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Supporting doctor-patient communication: Providing a question prompt list and audio recording of the consultation as communication aids to outpatients in a cancer clinic

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ABSTRACT

Objective: To document the effect of a cancer specific question prompt list (QPL) on patients question asking and shared decision-making (SDM), and to evaluate the combined effect of the QPL and consultation audio recording (CAR) on patient outcomes.
Method: This exploratory study compared two groups of patients receiving either a QPL or combined QPL/CAR, to a control group. Measurements included number/types of questions asked, and physician SDM behavior (OPTION score). Questionnaire data included anxiety/depression and quality of life (QoL).
Results: A total of 93 patients participated (31 Control, 30 QPL and 32 Combined). Patients in the intervention groups asked more questions concerning prognosis ($p < .0001$), the disease ($p = .006$) and quality of treatment ($p < .001$) than patients in the control group, but no impact was found on the OPTION score. An increase in mean consultation length was observed in the intervention groups compared to the control group (44 vs. 36 min; $p = .028$). Patients rated both interventions positively.
Conclusion: Provision of the QPL facilitates patients to ask a broader range of questions, but does not increase physician SDM behavior.
Practical implementation: The combination of QPL and CAR seems feasible and should be tested in an implementation study following the disease trajectory.

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1. Introduction

Evidence based medicine is the cornerstone of medical treatment and it is argued that real evidence based medicine should include sharing decisions with patients through meaningful conversation [1]. Shared decision making (SDM) is defined by Charles et al. as involving at least two participants (the physician and patient) that both share information, take steps to build a consensus about the preferred treatment, and agree on the treatment to be implemented [2]. One of the assumptions underlying SDM is that the information is provided in a way that is understandable and adapted to the individual patients' need [3]. The Norwegian health care legislation ensures patients the right to receive necessary information and to participate in SDM [4].

In a UK study of 2331 cancer patients, the vast majority wanted as much information as possible [5]. Patients' strong preference for information is a consistent finding in over 25 years of communication research [6]. Asking questions during medical consultations may facilitate physicians to provide information, and it helps patients obtain the specific information that is most important to them. Furthermore, patients who actively participate in the medical encounter receive more facilitating communication from their physicians [7]. Question prompt lists (QPLs) and consultation audio-recordings (CARs) are communication aids that may facilitate question asking and information recall.

A QPL is a structured list of questions patients may want to ask their physician during the medical encounter and has been

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developed for various areas of cancer care [8–10]. QPLs can increase patients' question asking [11], especially regarding specific topics such as diagnosis and prognosis [12]. Furthermore, a shortened consultation length, reduced anxiety and improved information recall are found when the oncologist explicitly addresses the QPL [13]. Implementing QPLs in routine oncology practice is feasible, and in a study from 2012, 44% of patients provided with a QPL reported to have used it during their medical encounter [14]. There is some evidence suggesting that patients asking target questions may influence physicians towards more SDM behavior [15]. To our knowledge, the direct effect of QPLs on SDM has not been previously investigated.

CARs are audio recordings of consultations for the patient to keep. A Cochrane review found that most cancer patients provided with an audio file of the consultation listened to the audiotape, found it valuable and reported that it helped them inform their family and friends [16]. In a randomized control trial (RCT) by Hack et al. [17], men with prostate cancer given a CAR of their initial treatment consultation, reported being significantly better informed about aspects of their illness and treatment. Similar results were reported from a RCT of patients with oesophageal cancer [18], where patients provided with a CAR from the diagnostic consultation, demonstrated significantly better information retention without experiencing adverse psychological outcomes.

Even though both communication aids are highly valued by patients, the combination of QPL and CAR is sparsely explored except for a recent study of consultations in four different (non-cancer) outpatient clinics. In this study, providing the combination of a QPL and CAR, positively affected the patients' perception of being adequately informed [19].

To date, the effect of QPLs on patients' question asking has mainly been investigated in countries where English is the first language. However, based on literature review, this has not been done in Norway.

