Clinical Study

Information needs of patients in spine surgery: development of a question prompt list to guide informed consent consultations

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Abstract

BACKGROUND CONTEXT: Informed consent is mandatory before surgery and fundamental in the physician-patient interaction. However, communication is sometimes suboptimal.

PURPOSE: The objective was to develop a question prompt list (QPL) for patients undergoing spine surgery (spinal neurosurgery-QPL, "SN-QPL") to encourage them to acquire information during the informed consent consultation (ICC) and assess patients' information needs.

STUDY DESIGN/SETTING: We conducted a prospective uncontrolled single center study in order to develop a QPL for patients undergoing spine surgery.

PATIENT SAMPLE: Patients inclusion criteria were as follows: (1) planned spinal surgery, (2) age 18 to 80 years, (3) legal capacity, (4) ability to understand and respond to questionnaires, and (5) informed consent.

OUTCOME MEASURES: We applied the following self-report measures: the developed preliminary QPL with regard to surgery topics and assessment of patients' information needs.

METHODS: First, we performed a literature review, patient interviews, and two expert rounds. Subsequently, we validated a preliminary SN-QPL including 37 items before and after ICC with regard to importance of items and fulfillment of information needs in 118 patients. A principal component analysis followed by varimax rotation revealed the final SN-QPL.

RESULTS: For the final version of the SN-QPL, 27 items with following four reliable subscales were derived with satisfactory internal consistency: (1) scale SN-QPL-C, "complications and possible postoperative deficits" (n = 8 items, Cronbach $\alpha = 0.88$); (2) scale SN-QPL-P, "prognosis and follow-up" (n = 8 items, Cronbach $\alpha = 0.86$); (3) scale SN-QPL-I, "preoperative inpatient stay and organizational issues" (n = 5 items, Cronbach $\alpha = 0.75$); and (4) scale SN-QPL-S: "safety of the surgical procedure" (with n = 6 items, Cronbach $\alpha = 0.84$). The most unmet information needs were found in SN-QPL-P. The item with the greatest unmet information needs was "How much professional experience does my surgeon have?"

CONCLUSIONS: Our SN-QPL was well-accepted and perceived as helpful by patients awaiting spinal surgeries. It seems to address meaningful items and questions. It could therefore be useful in optimizing pre- and postoperative satisfaction. Further, our study identified many unaddressed questions warranting communication interventions. © 2018 Elsevier Inc. All rights reserved.

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Introduction

Decision-making for patients considering surgery is complicated and the consequences of surgery can greatly affect the patients as well as their families. Informed consent is not only mandatory before surgery but also a fundamental physician-patient interaction in order to establish a relationship of trust [1−3].

Communications before planned interventions in general and the Hippocratic Oath in particular have a very long tradition. Both have endured violations in history [4]. One of the most important documents developed in medical history is the "informed consent," expressing that the patient has been informed about and actively agrees to a planned intervention [2]. However, the process of informed consent in neurosurgery is often suboptimal: Ellamushi et al. showed that patients felt well-informed about a procedure but missed explanations about alternative therapies and risks of the surgery [5]. Furthermore, it has been shown that due to the stressful preoperative situation, most patients rarely remember all details of the informed consent consultation (ICC) [6,7]. The physician in the informed consent discussion sometimes fails to explain the procedure in a patient-centered manner and how patients might experience possible postoperative complications [2,8]. The decision-making process before surgery requires mutual confidence. Surgeons need to understand what matters to their patients and patients depend on their surgeons to understand the meaning of different treatment options and their respective risks and advantages and evaluate the consequences of each procedure individually [2,9].

Question prompt lists (QPLs) are structured lists designed to encourage patients to acquire important information during a medical consultation. QPLs aim to overcome barriers between patients and physicians. They increase patients' engagement and interest in decision-making. Activated and motivated patients will in turn gain more interest in the interaction with the physician. QPLs encourage the interest of patients to actively inquire about information on treatment options, risks, and respective advantages and disadvantages, emphasizing the patients' self-perceived capacity to actively engage in the decision-making process [10,11]. QPLs have been proven to be efficient in improving physician-patient communication in not only patients with cancer and receiving palliative care [12−16] but also other patient groups, such as children [17]. Sansoni et al. reported that although there is scarce data about QPLs, a QPL, provided by physicians before the consultation can increase patient questions in routine practice [18].

It has been reported that in patients awaiting a surgery, QPLs can increase the number of raised questions

about anesthesia and surgery and thereby facilitate a better balance between patients' expectations and likely outcomes [19−22]. Furthermore, they also promote a change in physicians' behavior with respect to better preparation of the consultation [14]. Patients themselves, when asked directly, rate QPLs mostly positive with regard to the fulfillment of their information needs and satisfaction [21,23,24].

