Information exchange in oncological inpatient care – Patient satisfaction, participation, and safety

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Abstract

Purpose: This prospective pilot study aimed to investigate patients’ perception of information exchange and its associations with patient satisfaction, participation and safety at inpatient oncology wards.

Methods and sample: Consecutive patients with cancer who spent ≥3 days at an oncological inpatient ward at the Department of Oncology, Karolinska University Hospital during the study period (March –August 2013) were invited to respond to EORTC-INPATSAT32 measuring patient satisfaction and a study specific questionnaire. Data on changes in medication and fall risk assessments was collected from the patients’ electronic health records.

Key results: A total of 104 patients (58%) participated in the study. Patients rated doctors’ and nurses’ information provision lower than their technical and interpersonal skills, and 13% considered the information exchange “excellent”. Changes in medication were registered for 83% of participating patients, which 56% of the patients were aware of. Fall risk assessment was registered for 73% of responding patients, and 39% reported having discussed risk of falling during the hospital stay. The Downton Fall Risk Index scores were not associated with actual falls or fall prevention actions.

Conclusions: Deficits were found on information exchange and information provision between health care professionals and patients. This might have a negative impact on known patient safety risks such as medication errors and falls. More effective strategies to perform fall risk assessments in an oncological inpatient setting are needed. Further studies evaluating interventions to improve participation and information exchange are necessary to increase patient satisfaction, participation and safety in oncological inpatient care.

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Introduction

Communication in health care is both complex and demanding. Providing patients and their families with adequate information concerning treatment and care is a challenge in most health care organisations. Traditionally, models of one-way information transfer have been used, which presuppose the health care provider as the expert communicator and the patient as a more passive receiver of information. However, person-centred care is driven by the patients’ needs and preferences and has proven to increase patient satisfaction, participation and safety (Alharbi et al., 2014; Zucca et al., 2014). This demands a shift to information exchange, a two-way dialogue where both patients and health care professionals contribute in partnership. A mutual exchange of information is also a prerequisite to ensure the understanding of the information, in both directions (Kreps, 2009; Lee and Garvin, 2003).

Patient satisfaction in cancer care is an important dimension in high quality service and can be described as the extent to which the patients’ health care experience matches the level and quality of care they expect. Studies have shown significant associations between patient satisfaction, adherence to treatment and high quality communication between patients and their health care providers (Bredart et al., 2005; Chow et al., 2009; Tomlinson and Ko, 2006).

Current Swedish laws also put clear demands on the health care system to meet both patients and their families’ rights to influence their own care. Patient participation is described as the health care staffs’ recognition and respect of each patient’s unique knowledge and individual view of different aspects of health and health care,
rather than just the invitation to be involved in decision making regarding treatment options (Eldh et al., 2006; Longtin et al., 2010).

Patients’ participation and perception of information are important, both for patient satisfaction and safety. In a recent, unpublished, survey from our department more than 50% of hospitalized cancer patients stated that the information exchange between shifts was insufficient. Well-informed patients are more likely to adhere with treatment recommendations, which is essential for the outcome and safety (Murphy et al., 2012). Several technical strategies to prevent errors have been implemented at many cancer centres (computerized prescribing, bar coding etc.) but involvement from patients and family members during hospital stays have also been described as an important safety strategy (Cohen, 2007; Martin et al., 2013). Patient participation is heavily promoted in patient safety contexts but there are few examples where interventions have been systematically evaluated (Hall et al., 2010; Lipczak et al., 2011; Schwappach, 2010). However, previous research have shown that cancer patients are willing to be more involved in patient safety, but that health care professionals rarely explain or discuss safety risks or preventive interventions (Martin et al., 2013; Schwappach and Wernli, 2010).

Two well-known patient safety risks for hospitalized cancer patients are medication errors (Lipczak et al., 2011) and falls (Capone et al., 2012; Spoelstra et al., 2013; Wolf et al., 2013). Medication errors might be particularly risky in oncology care with the use of extremely potent drugs where inadequate information exchange may have severe consequences (Cohen, 2007; Kullberg et al., 2013).

Fall risk assessments are typically performed by nurses at admission. Several fall risk assessment tools exist, and even if the effectiveness is not well studied in acute care settings for specific patient populations, they are widely used (Meyer et al., 2009; Wolf et al., 2013). Fall risk assessment is seen as a quality parameter of good nursing care and often linked to financial reimbursements. Fall risk prevention actions have proven to reduce the number of fall incidences for hospitalized cancer patients to some extent (Wolf et al., 2013). However, we found no studies on patient participation in fall risk assessment or prevention regarding hospitalized cancer patients.

The main objectives of this study were to investigate patients’ perception of information exchange and its associations with patient satisfaction, participation and safety at inpatient oncology wards.