Thus, the aim of this study was to investigate the effect of a culturally adapted Norwegian QPL [20] separately and in combination with a CAR in consultations with newly admitted patients to an outpatient cancer clinic. Our study was designed to test whether the QPL increased the number of questions asked by patients/caregiver in a Norwegian setting. Furthermore, we explored if and how the QPL affected the degree to which physicians included patients in SDM. We also examined to what extent the QPL, and the combined QPL and CAR, affected patients' satisfaction, their anxiety/depression and quality of life (QoL) compared with cancer patients receiving consultations without these tools.

2. Method

2.1. Setting

The study was conducted at the Cancer Outpatient Clinic at the University Hospital of North Norway (UNN), serving patients with a wide range of cancer diagnoses from the three northernmost counties in Norway.

2.2. Participants

2.2.1. Physicians

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

2.2.2. Patients

Patients were recruited from the Cancer Outpatient Clinic at UNN in three different time periods (assuming no seasonal variation in the admitted patients). We aimed to have one group of patients as a historic control group (Control group), one group of patients receiving the QPL only (QPL group) and one group receiving both QPL and CAR (Combined group). The recruitment occurred in the periods of April to June 2014 (Control group), April to June 2015 (QPL group) and November to January 2015/2016 (Combined group). Eligibility criteria included age 18 to 75, newly admitted to the Cancer department, Norwegian speaking and no cognitive dysfunction. The combined group also had to have access to a computer to play the audio recording.

Author AA identified patients from the participating physicians' outpatient lists. Eligible patients received a letter of invitation one week prior to their appointment. All participating patients signed an informed consent form and completed the first questionnaire prior to the consultation, which was audio recorded. Patients in the QPL and Combined group received the QPL by mail prior to the consultation. Patients in the Combined group received the CAR on a memory stick immediately after the consultation. One week after the consultation, all patients received a second questionnaire by mail.

2.3. Study design

This exploratory study was carried out with a quasi-experimental design. The data collection from the control group receiving regular care was completed prior to the recruitment of the intervention groups to minimize any learning effect on the physicians. In the first intervention group (QPL group) patients received the QPL prior to the consultation and in the second intervention group (Combined group) they received the QPL before consultation and a CAR after the consultation. Neither the patients nor the physicians were blinded to the interventions. Fig. 1 shows the study design.

2.4. Interventions

2.4.1. QPL

The Norwegian QPL is a 4-page A5 booklet (Appendix A) that applies to most oncology consultations, and was previously shown to have face validity and high patient acceptability [20]. The physicians were asked to address the QPL as early as possible in the consultation and to encourage the use of the QPL and question asking in general.

2.4.2. Consultation audio record (CAR)

A CAR was provided to patients in the Combined group only. The research nurse copied the CAR from a handheld audio recorder onto a memory stick. The memory stick was handed directly to the patient, and a copy was stored in the research database.

2.5. Analysis of the audio files (Immediate results)

Medical transcription staff at UNN transcribed all the audio files verbatim. Two trained psychology students at the masters level coded the consultations.

2.5.1. Questions asked by patients/caregivers

A manual for coding the questions was developed to ensure reliable coding. The physicians' verbal attempt to invite patients to ask questions was coded either as absent, basic or extended and in what part of the consultation it occurred (beginning, middle, end). Extended invitation was coded if the physician emphasized the importance of asking questions. The patient and caregiver questions were coded separately into one of 14 categories.

