

Original Article

A Qualitative Approach for the Development of a Patient Experiences Questionnaire in Primary Healthcare Settings

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Abstract

Background: Cognitive methodologies have been used in several areas of healthcare research for the development and evaluation of new instruments; nonetheless, their use in primary care settings along with the use of focus group methodology is rather limited.

Objective: Focus group methodology was used to evaluate and improve two developing measurement tools for evaluating patients' experiences about primary healthcare services in Greece.

Methodology: Two focus groups were conducted with 11 patients to test the perception, interpretation and usefulness of the questions of the new measurement tools. The agenda included 12 questions aimed at asking whether each question of the tools was understood and made sense by the participant in the same way as the researchers and if it was relevant to the primary care setting. The coding system of Willis (1999) was used to analyze the data.

Results: The analysis revealed 30 problems for a number of problematic items. These included 12 clarity problems, eight response categories, one knowledge problem, one sensitive content problem, one instruction problem and one formatting problem. Moreover, six new types of problems emerged which could not be classified according to the above coding system (inapplicable problems).

Conclusions: This methodological approach was useful in identifying questionnaire problems and the tool was redrafted by taking into account participants' perspectives.

Keywords: focus groups; instrument development; patient experiences; primary health care; Greece

Background

The development of a questionnaire with acceptable reliability and validity is a complex process and one of the key challenges for researchers. Poorly designed questions result in low data quality. It is necessary that the questions or/and items are clear, explicit and

comprehensive (Drennan, 2003). Initially, respondents need to understand the question, then recall information and decide on its relevance and finally provide an answer (DeMaio & Rothgeb, 1996; Collins, 2003; Tourangeau et al., 2000).

A number of cognitive question-testing methodologies have been identified in the

literature to optimize questionnaires prior to their distribution such as focus groups, cognitive interviewing, expert reviews and pilot studies (Dillman, 2000; Drennan, 2003). Cognitive methods are qualitative in nature and use cognitive theory to understand how interviewees perceive and make sense questions (Drennan, 2003). Their advantage over quantitative methods of pre-testing is that they provide information about the nature of the problems (Drennan, 2003). There are two main interview techniques used in cognitive methodologies: the “thinking aloud” technique where respondents verbalize their thoughts while answering the question and the “probing” technique where the researcher asks probing questions to understand interviewees’ perception and interpretation of questions. Such probes may be scripted or spontaneously created by the researcher (Beatty, 2004; Willis, 2004).

Cognitive methodologies have been used in several areas of healthcare research for the development and evaluation of new instruments (Grant et al., 1999; Pasick et al., 2001; Shaw et al., 2001; Chang et al., 2003; Collins, 2003; Drennan, 2003; Rosal et al., 2003; Ware et al., 2003; Springer et al., 2006; Knafl et al., 2007; Murtagh et al., 2007; Ahmed et al., 2008; Tavernier et al., 2011; Buers et al., 2014); nonetheless, their use in primary care settings along with the use of focus group methodology is rather limited. Only O’Donnell et al. (2007) used focus groups to improve the validity of a quantitative questionnaire for physicians’ decision making. This methodology can help researchers to distinguish potentially confusing questions while eliminating the interviewer bias (Beatty & Willis, 2007). We used focus groups to assess the perception and interpretation of the questions of two developing measurement tools for evaluating patients’ experiences about primary healthcare services in Greece and to identify possible unclear words or phrases. We indicated how this strategy can identify potential issues with questionnaires’ items including questions that cannot be understood as intended by the researcher.

Methodology

Study Design: The two draft questionnaires aimed to evaluate patients’ experiences about primary healthcare services in Greece were based on five dimensions of person-focused primary care including accessibility, continuity and

coordination, comprehensiveness, patient activation, and doctor-patient communication. These dimensions were ranked as the most important domains in published studies (Steine et al., 2001; Jenkinson et al., 2002; Aletras et al., 2006; Anagnostopoulos et al., 2012; Schafer et al., 2013; Pini et al., 2014; HCAHPS, 2015; Pierrakos et al., 2015; Frengidou et al., 2017; Lionis et al., 2017) and seemed to constitute important sources of satisfaction with the primary health care services in Greece. Moreover, interviews with Greek health care stakeholders, along with a detailed national and international literature review, enabled the researchers to develop valid comprehensive tools that will be used for periodic evaluation of public primary care settings in Greece. In several meetings, the research team carefully reviewed and discussed each item until the total items were selected for the final questionnaires that were distributed to the focus groups.