However, to date, there are scarce data about QPLs in surgical patients [22]. To our knowledge, no QPLs for patients awaiting spine surgery exist despite the potentially disabling risks of the procedure. We hypothesize that the information need and patient satisfaction can be improved further by using a QPL for spinal neurosurgical patients (SN-QPL).

We therefore aimed to develop an SN-QPL and describe the information needs of our patients scheduled for nonemergent spine surgery.

Materials and methods

Patients

Patients meeting the following criteria were eligible: (1) planned spinal surgery, (2) age 18 to 80 years, (3) legal capacity, (4) ability to understand and respond to questionnaires in German, and (5) informed consent.

The study was undertaken in concordance with the national law, institutional ethical standards, and Declaration of Helsinki. The protocol was approved by the Ethics Committee of the Statutory Physician Board of the State of Rhineland-Palatinate, Germany (reference number: 837.097.15 (9865)).

Theory regarding SN-QPL development

In order to improve the quality of the ICC, the main questions according to the literature [18,21] were as follows: What are the information needs of our patients? Which topics are in their focus? What is the optimal balance between too little and too much information (because it remains critical for the physician-patient interaction and can lead to over- and/or underinformed patients)?

Design

The course of the study is presented in Fig. 1. In brief, it consisted of two parts as proposed by Fischbeck et al. [21].

Part I, from August 2014 to July 2015: Patients who underwent surgery at our department were asked to create a list with their own pre- and postoperative questions they felt important and/or unanswered before and after elective spine surgery, and, on a voluntary basis, their ICCs were
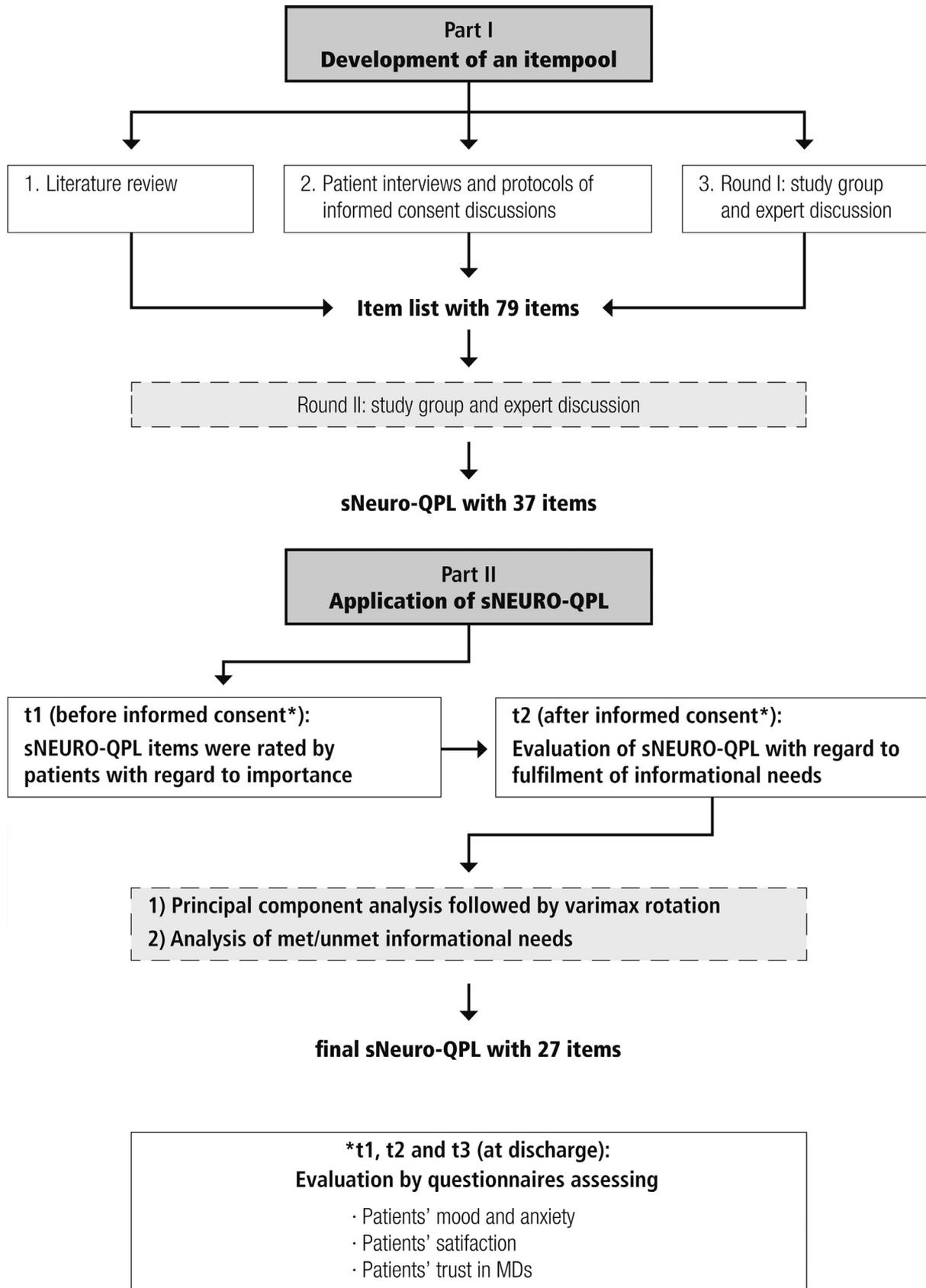
Fig. 1. Study flowchart including parts I and II: First, we performed a literature review, patient interviews, and a first expert round in order to collate all relevant topics for a QPL. In part II, the preliminary SN-QPL was evaluated twice during the inpatient stay of patients undergoing elective spine surgery shortly before (t1) and after (t2) giving informed consent.