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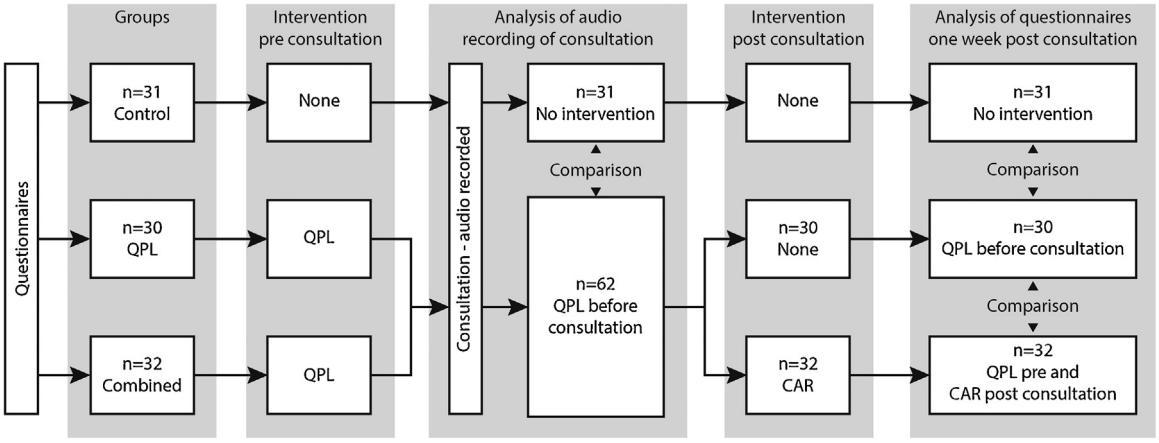

Fig. 1. Flow diagram of the study design.

2.5.2. Observed SDM

The OPTION 12 scale measures to what degree physicians engage patients in SDM [21]. It is widely used and proved applicable in the oncology setting [22]. The scale consists of 12 items evaluating doctor SDM behavior during a consultation. All the items are rated from 0 to 4, where 0 indicates the absence of SDM behavior and 4 indicates excellent performance.

SB and AA trained the coders, and after an initial consensus coding of OPTION on 11 consultations, individual coding was performed. The coding agreement was regularly checked throughout the coding process and differences were discussed by SB, AA and the two coders to ensure consistent coding.

The data were aggregated by calculating an OPTION sum score, which was transformed into a scale ranging from 0 (least involved) to 100 (most involved) as recommended by Elwyn et al. [21].

2.6. Questionnaire data

Patient characteristics were gathered in the pre consultation questionnaire and included age, gender, marital status, education, occupation and main language. The physician characteristics included gender and if they were specialists in oncology.

The anxiety/depression levels were measured before and one week after the consultation using the Hospital Anxiety and Depression Scale HADS [23], consisting of 14 items measuring the current level of symptoms of anxiety and depression. High scores indicate a higher level of anxiety/depression.

Health related quality of life was measured by the European Organization for Research and Treatment of Cancer (EORTC) QoL-C30 Version 3.0 [24] prior to and one week after the consultation. High scores indicate better quality of life.

The Control Preference Scale (CPS) [25] differentiates between patients preferring an active, passive or collaborative role in decision-making and was used to address the patients' preferred level of involvement in the pre consultation questionnaire.

The Cancer Patient Experiences Questionnaire (CPEQ) [26] is a Norwegian validated self-report instrument covering important aspects of outpatient cancer care and consists of 6 subscales. In this project, we used the scales concerning doctor contact and information retrieved. The possible scores on both scales range from 0 to 100, and a high score indicate high satisfaction.

2.7. Statistics

The sample size calculation was performed to decide the necessary sample size to detect significant differences in the number of questions between patients receiving the QPL and a control group. Initially, there was no similar previous research from a Norwegian setting, and the sample size calculation was based on international findings. We expected Norwegian patients to ask on average 12 questions (SD6) during the consultation and assumed a 30% increase to be clinically significant. We chose a 2:1 ratio (merging the QPL and combined QPL/CAR vs no intervention). The sample size calculations indicated that 27 patients were needed in the Control group to have 80% power to detect a difference on a 5% significance level.

Differences between the control group and the two merged intervention groups on total amount of questions, consultation length and on the OPTION score were analyzed by independent sample *t*-test. Differences regarding subgroups of questions were analyzed with Mann-Whitney *U* test due to a skewed distribution with high proportion of zero counts. Differences between the three individual groups on questionnaire data were analyzed using ANOVA and ANCOVA model. Effect sizes were provided by calculating Cohen's d and Partial Eta Squared.

