Research Paper

Is patient behavior during consultation associated with shared decision-making? A study of patients' questions, cues and concerns in relation to observed shared decision-making in a cancer outpatient clinic

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ABSTRACT

Objectives: To explore how cancer patients actively participate in consultations by asking questions and expressing emotional cues/concerns and to what extent this is associated with physician shared decision making (SDM) behavior.
Methods: This observational study included audio recordings of 31 primary consultation with patients at the Oncology Outpatient Clinic at the University Hospital of North Norway. The content (topics) and frequency of health related questions from patients/caregivers were registered along with emotional cues and concerns (VR-CoDES) and observed shared decision-making (OPTION). Patient reported outcomes were measured before and one week after the consultation.
Results: On average, 17 (SD 15) questions were asked, and 1.9 (SD 1.9) emotional cues and concerns were expressed by patients per consultation. The questions mainly pertained to treatment and practical issues. The mean OPTION score was 12 (SD 7.9) and was neither associated with questions nor emotional cues and concerns from patients.
Conclusion: Although patients were active by asking questions, observed physician SDM behavior measured by OPTION was low and not associated with patient **behavior** during consultation.
Practice implications: Further research on patients' influence on physician SDM behavior is needed.

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1. Introduction

Patient centered care is widely acknowledged as a central element of high-quality health care [1] and effective physician-patient communication is associated with improved health outcomes like reduced levels of anxiety [2,3]. Norwegian health care legislation has guaranteed patients the right to receive information and to be involved in decisions regarding their own health [4]. One of the assumptions underlying shared decision making (SDM) is that the provided information must be comprehensible and adapted to the individual patient [5]. Asking questions is an effective way for patients to receive information customized to meet their needs.

In a UK study of 2331 cancer patients, the majority preferred to have as much information as possible, both the good and the bad [6]. Patients' highest information need has been found to be in the time period close to when receiving the diagnosis [7]. Hagerty et al. reported that 98% of patients wanted their doctor to be realistic, provide opportunities to ask questions, and acknowledge them as individuals when discussing prognosis [8]. There is also evidence of today's patients being more active participants in the medical encounter when it comes to asking questions [9].

The frequency of questions asked by patients varies across cultures and settings [10–12]. Whether or not the individual patient raise questions during their consultations with the physician also depends on a complex interplay between individual factors of the patient and the physician, as well as the context of the consultation. Previous research has found question asking associated with patients' educational level [13] and level of anxiety [10]. Supportive talk and a partnership-building

communication style by the doctor may facilitate patient involvement, as well as patients expressions of worries and concerns.

Cancer patients may experience emotional distress during the entire course of treatment [14–18]. Worries may be expressed explicitly as questions or concerns, but also implicitly as hints or cues [19]. Physicians' recognition of patients distress may reduce anxiety and increase satisfaction [20]. However, doctors tend to be less responsive to patients' emotions than to their informational needs [19].

SDM has been defined by Charles et al. as a set of principles, involving at least the clinician and patient [21]: Both parties share information, both parties take steps to build a consensus about the preferred treatment and an agreement is reached on the treatment to implement. No gold standard exists for objectively measuring SDM. There is evidence that patients asking targeted questions can influence physician behavior towards more SDM [22]. To our knowledge, no previous study has explored patient's natural verbal behavior in the form of question asking and expression of cues and concerns in relation to observed SDM. However, it can be assumed that there might be a relationship between patients being active participants in the consultation and the level of physician SDM behavior. The purpose of this study was to examine how Norwegian cancer patients actively participate in consultations by asking questions and expressing cues and concerns and what patient characteristics determine this behavior. Furthermore, to explore to what extent this behavior is associated with SDM. We hypothesized that more active patients (asking questions and expressing cues and concerns) were more involved in SDM than less active patients.

2. Method

This study was part of a project exploring the effect of communication aids on question asking, SDM and patient reported outcomes (anxiety/depression/quality of life) and includes data from the control group.

2.1. Sample

Physicians and patients were recruited from the Cancer Outpatient Clinic at the University Hospital of North Norway (UNN). This outpatient clinic receives patients with various cancer diagnoses from the three northernmost counties in Norway, admitted for assessment of oncological treatment (chemotherapy, radiotherapy etc.).