protocoled systematically in order to identify relevant items(n=63).

Further, a literature search with the following items via PubMed was performed: "(neuro-) surgery informed consent," "patient doctor consultation surgery," and "informed consent spine surgery." Abstracts were reviewed for studies on informed consent in neurosurgery and spine surgery and revealed additional items (n=8). Additionally, 10 neurosurgeons proposed further eight questions for the list, which they often encounter during informative conversations.

This list consisting of 79 items was then condensed to a preliminary SN-QPL including 37 items, eliminating redundant items and/or those irrelevant to elective spine surgery by a group of experts (study group members, psychologists, and experienced neurosurgeons).

Part II, from July 2015 to June 2016: The preliminary SN-QPL was evaluated twice during the inpatient stay of patients undergoing elective spine surgery shortly before (t1) and after (t2) giving informed consent.

Before the informed consent discussion at t1, patients evaluated the importance of each item using a Likert scale (1=not important to 5=very important). The data of the patients underwent a principal component analysis in order to receive relevant factors (items of the QPL). The result of the principal components analysis is a set of vectors that best account for the observed correlation, and where the factors account for progressively less and less variance. However, the results are rarely easy to interpret. Therefore, we performed a varimax rotation of the factors that were retained in order to deduce dimensions, reflecting, as precisely as possible, the information needs of patients. Varimax rotation is a statistical method that makes the interpretation easier by maximizing the variance of the squared factors loadings by column [25].

After having given their informed consent (t2), patients indicated how intensively each item of the SN-QPL had been discussed by the neurosurgeons during the ICC, again using the Likert scale ranging from 1 (item was not at all discussed) to 5 (item has been intensively discussed) (Supplementary Material Table 2). The values of the Likert scales at t1 and t2 were analyzed regarding the met/unmet information needs of the patients by defining the difference between scores.

Furthermore, sociodemographic factors and medical history were assessed by an additional questionnaire: age, sex, family status, financial and working status, education, diagnosis, medication, psychiatric history, and time at first diagnosis. Perceived pain was evaluated using a visual analogue scale (range 0−10). Patients' mood, anxiety, general well-being, and physician related trust and satisfaction at t1 and t2 as well as postsurgically (t3) were also assessed, applying several self-reporting measures. However, we did not focus on these topics in this manuscript but on the development of the QPL.

Outcomes and statistics

The primary outcome of the present study was the development of an SN-QPL.

The secondary outcomes were assessment of met and unmet information needs of patients undergoing elective spine surgery, patient-reported outcomes, mood, anxiety, and other psychosocial measures before and after ICC. Here, we focus on presenting the primary outcome and the information needs of the patients as well as its fulfillment.

Data are described by mean and standard deviations (SDs) for normally distributed continuous variables and median and range for non-normally distributed continuous variables. Categorical variables were described in terms of absolute and relative frequencies. All comparative analyses were regarded as explorative, and no adjustment for multiple testing was done. p Values $<.05$ were considered as indicative of a statistical significant effect; however, they are presented primarily for descriptive reasons.

For the development of the SN-QPL scales, we used principal component analyses followed by varimax rotation, and Cronbach α coefficients were calculated for internal consistency.

In order to estimate the information needs, we calculated an average of every item at t1 (indicating the importance of the topic, Likert scale 1−5) and t2 (indicating the degree the topic had been discussed during the informed consent discussion from the patients' perspective, Likert scale 1−5). Regarding the fulfillment of the information needs, we calculated the difference of means t2−t1 for each item: If patients indicate underinformation regarding a certain item, the difference yields negative values; 0 means that information needs had been exactly met; overinformation is shown by positive differences.

The factors most likely influencing information needs were selected and categorized driven by content: age in three categories (27−50, 51−70, and 70−95 years), sex (male/female), and social class based on income as indicated by the patients (upper/middle/lower classes). For explorative analyses regarding the factors probably influencing the information needs, Kruskal-Wallis *H* and Mann-Whitney *U* tests were applied. Due to the explorative character, no further multivariable analyses were performed. All analyses were performed using SPSS version 23 (SPSS Inc., Chicago, IL, USA).