**Methods**

**Patients**

This prospective pilot study was conducted at the Department of Oncology, Karolinska University Hospital, the only hospital in the region providing acute oncological inpatient care. Consecutive patients, ≥18 years, discharged from two of four inpatient wards after ≥3 days length of stay were weekly identified from discharge lists and asked for participation during the study period (March–August 2013), see below. Patients not speaking Swedish or in a terminal stage of cancer disease were excluded.

**Procedures**

Lists of discharged patients were collected once a week and an information letter, questionnaires (described below) together with a prepaid return envelope were sent to patients within two weeks after discharge. A reminder was sent to those not responding within one week. Patients not wishing to participate could avoid the reminder by returning the questionnaires uncompleted. This procedure was performed by the authors with back up from one clinical nurse.

**Data collection**

The following data were registered from the patients’ electronic health records (EHR): gender, age, length of stay, diagnosis, co-habital status, reason for admission, treatment intention, fall risk assessment according to Downton Fall Risk Index (Meyer et al., 2009), and if medication changes were made during the hospital stay.

Changes in medication are often performed during a hospital stay and all prescribed medications are recorded in patients’ EHR. Patients’ awareness of prescribed medication is a prerequisite for adherence to medication, especially after discharge from hospital. Therefore, any type of changes in prescribed medication during the hospital stay were collected and then compared with patient-reported data regarding changes in medication.

The fall risk assessment (Downton Fall Risk Index) should be performed by a nurse within 24 h from admission, according to the hospital’s guidelines. The index contains the following items: previous falls, current medication, impairments (visual, hearing, cognitive) and ability to walk. The scores are summed to a total score (0–11 points). The total score and preventive fall risk action are documented by the nurse in the EHR.

**Questionnaires**

Patient satisfaction with care was measured by a questionnaire developed within the European Organization of Research and Treatment of Cancer (EORTC) Quality of Life Group. The questionnaire, EORTC-INPATSAT32 consists of 32 items organised in 11 multi-item scales and 3 single-item scales (Bredart et al., 2005). Patients rate their perception of physician’s and nurses’ technical skills (3 + 3 items), interpersonal skills (3 + 3 items), information provision (3 + 3 items), availability (2 + 2 items); other hospital staff’s interpersonal skills and information provision (3 items), exchange of information (1 item), waiting time (2 items); hospital accessibility (2 items), comfort (1 item), and general satisfaction (1 item). The EORTC-INPATSAT32 was specifically developed for hospitalized patients with cancer, and testing has demonstrated excellent internal consistency and convergent validity, and high reliability (Bredart et al., 2005).

We failed to identify a validated instrument assessing patient participation in the inpatient setting including involvement, information exchange, information/communication, medication, fall risk, and integrity. Therefore, we constructed items within these areas, based on the aims of the study and the literature in order to supplement the EORTC-INPATSAT32. The study specific questionnaire consisted of items on patient participation specific for inpatient cancer care including involvement (9 items), information exchange (2 items), information/communication (4 items), medication (5 items), fall risk (2 items), and integrity (2 items). The questionnaire consisted of 24 items and it is not yet tested for validity or reliability.

**Statistical methods**

No formal sample size calculations were performed for this prospective pilot study. The response format to the EORTC-INPATSAT32 is a 5-point scale, ranging from 1 (“poor”) to 5 (“excellent”). Response scores were linearly transformed to a 0–100 scale, with higher scores representing higher satisfaction (Bredart et al., 2005). Continuous variables are presented as means and standard deviations (SD). The response formats for the study specific
questionnaire is a 4-point scale ranging from “not at all/never” to “very much/always” for 22 items and “yes” or “no” responses for two items. Descriptive statistics were used to present results. Categorical variables are presented by the total number of patients responding to each question together with the distribution (percentage) over the response categories. Differences between responders and non-responders were tested using the Mann–Whitney test for continuous variables and with Fishers’ exact test for categorical variables.

Results

The questionnaires were sent to all patients fulfilling inclusion criteria (n = 178) and 104 (58%) responded. Characteristics for responders are shown in Table 1. The mean age was 62 years (SD 13.4), ranging from 19 to 85 years and the medium length of stay was 7 days (SD 71), ranging from 3 to 62 days. There were no statistical significant differences between respondents and non-responders regarding any of the variables presented in Table 1.

Data from questionnaires and electronic health records

The scores from the EORTC IN-PATSAT32 scales (Bredart et al., 2005) are presented in Table 2. Highest scores were found for the scale measuring nurses’ technical skills, nurses’ interpersonal skills and general satisfaction. Scales regarding information provision from doctors rendered lower scores, as did doctors’ availability, information exchange, access and comfort and cleanliness.

Regarding the items assessing information, 13% of respondents scored “excellent” on the single-item scale measuring information exchange. The corresponding figures for the other information items, doctors’ and nurses’ information provision and information provided at admission and discharge from the hospital were between 25% and 35%.