2.1.1. Physicians

Physicians at the Oncology Department at UNN receive a minimum of one year of clinical training before seeing newly admitted patients at the Outpatient Clinic. Physicians who fulfilled this requirement were invited to participate and written informed consent was obtained. Physicians involved in the design and implementation of the research project were excluded (four senior physicians).

2.1.2. Patients

We aimed to have 30 participating patients. Newly admitted patients were recruited from the participating physicians' outpatient lists in the period from April to June 2014. Eligibility criteria included: Age 18 to 75, Norwegian speaking, and able to complete questionnaires.

Author AA identified patients, and eligible patients received a written invitation approximately one week prior to their appointment. Those who agreed to participate when phoned by the study nurse, met with her before the consultation to sign a written informed consent and complete the pre-consultation questionnaire. The subsequent consultation with the physician was audio recorded. One week after the consultation, the patient received the post-consultation questionnaire by mail.

2.2. Analysis of audio records of consultation

The audio files were transcribed verbatim and the following elements were coded from the transcripts: Questions from patient/caregiver, emotional cues and concerns expressed by the patients along with physicians' responses and to what extent physician SDM behavior occurred. Coding was performed by two psychology students.

2.2.1. Questions from patients/caregiver

A manual was developed to ensure coding agreement. Patient and caregivers questions were coded into 14 categories.

Table 1 displays the 14 categories of topics questions were coded into.

One of the two coders coded questions in each consultation. Physicians' invitation to ask questions was coded as either absent, basic or extended, and whether it happened in the first/middle/last part of the consultation. Basic endorsement was coded when the physician asked if the patient had any questions. Extended endorsement was coded when the physician additionally emphasized the importance of asking questions.

2.2.2. Emotional cues and concerns

Patients' emotional cues and concerns, and physicians' responses were coded from the transcripts according to the Verona coding definition of emotional sequences (VR-CoDES) [23] and provider response (VR-CoDES-P) [24]. Author KL coded the transcripts after completing training with training material provided at the International Association for Communication in Healthcares' website (www.each.eu). Training was supervised by a member of the group of developers of the VRCoDES (SB). Coding of each exercise was successively discussed with the supervisor until the coding was in accordance with the recommended values in the training material. During the coding process, the coder and supervisor met regularly and reviewed the coding and discussed cases of uncertainties.

Due to the limited sample of consultations and the relatively low frequency of emotional cues and concerns, the subtypes of cues were not coded (only the frequency of events). In the carefully monitored coding process, the majority of consultations were based on a coder and supervisor consensus, and inter rater reliability was considered not applicable.

2.2.3. SDM

The OPTION scale measures to what extent physicians involves patients in SDM [25]. The scale includes 12 items evaluating

Table 1
Displays the 14 coding categories questions were coded into.

1.	When and how to ask questions
2.	Diagnosis
3.	Tests
4.	Prognosis
5.	Optimal care
6.	Multidisciplinary team
7.	Treatment options
8.	Treatment
9.	Costs
10.	Sources of information
11.	Relatives
12.	Life style
13.	Practical
14.	Other

physician SDM behavior. All items are rated from 0 to 4, where 0 indicates absence of SDM behavior and 4 indicates excellent performance.

The OPTION scale was translated according to best practice. Two translators fluent in English with Norwegian as their native language made separate translations. These were merged into one Norwegian translation by panel members SB and AA. A professional translator fluent in Norwegian with English as his native language back-translated this version into English. All translations were discussed by panel members SB and AA to decide on a final Norwegian version.

The two coders were trained by SB and AA. After three sessions of group training, individual coding was performed and all elements of each consultation were discussed to agree on the correct coder response. In 11 consultations, coding was decided upon consensus between the two coders, SB and AA. Following this initial coding, the two coders coded each consultation separately. After an additional 10 coded consultations the coding agreement was checked to keep consistent coding throughout the process.

The data were analyzed based on the mean of the scores of the two raters (except for the 11 consensus scored consultations), and the sum OPTION score was transformed into a scale ranging between 0 and 100 as recommended by the developer of the scale [25].

2.3. Questionnaire data

2.3.1. Patient characteristics
Data on patient characteristics collected in the pre consultation questionnaire included age, gender, marital status, education, occupation and main language.

Anxiety level was measured before the consultation using the Hospital Anxiety and Depression Scale (HADS) [26]. This widely used 14-item scale measures the current level of anxiety and depression. Each of the two seven-item subscales has a minimum value of 0 and a maximum value of 21.