The inter-rater reliability was analyzed using the intra-class correlation coefficient (ICC). All the statistics were performed using the Statistical Package for the Social Sciences (SPSS) version 23.

3. Results

3.1. Participants

All the physicians working at the Cancer Outpatient Clinic at UNN consented to participate in all three phases, except one physician who did not participate when including patients in the Combined group. The 93 consultations were distributed among 22 different physicians, each having between 1 and 9 participating patients throughout the three time periods of the study. Most consultations were conducted with senior (61%), male (56%) physicians.

In total, 150 patients were invited to participate in the study, and 34 of 46 (74%) accepted in the Control group, 31 of 43 (72%) accepted in the QPL group and 34 of 61 (56%) accepted in the Combined group. Among the patients aged 65 to 75 years who were asked to participate in the Combined group, only 10 of 25 (40%) accepted. Of the 15 non-participating patients, eight reported not having access to a computer, one reported to have access and for six patients these data were missing.

Six of the consultations were not audio recorded. Two of these were in the Control group, where the doctor did not feel comfortable recording the consultation, one was due to technical failure, two were because the consultations were rescheduled, and

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one patient in the Combined group declined to participate before the consultation.

While the Combined group had an even gender distribution, the Control group included relatively more female patients (65%), and the QPL group more male patients (63%). The gender distribution in the groups was reflected in the proportion of the primary tumor site being either breast or prostate cancer. Table 1 shows baseline characteristics and demographics of the patients in the study.

3.2. Analysis of audio records

The analysis in this section concerns the effects of the QPL on events occurring during the consultation. The results from patients receiving the QPL (QPL and Combined group together, n = 62) were compared to the Control group (n = 31). The second intervention in the Combined group (CAR) occurred after the consultation and did not affect the consultation. The mean consultation length for patients receiving the QPL (QPL and Combined group) was significantly longer, 44 (SD16) minutes compared to 36 (SD16) minutes in the Control group ($t = -2.23$, $p = .028$).

3.2.1. Question asking

The inter-rater ICC for the total amount of questions (computed from 27 consultations coded by both coders) indicated a good inter rater reliability (ICC = 0.84). Mean number of patient questions in the groups receiving the QPL (QPL and Combined group) was 23 (SD17) compared to 17 (SD15) in the Control group. An independent sample *t*-test did not reveal any significant difference between these groups ($t = -1.84$, $p = .070$).

A caregiver was present in 17 of 62 consultations (27%) in the merged intervention groups (QPL and Combined group) and in seven of 31 consultations (23%) in the Control group. Mean number of questions from the caregivers was 9.8 (SD15) in the merged intervention groups (QPL and Combined group) compared to 13 (SD 17) in the control group. An independent sample *t*-test did not reveal any significant difference in caregiver question asking ($t = 0.47$, $p = .64$).

In the merged intervention groups (QPL and Combined group), 73% (45 of 62) of the physicians explicitly addressed the QPL. Of those addressing the QPL, 51% (23 of 45) did so early in the consultation. The mean number of questions from patients/caregivers in these consultations was 35 (SD25), and significantly higher compared to 19 (SD12) in consultations where physicians addressed the QPL later ($t = 2.8$, $p = .008$). In 15% of the intervention consultations (9 of 62), the patient approached (proceeded) the physician in addressing the QPL and in 8% of the consultations (5 of 62) the QPL was not mentioned at all. Even though they were instructed to encouraged question asking, the physicians did so in only 15% of the consultations (9 of 62).

The questions were originally grouped into 14 categories. Due to low numbers of questions in some of the categories, the data were merged into related topics as described in Table 2.

Patients receiving the QPL (QPL and Combined group) asked significantly more questions concerning prognosis, the disease and quality of treatment. These differences were also present when including caregivers' questions into the analysis. The patient questions concerning practical issues were significantly more frequent in the Control group, and this difference was present when including caregiver questions.