Results

Items relevant to patients established in part I of the study

A total of 22 patients participated in part I of the study, with equal participation concerning sex distribution and a mean age of 57 years. Generally, more questions were asked by elderly (≥ 70 years) (mean=3.7, range 0−13) compared to younger (<49 years) patients (mean=1.6, range 0−4).

Table 1
Patients' characteristics, part II of the study (sNEURO-QPL development sample n=118)

Variable	n	%
Age (y)		
Mean (range)	64 (27−91)	
Missings	1	
Gender		
Female	64	54.7
Male	53	45.3
Missings	1	
Family situation		
Married	73	61.8
Single	6	5.1
Widowed	16	13.6
Divorced	12	10.2
In a relationship	9	7.6
Separated	2	1.7
Missings	0	
Education (school)		
None	3	2.6
9th Grade	61	52.1
10th Grade	27	23.0
High School	24	20.5
Others	2	1.7
Missings	1	
Education (profession)		
In education	1	0.9
No completed degree	12	11.0
Apprenticeship	68	62.4
University	17	15.6
Other	11	10.1
Missings	9	
Financial situation (patients' estimation)		
Very good	9	7.7
Good	64	54.7
Neither good nor bad	33	28.2
Difficult	9	7.7
Very difficult	2	1.7
Missings	1	
Patient decree prepared		
Yes	41	35.0
No	76	65.0
Missings	1	
Care level		
None	114	96.7
Grade 1	1	0.8
Grade 2	3	2.5
Missings	0	
Number of secondary diagnoses		
None	22	18.8
1-3	74	63.2
4-6	16	13.7
7-9	5	4.3
Missings	1	
Psychatric history		
Yes	12	10.3
No	105	89.7
Missings	1	
No. of previous spinal operations		
None	8	6.8
1-5	82	69.5

Table 1 (*Continued*)

Variable	n	%
>5	28	23.7
Medications		
Psychotropic drugs	13	11.0
NSAID	39	33.1
Opiates	24	20.3
Steroids	5	4.2
Diagnosis		
Disc herniation	45	38.1
Spinal stenosis	53	44.9
Other	20	17.0
Inpatient treatment in history		
No	9	7.6
Yes	108	91.5
Once	19	16.1
Twice	15	12.7
More than twice	74	62.7
Prior treatment for spinal diagnosis		
No	28	23.9
Yes	89	76.1
Physiotherapy	71	
Analgetics	66	
Surgery	31	
Bed rest	11	
Missings	1	

Our first analysis revealed multiple topics of interest for a QPL in spinal surgery. The items with regard to the surgical procedure were found to be of greatest importance for the patients: Most frequently asked questions during the ICC were regarding (a) duration of the surgery, (b) urgency of the surgery, and (c) when surgery was planned. A total of 37 items were chosen for the preliminary SN-QPL applied in part II of the study. They are presented in Supplementary Table 1.

Development of SN-QPL

In part II of the study, 118 additional patients took part, of whom the clinical and sociodemographic data are shown in detail in Table 1. In brief, 64 patients were female (54%); mean age was 64 years (range 27−91 years); most of the patients were in a relationship and had children; and only a minority had a history of psychiatric comorbidities (11%). The preliminary SN-QPL consisting of 37 items was evaluated before and after ICC as described above.

Applying principal component analysis and subsequent varimax rotation for reliable information needs, scales were developed with best internal consistencies. After categorization and deletion of redundant topics, items were evaluated and selected by the study group, psychologists, and neurosurgical experts in order to reduce the number of items for the final SN-QPL scales. If items should be dropped due to the component analysis, each item was discussed by the expert group. For

example, the item "What is the very worst thing that could happen during the operation?" should have been discarded due to statistics. However, we decided to retain it as we believe that it could be important for patients and is probably a question they are afraid of asking but still want to know.

Finally, 27 items could be distributed to four SN-QPL scales:

(1) SN-QPL-C: "complications and possible postoperative deficits" including eight items (mean of importance at t1=4.57, SD=0.54, Cronbach α=0.88)
(2) SN-QPL-P: "prognosis and follow-up" including eight items (mean of importance at t1=4.45, SD=0.59, Cronbach α=0.86)
(3) SN-QPL-I: "preoperative inpatient stay and organizational issues" with five items (mean of importance at t1=3.94, SD=0.83, Cronbach α=0.75)
(4) SN-QPL-S: "safety of the surgical procedure" with six items (mean of importance at t1=4.14, SD=0.79, Cronbach α=0.84)

The final items and psychometric properties of the SN-QPL are presented in Table 2.

Patients' information needs and fulfillment

Single items were analyzed with regard to the fulfillment of information needs of patients undergoing spine surgery. When patients indicate underinformation regarding a certain item, the scale difference yields negative values: In all four subscales, negative mean differences were observed indicating unmet information needs. The most unmet information needs were found in SN-QPL-P (prognosis and follow-up, scale difference mean=−1.74, SD=1.14), and the least in SN-QPL-I (preoperative inpatient stay and organizational issues, mean=−0.73, SD=1.30).

