing – original draft. **Ewa Lundgren:** Conceptualization, Formal analysis, Investigation, Supervision, Writing – review & editing. **Camilla Fröjd:** Supervision, Writing – review & editing. **Anna Lindam:** Formal analysis, Writing – review & editing. **Eva Jangland:** Conceptualization, Methodology, Supervision, Writing – review & editing.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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