Table 1
Baseline characteristics and demographics of patients in the 93 audio-recorded consultations. Patient characteristics were retrieved from questionnaire pre consultation. The type of cancer was retrieved from questionnaires one week after consultation. Goal of treatment was obtained from the transcripts. *Control Preference Scale measuring patients' preferred level of shared decision-making (SDM) from the pre-consultation questionnaire.

Characteristics	Control group (n = 31)		QPL group (n = 30)		Combined group (n = 32)		Total (n = 93)	
	No of patients	%	No of patients	%	No of patients	%		%
Mean age (SD)	57		63		59		60	
Sex								
Female	20	64.5	11	36.7	16	50.0	47	50.5
Male	11	35.5	19	63.3	16	50.0	46	49.5
Accompanying relatives	7	22.6	12	40.0	5	16	24	26
Marital status								
Married	19	61.3	18	60.0	17	53.1	54	58.1
Partnered	5	16.1	2	6.7	6	18.8	13	140
Unmarried	7	22.6	10	33.3	9	28.1	26	28.0
Education								
Year 10 and below	8	25.8	6	20.0	4	12.5	18	19.4
Year 10/HSC	12	38.7	9	30.0	15	46.9	36	38.7
Higher education <4yr	7	22.6	10	33.3	7	21.9	24	25.8
Higher education ≥ 4yr	4	12.9	5	16.7	6	18.8	15	16.1
First language								
Norwegian	30	96.8	30	100	30	93.8	90	96.8
Other	1	3.2	0	0	2	6.2	3	3.2
Tumor site								
Colon/anal	5	16.1	6	20.0	5	16.5	16	17.2
Breast	12	38.7	5	16.7	10	31.3	26	28.0
Prostate	0	0	5	16.7	7	21.9	12	12.9
Lung	1	3.2	0	0	0	0	1	1.1
Testicular	2	6.5	3	10.0	2	6.3	7	7.5
Other	6	19.4	7	23.3	6	18.8	20	21.6
Missing data	5	16.1	4	13.3	2	6.3	11	11.8
Therapeutic goal								
Curative	23	74.2	23	76.7	24	75.0	70	75.3
Palliative	8	25.8	7	23.2	8	25.0	23	24.7
Patients preferred SDM level*								
Active	4	12.9	3	10.0	3	10.0	10	11.0
Collaborative	7	22.6	10	33.3	12	40.0	29	31.9
Passive	20	64.5	17	56.7	15	50.0	52	57.1
Consultation length (mean, minutes)	36		45		43		42	

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Table 2
displays the 14 coding categories the questions were coded into, and the merged groups of related topics.

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

Table 3 shows number of questions related to the different topics for the patients and caregivers merged, and for the patients alone.

3.2.2. Observed physician shared decision making

The inter-rater ICC for the OPTION score (computed from 82 consultations coded by both coders) indicated a good inter-rater reliability (ICC = 0.85). The mean OPTION score in the control group was 12.1 (SD7.9) compared to 14.8 (SD9.2) in the two merged intervention groups (QPL and Combined group). An independent sample t-test did not find these mean OPTION scores different ($t = 1.42$, $p = .16$), suggesting no effect of the QPL on SDM as measured by the OPTION score.

3.3. Patient outcomes

The analysis of the questionnaire data one week after the consultation compared the Control group (n = 31), the QPL group (n = 30) and the Combined group (n = 32), receiving respectively, no intervention, the QPL and the combined QPL/CAR.

Analyzing data using ANCOVA model, adjusted for baseline values, did not reveal any differences in scores for anxiety/depression and QoL one week after the consultation.

Table 4 shows the mean scores for anxiety, depression and QoL one week after the consultation.

There was no significant difference between the three groups in how the patients evaluated the consultations with respect to the perceived physician contact and information retrieved.

Table 5 shows patients' rating of physician contact and information retrieved.

Table 4
shows the mean scores for anxiety, depression and total QoL as measured by HADS and EORTC QoL-C30 one week after the consultation. The scores are displayed by group, and ANCOVA was used to detect differences between the groups. Partial Eta Squared was calculated to display effect sizes.