The item with the highest negative difference between Likert scale scores for perceived importance and provided information indicating unmet information needs was "How much professional experience does my surgeon have?" (Item no. 36, mean=−2.57, SD=1.63). The item with the most met information needs was "On which part of the spine will my surgery be performed?" (Item no. 14, mean=0, SD=1.45). We also observed items with a high SD, indicating that some patients were satisfied with the amount of information provided on the respective item and others were not, for example, "Will I suffer from pain after surgery?" (Item no. 25, mean=−0.91, SD=2.03). The examples are shown in Fig. 2.

Most of the participants (71%) evaluated the SN-QPL as being very or fairly helpful in expressing their information needs before surgery during the ICC. Of the participants, 29% indicated that they asked more questions during the discussion due to the QPL.

Female patients rated more topics as important to obtain answers and had more often unmet information needs than men regarding all four scales of the SN-QPL (p<.001). No significant differences were found with regard to age and all other evaluated social factors.

Discussion

Informed consent is an important part of patient care during the preoperative routine workup, especially in the light of potentially life-changing risks of spinal surgery. There is growing interest in the development of programs and interventions to improve patients' active involvement in treatment decisions, especially while being informed prior to consenting to a procedure [13]. To the best of our knowledge, this is the first description of the development and use of a QPL for neurosurgical patients undergoing elective spine surgery.

In our first survey involving patients and experts, we observed that neurosurgeons were more focused on complications and medicolegal issues, whereas patients more often mentioned organizational issues and questions going beyond the surgical procedure itself. This not only emphasizes the different perspectives of the two groups, explaining some of the perceived communication deficits in the preoperative situation [22], but also highlights that nonprocedural issues such as socioeconomic problems have to be addressed in clinical routine (problems that may vary among departments due to different structures and procedures). The importance of these items was also pointed out during the evaluation in part II of the study, whereby "prognosis and follow-up" showed highly unmet information needs. Thus, we included many "organizational items" in our final QPL, topics that could vary in different spine surgery departments with regard to importance.

Patients rated most of the 37 items of the preliminary SN-QPL as important or very important, achieving an above average interest and information needs fulfillment for our patients. We found that the SN-QPL was well-received by clinicians and patients. A recently published meta-analysis showed that such interventions are of high importance but only rarely used so far [13]. However, at the same time, they seem to increase consultation length. This has to be taken into account when planning the introduction of a QPL in clinical routine. However, similar to other in-depth decision aids, it could be either sent to patients before admission to the hospital for the procedure or handed out directly on admission, giving patients time to read and understand the QPL prior to the final informed consent discussion or could be sent to the patient by mail together with the invitation for the ICC, giving patients time to read.

Information needs and fulfillment

We observed that patients were mostly underinformed in all subscales. The following explanations were found for this phenomenon. In our validation study, the surgeons performing the consultation had no access to the SN-QPL prior to the consultation. Therefore, they were not able to prepare the topics and questions with special interest to the individual patient. We therefore, despite applying a new tool, reported the *current state* but not the *desired state*, emphasizing that further investigations

Table 2
The final SN-QPL after principal component analyses with subsequent varimax rotation

Scale/Item no.*	It is ... *not/ slightly / moderately/ rather/very...* important for me that the surgeon discusses during the informed consent with me...	Source of items†
"Complications and possible postoperative deficits" (SN-QPL-C), eight items (mean of importance at t1=4.57, SD=0.54, Cronbach α=0.88)		
1	. . . if all symptoms will recover after surgery	P
6	. . . what I need to consider during activities of daily life, for example, driving a car, lifting and carrying loads	P
7	. . . if I will get special pain treatment after surgery	E
8	. . . if I will have pain after surgery	E
11	. . . if nerves and/or the spinal cord may be harmed during the operation	E
14	. . . where exactly (on the spine) the surgery will be performed	E
15	. . . if I will feel a lower level of mobility of the spine after the operation	P
16	. . . if my symptoms will improve immediately after surgery	E
"Prognosis and follow-up" (SN-QPL-P), eight items (mean of importance at t1=4.45, SD=0.59, Cronbach α=0.86)		
17	. . . if after surgery parts of the spinal body can rub against each other (eg, because of the removal of disc material)	P
19	. . . how long I must stay in bed after the operation	P
21	. . . how long the recovery process will take (eg, the wound, the nerves)	P
27	. . . if my problem can come back despite successful surgery	L
28	... if I have to maintain a distinct sleeping position after the surgery in order to avoid recovery problems	P
32	. . . how the further treatment will proceed after the surgery in the clinic	P
34	. . . how they proceed, if my complaints won't improve after surgery	E
35	. . . what I need to consider during sports (eg, swimming, gymnastics, cycling)	P
"Preoperative inpatient stay and organizational issues" SN-QPL-I, five items (mean of importance at t1=3.94, SD=0.83, Cronbach α=0.75)		
9	. . . how long the surgery will take	P
13	. . . when I will be discharged	P
22	. . . when the operation is scheduled	P
23	. . . if my symptoms can improve without surgery	P
26	. . . if the surgery can be postponed	E
"Safety of the surgical procedure" SN-QPL-S, six items (mean of importance at t1=4.14, SD=0.79, Cronbach α=0.84)		
3	. . . who will do the surgery	P
4	. . . if I get to know my surgeon before the operation	P
10	... if alternative therapies (physiotherapy, pain killers) could help me	P
25	. . . if I will be monitored in an intensive care unit after surgery	P
30	. . . what the very worst thing is that could happen during the operation	E
36	. . . how much professional experience my surgeon has	P