2.3.2. Decision making
A Norwegian version of the validated Control Preference Scale (CPS) [27] was used to address patients preferred level of involvement in treatment decision-making in the pre-consultation questionnaire. The CPS differentiates between patients wanting an active, passive, or collaborative role in decision-making.

2.4. Statistics

Descriptive statistics were used to display frequency. Simple and multiple linear regression analyses, with questions from patient, patient/caregiver and number of cues/concerns as dependent variables, were used to explore associations between patient verbal behavior and patient/consultation characteristics. Pearson correlation coefficient was used to address the relationship between patient question asking and expression of cues and concerns.

The relationship between patient question asking and observed SDM was explored by recoding consultations into three groups based on number of questions asked

Oneway ANOVA was used to compare mean OPTION scores for these groups. Independent sample t-test was used to assess the relationship between the OPTION scores in consultations where cues and concerns were expressed, compared to consultations where this behavior did not occur. ANCOVA was used when introducing anxiety before consultation as a covariate in these two analysis.

Inter-rater reliability for coding of OPTION Scores and questions during consultation were computed by the intraclass correlation coefficient (ICC). Data were analyzed using SPSS version 23.

3. Results

3.1. Participants

A total of 19 physicians were invited to participate and all accepted. Of the 19 physicians, 13 had one or more participating patients (range 1–4). Most physicians were female (7 of 13) and senior physicians (8 of 13).

Of the 46 eligible patients invited, 34 (74%) consented to participate. Three consultations were not audio recorded; two because the physician did not feel comfortable making the audio recording and one due to technical failure. Thus, a total of 31 audio files were available for analysis and included in the study. All

Table 2
Baseline characteristics of 31 consultations with newly admitted cancer patients. Patient characteristics were retrieved from questionnaire pre consultation. The type of cancer was retrieved from questionnaires one week after consultation. Goal of treatment, treatment decision, and type of implemented treatment were obtained from transcript.

	No of patients	%
Patient Age, years		
Mean	57	
SD	14	
Patient Gender		
Female	20	64
Male	11	36
Caregiver present	7	23
Patient marital status		
Married	19	61
Partnered	5	16
Unmarried	7	23
Patient education		
Year 10 and below	8	26
Year 10/HSC	12	39
University degree	7	23
Higher degree	4	13
Patient first language		
Norwegian	30	97
Other Nordic	1	3
Patient primary tumor site		
Colon/anal	5	16
Breast	12	39
Lung	1	3
Testicular	2	7
Other	6	19
Missing data	5	16
Patient anxiety score[a]		
Mean	5.0	
SD	3.5	
Patients preferred SDM level[b]		
Active	4	13
Collaborative	7	23
Passive	20	64
Goal of treatment		
Curative	23	74
Palliative	8	26
Treatment decision		
Adjuvant treatment	18	58
Primary treatment	9	29
No treatment	3	10
Continuing treatment	1	3
New implemented treatment		
Radio therapy	14	52
Systemic therapy	13	48

[a] Measured by Hospital Anxiety and Depression Scale (HADS) pre consultation.
[b] Control Preference Scale measuring patients' preferred level of shared decision making (SDM) pre-consultation.

patients completed the pre-consultation questionnaire and 26 of 31 (84%) completed the one week follow-up questionnaire.

Table 2 shows the patient characteristics of the 31 consultations.

3.2. Audio files

The mean consultation length was 36 min, ranging from 11 to 73 min.

3.2.1. Physicians inviting patients to ask questions

In 90% (28 of 31) of consultations physicians verbally invited patients to ask questions. Most often, (18 of 28) the invitation came at the end of the consultation. None of the physicians explicitly endorsed the importance of asking questions.

3.2.2. Questions from patients/caregiver

The ICC for the total number of questions (from 14 consultations coded by both coders) indicated good inter-rater agreement (ICC = 0.84).

The number of questions asked by the patients varied widely from one to 63 questions (mean 17, SD 15, median 11). Caregivers were present in seven of the consultations and had an active role by asking questions in five of these. Questions raised by caregivers were relatively fewer than questions asked by the patients, except for one consultation in which the caregiver asked more questions than the patient. When including caregiver questions, the mean number of questions per consultation was 20 (SD 21, median 13).