	Control Mean (SD)	QPL	Combined	Partial Eta Squared	P value
Anxiety	3.9 (3.4)	3.6 (3.2)	4.5 (3.1)	0.008	0.73
Depression	2.0 (2.6)	2.5 (2.9)	2.6 (2.5)	0.026	0.38
Quality of Life	64 (20)	67 (19)	70 (20)	0.038	0.27

3.3.1. Patients' assessment of the communication aids

Of the patients receiving the QPL (QPL and Combined group), 53 of 56 (95%) said they read it, and 41 of 55 (75%) said they used it during the consultation. Thirty-five of 56 (66%) reported it to be useful to a large/very large extent. Furthermore 37 of 56 (66%) thought it might be useful in further consultations.

In the Combined group, the patients received the CAR directly after the consultation. In the questionnaire one week after consultation, they were asked to evaluate this communication aid, and 14 of the 30 responding patients (47%) reported that they had listened to the CAR one or more times. Of the 14 patients who had listened to the CAR, 11 reported it to be useful to a large extent, two patients reported it to be useful to some extent and one patient reported it to be less useful. Of the 16 patients who did not listened to the CAR, seven patients stated that they would listen to it later, three suggested they might listen to it later and four stating they would not listen to it. Seven patients let their partner/spouse listen to the CAR, two patients shared it with their children and one had other family/friends listen to it.

4. Discussion and conclusion

4.1. Discussion

Acknowledging the importance of communication, this study explored communication aids in a Norwegian oncology setting. The study was designed as an explorative intervention study of a QPL alone and in combination with a CAR compared with regular consultations.

Patients provided with the QPL did not ask more questions in total, but they tended to ask a broader range of questions, including more questions concerning prognosis, the disease and quality of treatment. This is in line with results in a review by Dimoska from 2008, suggesting that QPLs may cause patients to shift their focus of attention away from disease history and treatment to prognosis and diagnosis [12]. In our study, the number of questions from the

Table 3
shows mean number of questions related to the different topics for patient and caregiver merged and for patients alone. The data on specific groups of questions were analyzed using Mann-Whitney *U* test and analysis of total amount of questions were done using independent sample *t*-test.

Topic	Questions from patients and caregivers				Questions from patients			
	QPL/Combined group n = 62	Control group n = 31	Difference in mean	P value	QPL/Combined group n = 62	Control group n = 31	Difference in mean	P value
Treatment	10.4	8.4	2.0	0.05	9.2	7.5	1.7	0.09
Practical	3.0	4.7	−1.7	0.041	2.5	4.0	−1.5	0.03
Prognosis	1.7	0.2	1.5	<0.001	1.7	0.1	1.6	<0.001
The disease	5.6	2.9	2.7	0.002	5.0	2.5	2.5	0.001
Quality of treatment	1.5	0.2	1.3	<0.001	1.5	0.1	1.4	<0.001
Support	1.8	1.3	0.5	0.11	1.8	1.4	0.4	0.10
Other	2.1	2.2	−0.1	0.42	2.0	1.7	0.3	0.25
Total	26.1	**19.8**	**6.3**	**0.15**	**23.4**	**16.9**	**6.5**	**0.07**

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Table 5
Patients' rating of physician contact and information retrieved. Higher scores indicated higher satisfaction. P value for between group ANOVA. Partial Eta Squared was calculated to display effect sizes.

	Control group Mean (SD)	QPL group	Combined group	Partial Eta Squared	P value
Physician contact (0–100)	81 (14)	84 (12)	84 (11)	0.013	0.42
Information retrieved (0–100)	76 (14)	79 (13)	81 (13)	0.022	0.18

patients and caregivers was higher in the consultations where the physicians addressed the QPL early in the consultation, suggesting an additional effect when physicians address the QPL.

