Medical Science

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Cognitive interview for developing the instrument for high risk patients with diabetes and hypertension for Chronic Kidney diseases - Instrument about Measurement of Perception, Awareness, Social Support (I am PASS) scale

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ABSTRACT

Objectives: The objective is developing an instrument to assess the perception, awareness and social support for his risk patients with diabetes and hypertension towards chronic kidney diseases using cognitive interview. *Methods*: The items of PASS instrument were identified after extensive literature review and with the experts. Think aloud method of cognitive interview was used for the field staff and patients with diabetes and hypertension. *Results*: Six field staff and five patients with diabetes and hypertension were involved. Revised version of PASS instrument with 40 item instrument with 5 point likert scale was found to be a simple, user friendly, easily comprehensive version which takes about 30-40 minutes for an individual to respond. *Conclusion*: This multidimensional PASS instrument is based on health belief mode and its items comprises perception, awareness related to various aspects of chronic kidney diseases and its risk factors.

Keywords: Cognitive interview, Chronic Kidney diseases, Perception, Awareness, Social Support

1. INTRODUCTION

The designing and development of a psychometric instrument is a complex process and involves multiple steps involving searching from literature, cognitive interview, phrasing and re-phrasing of the items and questions and

assessing reliability and validity (Ahmed et al., 2009; Barnes et al., 2004; Beck et al., 2017; Drennan, 2003; Kaptein et al., 2008; Petrie & Weinman, 2006; Reeve et al., 2017). The searching of literature involves the first aspect to assess if a suitable instrument is already available. If it is available, then there is a need to ascertain if culturally suitable instrument in local language which is understandable for the population is available (Barnes et al., 2004; Beck et al., 2017; Chilcot et al., 2011; French & Weinman, 2008; Griva et al., 2009). Once it is confirmed that the research question involves an abstract concept which cannot be answered by suitable available instrument then the research team needs to plan the same. After thorough review of literature it is observed that there is a need to design and develop an Instrument About Measurement of Perception, Awareness, Social Support (I am PASS) scale - developed for high risk patients with diabetes and hypertension for Chronic Kidney diseases for Indian population (Abdel-Kader et al., 2009; Barnes et al., 2004; Chen et al., 2009; Chilcot et al., 2011; Clarke et al., 2016; Searle et al., 2007; Tan et al., 2010).

Cognitive interview is a newer methodology being used as an important aspect of designing and development of psychometric instruments and is being considered as a necessary step. This technique was first developed by psychologists Ed Geiselman and Ron Fisher for improving the interviews of witnesses by police to enhance reliability and accuracy of the information retrieved about the crime. The instrument involves an abstract concept and also needs to have similar methodology and hence it became a standard aspect in instrument development. This qualitative method uses the question response process of the participants with respect to comprehension, retrieving or recalling the information, processing the information, decision and judgment making process to respond to the questions (Ahmed et al., 2009; Barnes et al,. 2004; Beck et al., 2017; Drennan, 2003; Kaptein et al., 2008; Petrie & Weinman, 2006; Reeve et al., 2017).

There is limited literature and instruments to assess the perception, awareness and social support for his risk patients with diabetes and hypertension towards chronic kidney diseases (Abdel-Kader et al., 2009; Barnes et al., 2004; Chen et al., 2009; Chilcot et al., 2011; Clarke et al., 2016; Pagels et al., 2012; Sawicki et al., 2011; Searle et al., 2007; Tan et al., 2010; Watkins et al., 2000) and this is one of the important aspects of management for these patients so that correct perception and awareness is imparted and an appropriate social support system can be developed for better management and care of the diseases and its clinical management and prevention of development of complications (Abdel-Kader et al., 2009; Chen et al., 2009; Chilcot et al., 2011; Clarke et al., 2016; Covic et al., 2004; Fowler & Bass, 2006; Griva et al.,2009; Jansen et al., 2013; Klang & Clyne, 1997; Klang et al., 2014; O'Connor et al., 2008; Searle et al., 2007; Tan et al., 2010; Watkins et al., 2010). Hence it was decided to use cognitive interview methodology for Instrument About Measurement of Perception, Awareness, Social Support (I am PASS) scale - developed for high risk patients with diabetes and hypertension for Chronic Kidney diseases for Indian population.