* Items ordered according to the subscales and numbered according to the order they were listed in the preliminary SN-QPL in part II of the study.
† E, Experts; P, patients; L, literature.

analyzing the best application mode of the SN-QPL are still needed such as better involvement of surgeons. The results are in line with others who showed that the communication between surgeons and patients in ICCs does not lead to preoperative decision-making in an informed and self-determined manner [2,9,26,27]. Further, surgeons often avoid encouraging patients to pose "relevant" questions [22,28].

Certainly, in our situation, the communication could have been improved when applying the SN-QPL more actively in the procedure as intended for the future, for example, not only handing it out to the patients. However, during this part of the study, the main focus was on the validation of the SN-QPL, not the evaluation on how it changes the physician-patient interaction.

The surgeon performing the ICC focused on the procedure itself, explaining complications, risks, and alternative treatment options guided by a structured form due to legal reasons [1,3,4]. In contrast, patients expected topics on organizational issues and information about the inpatient stay to be discussed in the ICC. The QPL could therefore be viewed as a supplement to the structured informed consent forms necessary for medicolegal reasons, giving patients the opportunity to request further information if needed. However, patients need to be encouraged by the surgeon to ask questions; otherwise, the anticipated effect of the QPL disappears as shown by others [29]. This indicates that the application mode of a QPL has to be investigated in detail; for example, should it be handed out to the physician routinely or should the conversation about additional issues not be started? Furthermore, which interventions are necessary to improve patients' active involvement in treatment decisions should be evaluated. Again, this
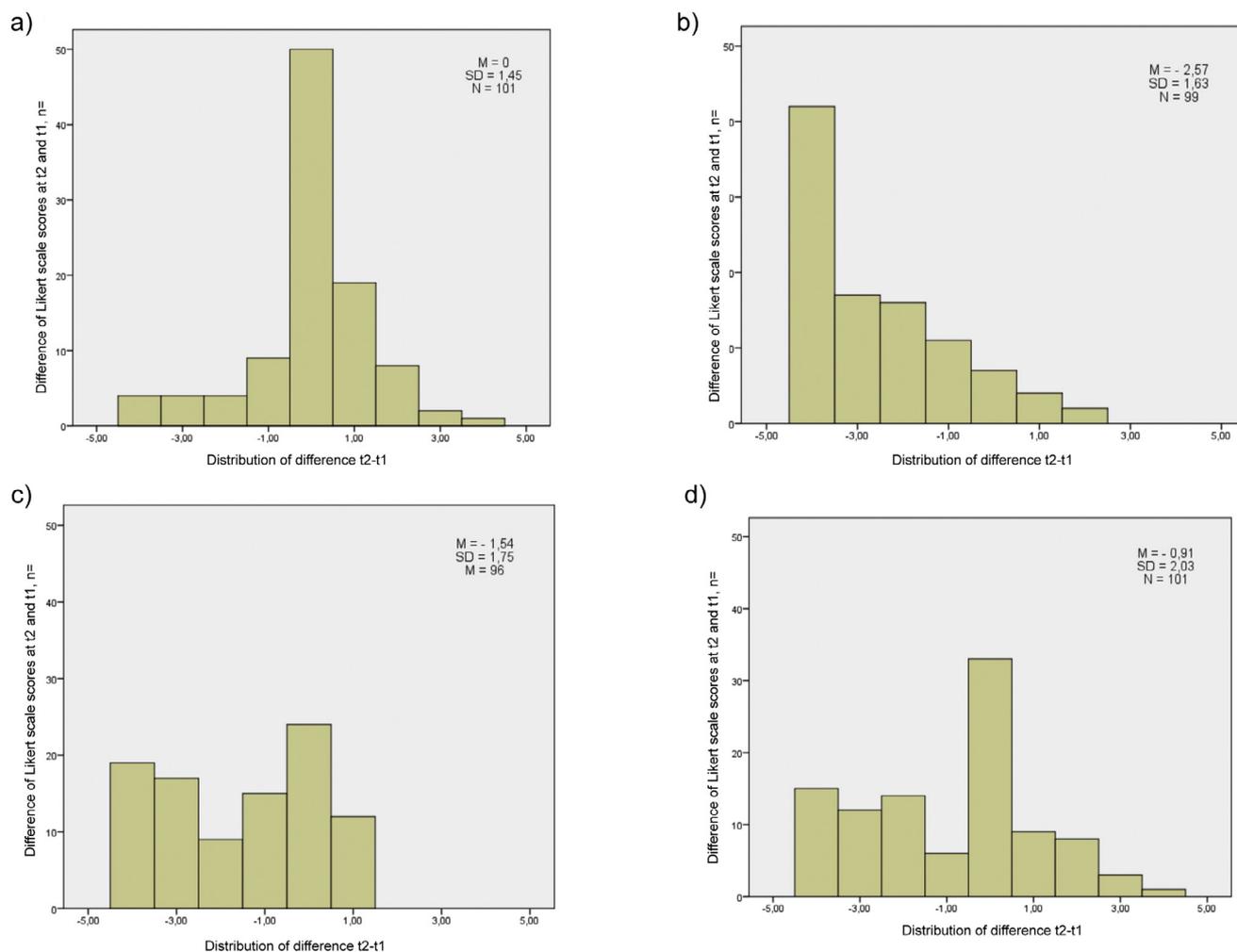
Fig. 2. Examples of (a) met information needs, Item no. 14, "On which part of the spine will my surgery be performed?"; (b) unmet information needs, which was observed in Item no. 36, "How much professional experience does my surgeon have?"; and (c, d) items with a double-peaked distribution or high standard deviation, indicating that some patients were satisfied with the amount of information provided on the respective item and others were not, Item no. 4, "Will I get to know my surgeon before the operation?", and Item no. 25, "Will I suffer from pain after surgery?". Distribution of difference t2−t1 indicates met (difference=0 or positive results) or unmet (difference indicated negative results) information needs.