Table 1

<table>
<thead>
<tr>
<th>Characteristics of responding patients.</th>
<th>N = 104</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender:</td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>37 (36)</td>
</tr>
<tr>
<td>Females</td>
<td>67 (64)</td>
</tr>
<tr>
<td>Cohabitation:</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>70 (67)</td>
</tr>
<tr>
<td>No</td>
<td>33 (32)</td>
</tr>
<tr>
<td>Missing</td>
<td>1 (1)</td>
</tr>
<tr>
<td>Diagnostic groups:</td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>25 (24)</td>
</tr>
<tr>
<td>Head &amp; neck</td>
<td>20 (19)</td>
</tr>
<tr>
<td>Urological</td>
<td>15 (14)</td>
</tr>
<tr>
<td>Gynaecological</td>
<td>19 (18)</td>
</tr>
<tr>
<td>Sarcoma</td>
<td>6 (6)</td>
</tr>
<tr>
<td>Gastro-Intestinal</td>
<td>13 (13)</td>
</tr>
<tr>
<td>Lung</td>
<td>5 (5)</td>
</tr>
<tr>
<td>Unknown</td>
<td>1 (1)</td>
</tr>
<tr>
<td>Treatment intention:</td>
<td></td>
</tr>
<tr>
<td>Curative</td>
<td>47 (45)</td>
</tr>
<tr>
<td>Palliative</td>
<td>56 (54)</td>
</tr>
<tr>
<td>Unknown</td>
<td>1 (1)</td>
</tr>
<tr>
<td>Admission:</td>
<td></td>
</tr>
<tr>
<td>Acute</td>
<td>72 (69)</td>
</tr>
<tr>
<td>Planned</td>
<td>32 (31)</td>
</tr>
<tr>
<td>Main reason for admission:</td>
<td></td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>22 (21)</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>13 (13)</td>
</tr>
<tr>
<td>Diagnostic work-up</td>
<td>4 (4)</td>
</tr>
<tr>
<td>Side effects</td>
<td>25 (24)</td>
</tr>
<tr>
<td>Pain</td>
<td>20 (19)</td>
</tr>
<tr>
<td>Other reason</td>
<td>20 (19)</td>
</tr>
</tbody>
</table>

Responses to the study specific questionnaire revealed deficiencies in the information exchange between shifts and patients’ participation. A total of 22 patients (22%) reported that the staff “never” or “sometimes” brought forward information between shifts without patient’s reminder. Regarding participation, about half of the patients (n = 50, 49%) reported limited influence (“not at all” or “a little”) over how their care was planned. A slight majority (n = 53, 52%) of the patients expressed a wish to be more involved (“a little”, “quite a bit”, or “a lot”) in decisions concerning care and treatment. More than half of the patients, 58% (n = 59) reported no awareness about what was documented in their electronic health record (EHS). The study specific questionnaire, together with number of responses in each response category, are presented in Table 3.

Changes in medication

Changes in medication were registered in the EHS for 86 (83%) of the responding patients during their hospital stay. According to responses in the study specific questionnaire, 48 (56%) patients reported that they were aware of these changes, and 38 (44%) patients left the hospital without recognizing the alterations in their medication. In addition, four patients reported changes in medication that could not be confirmed in the EHS. A total of 49 patients (47%) stated they did not wish further information concerning medication. Of these, 23 reported no medication changes during their hospital stay. This could be confirmed in the EHS for 7 of these patients.

Fall risk

Fall risk assessment, according to Downton Fall Risk Index, was performed for 76 (73%) of the responding patients. Eleven of these patients (15%) scored >3, indicating high fall risk. Fall prevention actions were registered in the EHS for 30 (29%) of the responding patients, including patients with a Downton score ≤2 (n = 15). A total of 39 (39%) of the responding patients reported having discussed fall risk during their hospital stay. For those 30 patients with documented fall prevention actions, 15 reported having discussed fall risk during hospital stay.

Four patients reported having experienced an actual fall during hospitalization. One with Downton score 4 (high fall risk), two with score 0 (no fall risk), and the final patient was not fall risk assessed. For two of these four patients, fall prevention actions were
registered in the EHR. One patient reported having discussed fall risk during the hospital stay.

Discussion

The main findings in this study concern deficits in information exchange between hospitalized cancer patients and health care staff. The insufficiencies concerned both health care professionals’ information provision and awareness about performed actions, such as changes in medication and fall risk assessment. For patients, adequate information is a prerequisite to participate in their care and health care professionals also need sufficient information from patients. These findings are important to oncology nursing since effective information exchange is crucial for clinical nurses when they assess and educate cancer patients and their families, perform symptom management and coordinate care.