Study sample consisted of patients who had used a hospital’s outpatient department and a health centre in Athens at least one time in the past. To be eligible for the study, participants had to be willing to participate and have visited the previous primary care settings in the past. A total of 35 users were contacted by telephone and asked to participate in the study. Among them, 11 patients agreed to participate to the study; six participated in the hospital’s focus group and five in the second group of the health centre. Focus groups were conducted in a location convenient to all participants and were digitally recorded with the permission of the study participants. The demographic characteristics of the participants are presented in Table 1.

Development of the Focus Groups Agenda: A focus group agenda was developed in order to test the perception, interpretation and usefulness of the questions of the new measurement tools designed to evaluate patients’ experiences about public primary healthcare services in Greece. In total, 12 questions were developed; ten examined each question individually and two considered general aspects of the tool (Table 2). The questions aimed at asking whether each question of the tool was understood and made sense by the participant in the same way as the researcher and if it was relevant to the primary care setting (“scripted probes”). We also used a number of “spontaneous probes” in case an interesting point came up that could not be covered by the predefined probes.

Table 1: Participants’ characteristics of the focus groups

Characteristic	N (%)
Gender	
Male	4 (36.4)
Female	7 (63.6)
Age (mean, standard deviation)	44.5 (12.2)
Nationality	
Greek	11 (100.0)
Other	0 (0.0)
Highest level of education	
High school	7 (63.6)
BSc	2 (18.2)
MSc	2 (18.2)
Health status	
Excellent	1 (9.1)
Very good	4 (36.4)
Good	6 (54.5)
Moderate	0 (0.0)
Bad	0 (0.0)
Chronic diseases	
None	7 (63.6)
One	2 (18.2)
Two	0 (0.0)
≥3	1 (9.1)
Don’t know	1 (9.1)

Table 2: Cognitive probes

1. Can you repeat the question I just asked in your own words?
2. How did you arrive at that answer?
3. How sure of your answer are you?
4. Was that easy to remember?
5. Are the response options appropriate?
6. Is the question straightforward?
7. Is that easy or hard to answer?
8. Do you think the question is relevant?
9. What does the term X mean to you?
10. Tell me what you are thinking?
11. Would you add any question?
12. What do you think of the size of the tool?

Procedure of Data Collection

After a short introduction of all the members of the group, the principal investigator explained the aim and the procedure of the focus group, clarified that the focus group session was being audio-recorded and obtained a written consent of each respondent before starting the group. The

researchers emphasized that the purpose of the group was mainly to identify wording problems to improve questions’ comprehension rather than the actual answers to the questions.

We used “thinking aloud” (respondents read the questions loud and verbalize their thoughts) and “probing” (the researcher asks probing questions

to understand interviewees' perception and interpretation more clearly) cognitive interviewing methods at the same time.

First of all, we asked the participants to prioritize the dimensions of healthcare and to highlight the important aspects of care. Then, each participant was provided with a sample questionnaire and adequate time to answer each question; the concurrent approach was used to ask the participants what they were thinking while or shortly after answering each question (e.g., "tell me what you are thinking"). The probing questions (Table 2) were used to facilitate these discussions (e.g., "what does this term mean to you?"). In addition, the observer took fieldnotes of participants' behaviour including body language, laughs, sighing and voice quality. Each focus group lasted around one hour and a half.

Ethical issues

The anonymity of the participants was ensured as participants were orally and in written informed about the purpose and methodology of the study so as to decide whether or not they were willing to participate voluntarily and anonymously. Signed consent forms were delivered to the researchers prior to the implementation of the focus group methodology. Additionally, written permission to carry out the study was granted by the Ministry of Health and the study was supported by the WHO Regional Office for Europe.