Fig. 1 shows distribution of questions from patients/caregivers by topics.

The most frequent type of questions from patients and caregivers were concerning treatment 42% (261 questions) and practical issues 24% (154 questions). On average, each consultation had 8.7 questions (SD 10.4) concerning treatment and 5.0 questions (SD 5.3) concerning practical issues. Only seven of the 615 questions (1%) referred to prognosis, occurring in 4 of the 31 consultations. Four of the 615 questions (0.7%) dealt with treatment options, occurring in 2 of 31 consultations. In the follow-up questionnaire, the vast majority of patients 96% (25 of 26) reported that they had good opportunity to ask questions.

Associations between number of patient questions per consultation and selected characteristics of the patient and setting were assessed in a regression analysis. The analysis included gender, age, educational level, anxiety score, presence of caregiver, curative/palliative setting and consultation length as independent variables in both the univariate and the multivariable regression model. A separate analysis included both caregiver and patient questions. Pre consultation anxiety was significantly associated with the number of questions throughout all analysis. Educational level was significantly related to the number of questions only when including caregiver questions. The association between the number of questions and consultation length found in the univariate analysis lost its significance when included in the multivariable analysis.

Table 3 shows results from univariate and multivariable regression investigating the association between patient and patient/caregiver questions and patient/consultation characteristics.

3.2.3. Emotional cues and concerns

A total of 40 cues and 18 concerns were identified. Although cues and concerns were absent in one third of the consultations, the majority of patients, 22 of the 31 (71%) expressed one or more cue or concern during the consultation. The mean number of cues per consultation was 1.3 (SD = 1.35, range 0–5), and the mean number of concerns was 0.6 (SD = 1.09 range 0–5). The majority, 47 of the 58 (81%) cues and concerns were physician-initiated versus patient-initiated. Furthermore, the physicians' response to patients' cues and concerns were more frequently (45/58, 78%) explicit and inviting, and less non-inviting. Patients asking more questions expressed significantly more cues and concerns than those asking few questions (r(29) = 0.47, p = 0.007). Association between number of cues and concerns per consultation in relation to patient characteristics was estimated in regression analysis. Independent variables included gender, age, educational level, anxiety score, presence of caregiver, palliative/curative setting and consultation length. The association between number of cues and concerns and consultation length found in the univariate analysis lost its significance when included into the multivariable analysis. Pre consultation anxiety was the only factor significantly associated to number of cues and concerns in both the univariate and multivariable regression model.

Table 4 shows the results from univariate and multivariable regression analysis investigating the association between patient
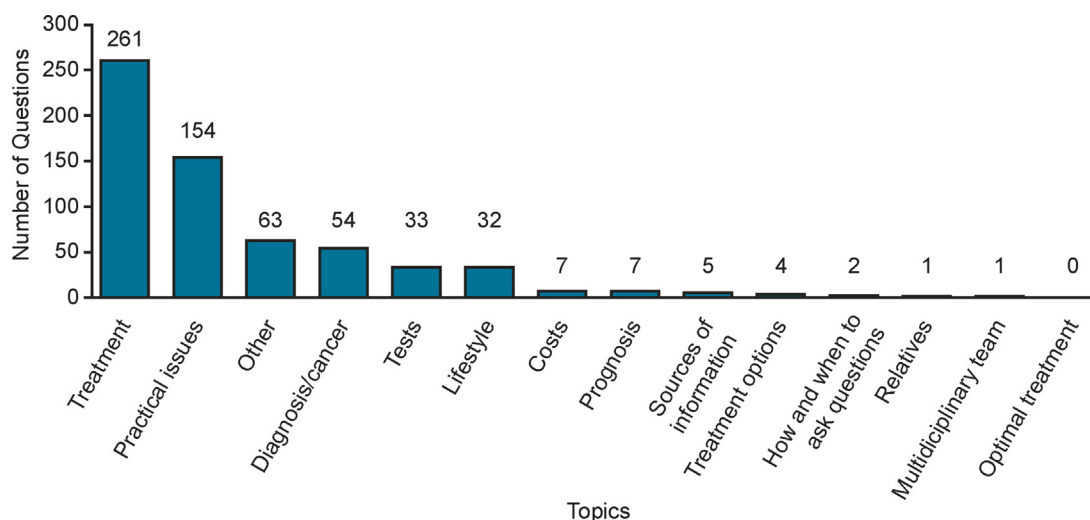

Fig. 1. Percentage distribution of topics in 615 questions asked by patients and caregivers during 31 primary consultations at the Oncology Outpatient Clinic.