seems to reinforce the importance of physician initiative in improving communication.

Limitations of the study

The results of our study should be interpreted in the context of several limitations: (1) This was a single-arm study meant to develop a new SN-QPL for patients undergoing elective spine surgery. Thus, the optimal application mode and effect of this QPL on not only patients' understanding of the surgery and their individual situation but also patients' well-being, mood, anxiety, and satisfaction still have to be analyzed in a randomized controlled study. (2) Patients were recruited at a university medical institution; these findings should not be considered fully generalizable. The SN-QPL may require other contents, when used by patients and physicians of other clinics, with differing communication styles and other structures in different health-care settings.

Conclusions

We were able to develop the first QPL, the SN-QPL, which not only was well-accepted by the patients but also showed relevant information needs in the preoperative situation of neurosurgical patients scheduled for spinal surgery. Nevertheless, its implementation into the clinical routine to improve the physician-patient interactions is an important body of work that must be undertaken and further deepened. The optimal application mode and the effect on pre- and postoperative satisfaction and physician-related trust of patients must be evaluated further. Our study identified many unaddressed questions during ICCs using the commercially available forms for informed consent only

Acknowledgments

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at https://doi.org/10.1016/j.spinee.2018.08.015.

References

[1] Schmitz D, Reinacher PC. Informed consent in neurosurgery–translating ethical theory into action. J Med Ethics 2006;32(9):497–8.

[2] King JS, Moulton BW. Rethinking informed consent: the case for shared medical decision-making. Am J Law Med 2006;32(4):429–501.

[3] Park J, Park H. Surgical Informed Consent Process in Neurosurgery. J Korean Neurosurg Soc 2017;60(4):385–90.

[4] Mallardi V. [The origin of informed consent]. Acta Otorhinolaryngol Ital 2005;25(5):312–27.

[5] Ellamushi HE, Khan R, Kitchen ND. Consent to surgery in a high risk specialty: a prospective audit. Ann R Coll Surg Engl 2000;82(3):213–6.

[6] Krupp W, Spanehl O, Laubach W, Seifert V. Informed consent in neurosurgery: patients' recall of preoperative discussion. Acta neurochirurgica 2000;142(3):233–8. discussion 8-9.

[7] Kondziolka DS, Pirris SM, Lunsford LD. Improving the informed consent process for surgery. Neurosurgery 2006;58(6):1184–9. discussion -9.

[8] Pecanac KE, Kehler JM, Brasel KJ, et al. It's big surgery: preoperative expressions of risk, responsibility, and commitment to treatment after high-risk operations. Ann Surg 2014;259(3):458–63.

[9] Braddock C, 3rd Hudak PL, Feldman JJ, Bereknyei S, Frankel RM, Levinson W. "Surgery is certainly one good option": quality and time-efficiency of informed decision-making in surgery. The Journal of bone and joint surgery American volume 2008;90(9):1830–8.