Overall, the mean scale scores for patients’ satisfaction regarding information in this study were comparable to data from Bredart et al. (2005) in which 647 patients from 9 countries participated. The levels of satisfaction, expressed as mean scale scores, were quite high. This is a common finding when it comes to patient satisfaction and it has been suggested that dissatisfaction only are reported if extremely negative events have been experienced. To interpret the results with regard to information, we examined differences in the fractions of patients who scored “excellent”, and thus, were clearly satisfied, on the items relating to information. While 25–35% scored “excellent” on the scales measuring information provision, from health care staff to patient, only 13% scored “excellent” on the item measuring information exchange between health care staff, underscoring the need for improved information exchange.

Half of the patients reported not being able to influence the planning of their care or being aware of the documentation in their EHR. Patients’ access to their EHR has become increasingly common. The importance for health care professionals to acknowledge patients as true partners and provide possibilities for joint planning and decision making cannot be overestimated.

A vast majority (86%) of the responding patients had their medication altered during hospital stay, but only half of the patients were aware of these changes. Adherence is a well-known issue in cancer care (Hsieh et al., 2014). If patients are not aware of the medication changes, there is an obvious risk for unintentional non-adherence. An interesting finding is that 49 patients did not wish for more information regarding their medication. Some of these patients were not aware that their own medication had been changed. This implicates that the solution is not just to offer more information but to ensure exchange of information.
It has been suggested that nurses in acute care settings mainly have a task-oriented view on medication administration and thereby miss the opportunity to exchange information with patients on a daily basis (Liu et al., 2012). Repeated information exchange concerning medication, for instance during administrations and handover sessions could probably improve both patient participation and safety. Health care professionals’ attitudes towards involving patients in error prevention have been described as generally positive, but dependant on what type of errors being discussed (e.g. staff reacted negatively when patients questioned their hand sanitization, but positive when medical errors were detected) (Schwappach et al., 2013). In addition, the reluctance to involve hospitalized cancer patients in safety concerns due to fear of putting extra burden on an already vulnerable group have also been described (Martin et al., 2013). This enhances the need for a daily ‘safety check’, for example during shift handovers.

An important finding was that fall prevention measures were performed (according to EHRs) for a third of the responding patients, out of which half had been assessed to have a low fall risk according to Downton Fall Risk Index. This raises questions about the usefulness of Downton Index in the inpatient oncology setting, since nurses seem to identify fall risks not covered by the instrument. Several fall-risk factors for hospitalized cancer patients, frequent at inpatient wards, have previously been identified. Such as having advanced cancer, undergoing chemotherapy (Stone et al., 2012), intake of neuroleptics, opioids, corticosteroids (Pautex et al., 2009), and being fatigued (Capone et al., 2012). In our study, two of the four patients who reported a fall were assessed to have no fall risk at all according to Downton Index. The Downton Index (Downton, 1993) was developed for geriatric patients (Meyer et al., 2009; Nyberg and Gustafson, 1996). Together with the fact that nurses identified fall risks where Downton Index did not, and that frequent fall-risk factors for cancer patients are not included in the instrument is problematic and its applicability in the inpatient oncology setting should be further investigated.

There are several limitations with this study that need to be addressed. First of all, this prospective pilot study included only one measurement of a cohort, making it impossible to draw any causal conclusions. The study specific questionnaire was not tested for validity and reliability and the study sample was fairly small, and the response rate quite low, perhaps due to the study population consisting of seriously ill patients often in a palliative situation. However, no statistical differences in studied patient characteristics were found between responders and non-responders suggesting that responders were representative for patients fulfilling inclusion criteria. We did not collect data on types of drugs prescribed, number of prescribed drugs or changes. In order to minimize the time and effort required to participate in the pilot, we only asked patients to complete two questionnaires and thus, we have no data on e.g. health-related quality of life or educational level. All these factors could have had an impact on the information exchange process regarding medication. We did, however, use a consecutive sample to promote a representative population, we used a validated instrument where possible and the analysed data consisted of both patient reports and information from EHRs.

Conclusions

Effective information exchange is of great importance for the delivery of high quality oncological in-patient care. Insufficient information exchange may negatively impact known patient safety risks, such as medication errors and falls. Patient satisfaction is an important factor in optimizing care but high levels of patient satisfaction does not automatically translate into active participation. Patient participation is essential, though patients need to be fully aware of, for instance, prescribed medication and medication changes to be able to contribute to safe treatment and care.

More efficient strategies for fall risk assessments in cancer care are needed. The usefulness of fall risk assessment tools in oncological inpatient care needs to be improved. Both fall risk assessment and fall preventive actions need to be a part of the information exchange process during the hospital stay. Studies on more systematic approaches to improve information exchange, such as person-centred handovers are needed, and on-going, to increase patient satisfaction, participation and safety in oncological inpatient care.

Conflict of interest

The authors declare no conflict of interest and there has been no significant financial support.

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