Table 3

Univariate and multivariable regression investigating the association between patient and patient/caregiver.questions and patient/consultation characteristics. Male gender as reference group. Age, educational level, anxiety score and consultation length handled as continuous variables, caregiver present and curative/palliative setting as dichotomous variables.

	Univariate analysis		Multivariable analysis	
	Unadjusted regression coefficient	p-value	Adjusted regression coefficient	p-value
Number of questions from patients				
Gender	−0.86	0.88	−2.20	0.66
Age	−0.061	0.77	0.04	0.82
Educational level	4.48	0.11	5.39	0.075
Anxiety score (pre consultation)	2.47	0.002	2.94	0.001
Caregiver present	6.40	0.33	−5.80	0.44
Curative/palliative setting	−1.72	0.79	3.43	0.57
Consultation length	0.39	0.025	0.32	0.12
Total number of questions from patients and caregivers				
Gender	1.30	0.88	0.90	0.89
Age	−0.22	0.46	−0.05	0.84
Educational level	8.23	0.035	8.07	0.049
Anxiety score (pre consultation)	3.30	0.006	3.56	0.002
Caregiver present	19.4	0.033	4.51	0.65
Curative/palliative setting	−0.29	0.98	3.68	0.64
Consultation length	0.70	0.003	0.41	0.13

Table 4

Univariate and multivariable regression investigating the association between number of cues and concerns from patients and patient/consultation characteristics. Male gender as reference group. Age, educational level, anxiety score and consultation length handled as continuous variables, caregiver present and curative/palliative setting as dichotomous variables.

	Univariate analysis		Multivariable analysis	
	Unadjusted regression coefficient	p-value	Adjusted regression coefficient	p-value
Number of cues and concerns				
Gender	1.21	0.095	1.16	0.089
Age	0.01	0.62	0.02	0.35
Educational level	−0.07	0.85	−0.14	0.71
Anxiety score (pre consultation)	0.32	0.003	0.29	0.007
Caregiver present	1.46	0.078	0.03	0.98
Curative/palliative setting	0.34	0.67	0.12	0.88
Consultation length	0.04	0.05	0.05	0.056

cues and concerns in relation to patient/consultation characteristics.

3.2.4. OPTION score

The ICC for the total OPTION scores (computed from 20 consultations coded by both coders) indicated acceptable inter-rater agreement (ICC = 0.78). The mean score was 12 (SD 7.9), with scores ranging from 2 to 30 (a higher score indicating a higher degree of SDM). OPTION score was not associated with physician characteristics (gender or senior/junior physician).

3.2.5. Assessing the relation between patient behavior and shared decision making

When assessing the relationship between questions during consultation and observed SDM, we included questions from caregivers when present, since questions from patients and caregivers often complement each other. For further analysis, consultations were grouped according to the number of questions asked: Consultations with few (0–9), medium (10–19) and many (20+) questions. Oneway ANOVA did not reveal any significant difference in OPTION scores between these groups (F(2,28) = 1.09, p = 0.35). Further, the independent sample t-test did not reveal any significant difference in mean OPTION score in consultations in which patients expressed emotional cues and/or concerns compared to those consultations in which this behavior did not occur (t = −1.09, p = 0.29). Introducing anxiety before consultation

as a covariate in these two analysis (using an ANCOVA model) did not reveal any significant difference in OPTION scores between patients in the different groups.

Table 5 displays the 31 consultations grouped according to number of questions from patients/caregivers and presence of cues and concerns along with mean OPTION score.

Questions concerning treatment options and prognosis were rare in our material and made analysis on their potential individual effect on OPTION score impossible.

4. Discussion

This study explored central elements of communication in a sample of 31 consultations with newly admitted patients in a Norwegian cancer outpatient clinic. The patient verbal behavior that was explored included patient/caregiver questions and patients' expression of emotional cues and concerns. Physician behavior included verbal expressions indicating SDM behavior. Patients' reported pre-consultation anxiety level and their preference for involvement in the decision-making process were also obtained. The number of questions during the consultations varied considerably, increasing with higher levels of anxiety. Previous studies have also shown the number of questions to vary considerably between individual patients, but also in different oncology settings [10,12,29]. The majority of questions from both patients and caregivers in our study referred to treatment and

Table 5
The 31 consultations grouped according to number of questions occurring from patients/caregivers and presence of cues and concerns along with mean Option score.