Data analysis: Focus groups were transcribed verbatim and all the transcribed data were imported into NVivo 7 software. Problems were coded by using mainly the system of Willis (1999) which classifies questionnaire problems into seven categories: i) clarity/comprehension (wording, vague terms), ii) knowledge (recall problems), iii) assumptions, iv) response categories (missing, vague, overlapping), v) sensitive content, vi) instructions and vii) format.

Results

Identified Problems

Each focus group assessed 48 questions included in each questionnaire ("*Patients' Experiences with a Specialist at a Hospital's Outpatient Department*" questionnaire and "*Patients' Experiences with a Specialist at a health centre*" questionnaire). We identified 30 problems (12 clarity problems, eight response categories, one knowledge problem, one sensitive content problem, one instruction problem and one

formatting problem). The most problematic items of each category are outlined below.

Clarity problems: Focus groups identified questions and statements that were not clear and explicit. Almost all participants in both focus groups experienced clarity problems with the question: "*The specialist knows the problems and illnesses that I had in the past from medical records*"; participants could not understand the statement and various interpretations emerged including whether the doctor *should* know patients' problems or how patients can be sure that the doctor knows their illnesses. Thus, this question was changed to "the specialist asks me about my medical history" which is more explicit. Similar problems occurred with another statement: "*The doctor has access to the results of my diagnostic exams occurred in the recent past in other facilities*" which was revised to "*The specialist asks me about the results of my diagnostic exams occurred in the recent past*".

Many participants faced difficulties with the following item: "*This specialist's guidelines/instructions about medications are in line with those provided by other doctors*". Respondents found very difficult to make sense of the question and were not able to answer it. They mentioned that the question was not clear:

"*It's not...I don't understand it, I could not answer it...namely if the GP agrees with what the endocrinologist prescribes me (...) the time, the medication...I don't understand the question*" (Amelia, 2nd focus group).

Participants struggled with the phrase "*are in line*" because only a few doctors ask the patients' existing medication before prescribing a new medication. Respondents indicated that doctors usually prescribe a medication and then patients ask them if there is a problem with another treatment they may follow. Therefore, the statement was modified to "The specialist prescribes to me medication taking into consideration all medications that other doctors have already prescribed".

The analysis also revealed that a number of clarity problems existed due to overlapping wording. For example, one statement that was identified as problematic by the interviewees was the following: "*The specialist clearly explains to me all aspects of my health situation and health problems*". Participants suggested that the terms "health situation" and "health problems" were

similar and overlapping and highlighted the need to simplify the question which eventually was changed to “The specialist clearly explains to me all aspects of my health situation”. Finally, in the statements regarding the nurses’/health visitors’ behavior, the term “health visitor” was deleted because most respondents were unfamiliar with the term or were not sure which professionals the term includes. The last problem can also be classified as a knowledge problem.

Response Categories

We identified eight response categories problems which we classified into three different types: three missing responses, three clarity problems and two recall problems.

Regarding the missing responses, comments from many participants indicated that the term “don’t remember” should be added as a possible response in a number of questions because patients may not actually remember some kind of information. For instance, in the first question of both questionnaires “*Over the past six months, how often did you visit or consult this facility?*” the response “don’t remember” was added in order to provide a possible answer for those who cannot remember how many times they visited a facility.

Participants also shared their opinion concerning a number of clarity issues of some response categories. For example, two responses of the question “*What is the reason for your visit to this facility today?*” were identified as unclear by many participants of both focus groups. These included the two last possible answers “second opinion” and “other” which were reformulated to “visit for a second opinion” and “other (please define:.....)” which were deemed as more explicit according to the participants’ perspectives.

Confusing response categories where participants faced difficulties in remembering the required information were also identified by the focus groups. Two questions had response categories with such difficulties: “*How many days did you wait between the appointment and this visit?*” and “*How long did you wait today between arriving at the facility and the consultation?*” According to the respondents, the possible responses were worded in a day-counting manner which caused recall problems to them.

Consequently, the responses were rewritten in the following way in order to be easier for the

participants to retrieve an answer: “I waited one week”, “I waited from one week to 1 month”, “I waited more than one month”, and “less than half an hour”, “from half to one hour”.

Other problems

Participants in both focus groups addressed a number of other problems including one knowledge problem and one sensitive content problem.