Even though the patients in our study provided with the QPL did ask more questions concerning prognosis and quality of treatment (including treatment options), the analyses did not demonstrate any increase in observed SDM behavior. Knowledge of the prognosis and treatment options are essential to enable physicians to decide on which treatment to offer. A shift in consultations towards discussing these elements more thoroughly might help patients increase their ability and desire to participate in SDM. A study from 2011 exploring the effect of standardized patients asking general practitioners for treatment options, their benefit and harms and the likelihood of these to happen, found increased physician SDM behavior as measured by OPTION [15].

Whereas providing a QPL mainly targets patients, the OPTION score only measures physician behavior. One can argue that a procedure focusing on provider behavior alone, and not integrating the patients activity, is problematic since the concept of SDM includes some sort of patient participation. Although patients' behavior will affect physician behavior, a more integrative model for measuring SDM including patient behavior, as proposed by Clayman [27], might have been more appropriate.

Neither anxiety/depression nor QoL at one-week follow-up were affected by the two interventions. Both communication aids were well received by patients in this study, but neither the patients' experience with physician information nor physician contact was affected by the QPL or the combined QPL/CAR. A nationwide study from 2009, including 7212 Norwegian cancer patients, reported a relatively lower CPEQ mean score (68) on satisfaction with information retrieved [28] compared to 76 in the Control group, 79 in the QPL group and 81 in the Combined group in our study. Theses scores are indicating that, compared to the national level, the patients in this study felt well informed. The questionnaire evaluating the communication aids was scheduled one week after the consultation. This might have been too soon after the consultation to evaluate the effect of CARs, since a relatively large proportion of patients stated they would listen to the CAR later.

Our study revealed a significant increase in the consultation length when patients were provided with the QPL. In contrast, Brown et al. [13] found physicians' endorsement of the QPL to shorten the consultation length. While Brown et al. included only nine physicians from two university hospitals, our study included 22 physicians from one university hospital. Physician compliance to encourage question asking was low in our study (only 15%) and might be a result of including several physicians with a varying interest in communication.

Newly admitted patients the Cancer Outpatient Clinic at UNN are scheduled with a timeframe of approximately 40 min, and an increased consultation length might be a challenge in a busy outpatient clinic. On the other hand, providing patients with necessary information is time consuming, and subsequent consultations might be shorter because more topics have already been discussed.

One advantage in this study is that nearly all the eligible physicians at this cancer department participated. Many former studies have included one or few physicians from different institutions, and this might be those particularly interested in communication.

Limitations in this study include the limitation of a single center study and the small sample of patients. This exploratory study had a quasi-experimental design with the entire control group preceding the consecutive intervention groups. Although not conducted as a RCT, this design might be beneficial to minimize any learning effect of the QPL intervention on physicians. The number of patients accepting the invitation in the Combined group was considerably lower than for the other groups, and some of the difference was due to not having access to a computer to listen to the audio file. Still, other factors might have affected the participation rate in this part of the study.

This study only included patients who were well enough to attend an outpatient consultation, making it difficult to generalize the results to an inpatient setting. Furthermore, it only explored the impact of the communication aids in a primary consultation at the Oncology clinic and not throughout the disease trajectory.

4.2. Conclusion

Our research showed that providing patients with a QPL did not affect total amount of questions from patients and caregivers, but increased specific questions concerning prognosis, the disease and quality of treatment. Despite the QPL facilitating patients and caregivers to ask more questions concerning prognosis and quality of treatment, important elements in the decision making process, it did not affect physician SDM behavior. Even though we did not find any significant change in patient outcomes when combining the QPL and a CAR, patients rated both communication aids positively. We also observed a significant increase in mean consultation length in the intervention groups compared to the control group.

4.3. Practical implication

While the QPL can be implemented easily in routine care, CARs need additional technical solutions to be suitable as standard of care. CARs provided to patients need to be integrated in the work flow and also take care of the juridical aspect of providing patients with CARs. Thus, providing the combination of QPL and CAR as routine practice in the oncology setting should be further explored in an implementation study.

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 were 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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