Number of questions occurring in consultations	Number of consultations	Mean Option score (SD)
0–9	n = 11	9,3 (6.0)
10–19	n = 10	13,3 (10.1)
20+	n = 10	13,9 (7.2)

Emotional cues and concerns	Number of consultations	Mean Option score (SD)
No	n = 9	14.5 (10.0)
Yes	n = 22	11.1 (6.9)

practical issues, whereas questions concerning central issues such as prognosis and treatment options occurred in very few consultations. This could be due to information provided by the physicians without the patients asking for it or in previous encounters with other health care workers. However, research has found that patients ask more questions concerning prognosis when provided with simple communication aids, such as a question prompt list [30,31], suggesting patients to ask these type of questions when prompted to.

Cancer patients usually express 2–3 cues and concerns during consultations [32]. In this study, we found that patients expressed relatively few emotional cues and concerns (mean 1.9) during the consultations and that number of cues and concerns was related to level of anxiety pre consultation. Most cues and concerns were initiated by physicians, suggesting physicians' behavior to be important for patients to express their emotional concerns.

Norwegian health care legislation ensures patients the right to be involved in decisions regarding their own health [4]. The lack of consensus in defining SDM makes it difficult to explore in practice [33] but OPTION has been suggested as an efficient and sensitive coding system for SDM in the oncology setting [34]. The OPTION scores in this study indicated a relatively low level of physician SDM behavior, and comparable low levels have previously been reported in the oncology setting [34]. The low OPTION scores in our study might reflect the seriousness of the disease and that the majority of patients in our study initially preferred a passive role in the decision-making process. Furthermore, decisions may vary in how well they fit a SDM process. Some situations may have one strong evidence-based option that indeed should be recommended by the physician, while other decisions may have multiple options with less clear evidence, and be more preference-sensitive. Unfortunately, we have no data on the type of decisions in this study. This should be Included in future studies. The low SDM level may also reflect that some of the items in this original OPTION scale are seldom used, and a five item OPTION coding system has been introduced [35] to better utilize the full scale. In our sample, the level of observed SDM was neither related to number of questions nor the presence of cues and concerns. However, the small sample size gives this study a limited power to detect a small difference in OPTION score between the groups. Patients asked few questions concerning treatment options and prognosis, which are central elements of SDM. This made it difficult to further explore the relationship between patients asking specific questions and the observed physician SDM behavior.

The main limitation of this study is the small sample of patients and the limitations of a single center study. On the other hand, one of the strengths is that all eligible physicians at this oncology department accepted participation in the study. In studies involving single physicians from different institutions it may be expected that physicians with particular interest in communication would be most likely to participate. The patients in this study were mostly female (64%). Although gender was not associated with the number of questions or cues and concerns, this skewed gender distribution might have affected other aspects of the study.

5. Conclusion

Patients tended to be active in asking questions and the number of question increased with increasing levels of anxiety. Providing prognostic information and treatment options seems to depend upon physicians, since patients articulated few questions exploring these topics. Emotional issues were also related to level of anxiety and mostly initiated by physicians, which further supports physicians' important role in facilitating communication. This study found no association between the number of questions or emotional cues and concerns from patients and physician SDM behavior.

5.1. Practical implementation

Patients being active during consultation by asking questions and expressing emotional cues and concerns, does not appear to alter physicians' behavior to involve patients in SDM. In this sample, questions concerning treatment options and prognosis were very few. Further research on patients' influence on physician SDM is desirable, and one potential hypothesis is that providing patients with communication aids might broaden patients' repertoire of questions and thereby affect physician SDM behavior.

Ethics

This study was carried out in accordance with The Code of Ethics of the World Medical Association (Declaration of Helsinki). It was declared a quality assurance project by the Regional Committee for Medical and Health Research Ethics (REK) and approved by the Data Protection Official for Research (NSD) representative at the hospital. All patient/personal identifiers have been removed or disguised so the patients/persons described are not identifiable and cannot be identified through the details of the story.

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