Almost all respondents experienced a knowledge problem with the statement “*There is sufficiency of essential medical supplies (e.g. medications, consumables, etc)*”. They thought that they were not able to know this information. As one interviewee from the 1st focus group noted: “*Well...I don’t know that exactly (...) I suppose...I don’t know*” (Gabriel, 1st focus group).

Therefore, because participants struggled with answering that question, we decided that it was necessary to delete this question. The most disturbing question that was determined by the focus groups was the one that focused on the living situation of the patients (“*The specialist asks me about my living situation*”). Participants felt very uncomfortable with answering this question and found it very intimate and for that reason we classified it as a sensitive content problem. Most of the respondents noted that only in case the doctor notices signs of poverty he or she could ask more personal questions. Apart from being a sensitive question, participants mentioned that the question was not clear enough. Various interpretations emerged including nutrition problems, exercise habits and employment. Because of the sensitivity and comprehension problems, we suggested that the question should be deleted.

Discussion

The data derived from the focus groups enabled us to reframe or delete existing questions and develop new ones. Our data indicated a number of issues which contributed to measurement errors including clarity problems, response categories and knowledge problems and sensitive content and formatting problems. Both thinking aloud” and “probing” techniques helped us to discover ambiguous items and determine how they can be modified.

For each item, both scripted and spontaneous probes were asked as a result of the groups’ dialogue and participants’ thoughts. Researchers’

and interviewees' comments and group interaction rather than individuals' perceptions provided important information regarding the sources of the problems.

We found that clarity problems appeared more often than other problems. The major types of such problems described in this study were respondents' lack of awareness of specific terms or phrases, abstract questions which created assumptions and misinterpretation of questions. Including more details in a question turned out to be more helpful for respondents than generic ones.

Many respondents also believed that the response categories of several questions were problematic. This was because there were missing or unclear responses and sometimes the possible answers were too complicated. By analyzing the data, we decided to change the wording of some responses to be more explicit and add some terms to cover more possible answers. There was only one question that was considered to be sensitive and was referring to the living situation of the patients. The focus group methodology allowed us to discuss several aspects of this question and interviewees' beliefs around it. Participants revealed that they felt very uncomfortable with answering this question and found it very intimate and for that reason we excluded it from the instrument.

Finally, the questionnaire included some items that were deemed to be confusing for the members of the groups for a number of reasons such as knowledge and repetition problems, instruction issues, formatting difficulties and questions that were not applicable to the specific context. The two groups recommended that the above items should be deleted or reframed.

Authors have argued that conducting cognitive question-testing methodologies cannot determine all the problems of a measurement tool (Willis, 1999; Drennan, 2003). However, our study endorses the findings of O'Donnell et al. (2007) who suggest that the use of focus group methodology allows researchers to gain a better understanding of alternative perceptions of a survey's questions because of the different views provided during the group discussion. For example, several questions were rewritten because they contained professional terminology that was not comprehended by lay people as it became apparent during the dialogue between members. Another limitation of this methodology

is that respondents may hesitate to reveal that there are questions they do not understand and that the selected sample may not be representative of the whole target population (Drennan, 2003).

In order to eliminate the first disadvantage, researchers explained in detail the purpose of the study and tried to build rapport with the interviewees from the beginning of the process. Regarding the second challenge, in cognitive methods it is not necessary to include a large number of participants to evaluate a questionnaire as their aim is to consider the thoughts of a few participants and not generalize the findings to the wider population (Beatty & Willis, 2007). Focus group methodology can help researchers to identify problematic items and their nature in a questionnaire and how they can be reframed, and according to our knowledge, this is the first study using focus groups to evaluate measurement tools for assessing patient experiences about primary health care services. Consequently, our study contributes to the literature by highlighting the use of focus group methodology as a cognitive method to optimize a tool.

Conclusion

Our findings highlighted the benefits of focus group methodology in developing new measurement tools as it elicits problems that could not be identified by using other techniques. Therefore, it is recommended to integrate focus group methodology in the development process of questionnaires. Nonetheless, submitting reframed questions to additional cognitive testing in other groups may enhance the possibility that questionnaires are being understood similarly across different individuals. Further research is also needed to assess this method's advantages and disadvantages in relation to other cognitive testing methods.

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