[10] Entwistle VA, Carter SM, Cribb A, McCaffery K. Supporting patient autonomy: the importance of clinician-patient relationships. J Gen Intern Med 2010;25(7):741–5.

[11] Elwyn G, Frosch D, Thomson R, Joseph-Williams N, Lloyd A, Kinnersley P, et al. Shared decision making: a model for clinical practice. J Gen Intern Med 2012;27(10):1361–7.

[12] Walczak A, Butow PN, Clayton JM, Tattersall MH, Davidson PM, Young J, et al. Discussing prognosis and end-of-life care in the final year of life: a randomised controlled trial of a nurse-led communication support programme for patients and caregivers. BMJ Open 2014;4(6):e005745.

[13] Kinnersley P, Phillips K, Savage K, Kelly MJ, Farrell E, Morgan B, et al. Interventions to promote informed consent for patients undergoing surgical and other invasive healthcare procedures. Cochrane Database Syst Rev 2013(7):CD009445.

[14] Brandes K, Linn AJ, Butow PN, van Weert JC. The characteristics and effectiveness of Question Prompt List interventions in oncology: a systematic review of the literature. Psycho-oncology 2015;24(3):245–52.

[15] Walczak A, Mazer B, Butow PN, Tattersall MH, Clayton JM, Davidson PM, et al. A question prompt list for patients with advanced cancer in the final year of life: development and cross-cultural evaluation. Palliative medicine 2013;27(8):779–88.

[16] Amundsen A, Bergvik S, Butow P, Tattersall MHN, Sorlie T, Nordoy T. Supporting doctor-patient communication: Providing a question prompt list and audio recording of the consultation as communication aids to outpatients in a cancer clinic. Patient Educ Couns 2018 Apr 22 pii: S0738-3991(18)30191-5. doi: 10.1016/j.pec.2018.04.011.

[17] Lemmon ME, Donohue PK, Williams EP, Brandon D, Ubel PA, Boss RD. No question too small: development of a question prompt list for parents of critically ill infants. J Perinatol 2018;38(4):386–91.

[18] Sansoni JE, Grootemaat P, Duncan C. Question Prompt Lists in health consultations: A review. Patient Educ Couns 2015 Jun 3 pii: S0738-3991(15)00258-X. doi: 10.1016/j.pec.2015.05.015.

[19] Smets EM, van Heijl M, van Wijngaarden AK, Henselmans I, van Berge Henegouwen MI. Addressing patients' information needs: a first evaluation of a question prompt sheet in the pretreatment consultation for patients with esophageal cancer. Dis Esophagus 2012;25(6):512–9.

[20] Clayton JM, Butow PN, Tattersall MH, Devine RJ, Simpson JM, Aggarwal G, et al. Randomized controlled trial of a prompt list to help advanced cancer patients and their caregivers to ask questions about prognosis and end-of-life care. Journal of clinical oncology: official journal of the American Society of Clinical Oncology 2007;25(6):715–23.

[21] Fischbeck S, Zimmer S, Laufenberg-Feldmann R, Laubach W. [Question prompt list for premedication consultation: Patient-oriented information on anesthesia]. Anaesthesist 2014;63(11):832–8.

[22] Taylor LJ, Rathouz PJ, Berlin A, Brasel KJ, Mosenthal AC, Finlayson E, et al. Navigating high-risk surgery: protocol for a multisite, stepped wedge, cluster-randomised trial of a question prompt list intervention to empower older adults to ask questions that inform treatment decisions. BMJ Open 2017;7(5):e014002.

[23] Langbecker D, Janda M, Yates P. Development and piloting of a brain tumour-specific question prompt list. European journal of cancer care 2012;21(4):517–26.

[24] Brown RF, Bylund CL, Li Y, Edgerson S, Butow P. Testing the utility of a cancer clinical trial specific Question Prompt List (QPL-CT) during oncology consultations. Patient Educ Couns 2012;88(2):311–7.

[25] Sherin RJ. A matrix formulation of Kaiser's varimax criterion. Psychometrika 31 1966: 535–8.

[26] Kruser JM, Pecanac KE, Brasel KJ, Cooper Z, Steffens NM, McKneally MF, et al. "And I think that we can fix it": mental models used in high-risk surgical decision making. Ann Surg 2015;261(4):678–84.

[27] Fagerlin A, Sepucha KR, Couper MP, Levin CA, Singer E, Zikmund-Fisher BJ. Patients' knowledge about 9 common health conditions: the DECISIONS survey. Med Decis Making 2010;30(5 Suppl):35S–52S.

[28] Schwarze ML, Redmann AJ, Alexander GC, Brasel KJ. Surgeons expect patients to buy-in to postoperative life support preoperatively: results of a national survey. Crit Care Med 2013;41(1):1–8.

[29] Yeh JC, Cheng MJ, Chung CH, Smith TJ. Using a question prompt list as a communication aid in advanced cancer care. J Oncol Pract 2014;10(3):e137–41.