2. MATERIAL AND METHODS

Participating sites and population
The participants for the cognitive interview were field staff members and patients with diabetes and hypertension attending the rural health center of the department of community medicine.

Ethical committee approval
The institutional Ethics Committee approval is obtained (IEC-NI-12/AUG/29/40) and informed consent is obtained from study participants.

Development of Instrument and discussion with experts in the field
The instrument was developed with the help of experts in the field who have experience in psychometrics as well nephrology particularly chronic kidney diseases. With the guidance from these experts and processing the information available from review of literature on this topic, an instrument was prepared. Multiple sessions of the discussion were done among the experts to finalise the most appropriate instrument to assess the perception, awareness and social support aspects of the instrument. The instruments consisted of 150 items and were reduced into 40 items. This instrument was prepared using health belief model which is based important aspects involving perceived susceptibility (perception of susceptibility to a disease or condition), perceived seriousness (beliefs concerning the effects a given disease), perceived benefits of taking action (action toward the prevention of disease or toward dealing with an illness), barriers to taking action (barriers relate to the characteristics of a treatment or preventive measure may be inconvenient, expensive, unpleasant, painful or upsetting) and cues to action.

Development of Cognitive interview Schedule and discussion with experts in the field

In consultations with experts, a cognitive interview schedule was prepared. Field staffs were asked to be available for at least 1 hour's session for cognitive interview in a single sitting. Three sittings were required for all field staff at individual level. The think-aloud method of cognitive interview was used. In the think-aloud method subjects are advised to think-aloud as they read the questions and inform the interviewer what they fill when they read the questions. A special training with this think-aloud method was done for study participants.

Modifying the instrument analysis of the data, final instrument development and Feedback in consultation with experts

After the development of the instrument, the first cognitive interview was performed with field staff members and as per information collected, the instrument is revised for using the cognitive interview in study patients with diabetes and hypertension at rural health & training center. The information of the cognitive interview was collected and suggestions for changing, rephrasing of the questions, wording and formatting in the questions were done for improving the instrument. This instrument was again discussed with the experts and the final instrument was developed. The whole process first was performed with English instrument with field staff and then Tamil version of the instrument while only Tamil version of the instrument was used for cognitive interview with patients. In both the process of cognitive interview, each item was reviewed for its appropriateness for the instrument. Since think-aloud is not the natural method, question prompts were used for some of the questions.

3. RESULTS

Participants

Six field staff and five patients participated in the cognitive interview process. After initial training, they used the think-aloud method and their observations were noted for making required changes in the instrument. In the first phase of cognitive interview, six field staff went through the process one after another without listening to each other as per cognitive interview schedule prepared using English version of the instrument. The observations were discussed with the experts and then Tamil version of the instrument was prepared. In the second phase, Tamil version of the instrument was used for cognitive interviews with the same field staff and observations and suggestions were obtained. In the third phase, after due modifications in the instrument in consultations with the experts on the basis of the feedback and observations received from field staff, cognitive interview with patients attending the rural health & training center was performed using the Tamil version of the instrument.

Time to complete the instrument, long questions, long instrument, response time for each item

Participants felt that the instrument is very long and it takes more than 90 minutes to complete 101 questions. Some of the questions which are similar in nature need to be combined. The appropriate time of completion needs to be not more than 30 minutes. The first phase with English version took longer with 101 questions and was revised to 65 questions for the second phase and after the second phase; they were revised to 40 questions. Due to the reduction of questions to 40 questions, now the required time for completion of instrument became less than 30 minutes. The response time for each item was noted and items which were longer and difficult to comprehend were taking longer time.

Comprehension & Judgments

Each phase, the comprehension difficulties with each item of the instrument was noted. Comprehension difficulties were found while using Tamil version of the instrument to find the appropriate word for the English word and the most suitable word was used in the local language. Comprehension difficulty with lengthy statements was identified and items were simplified. The question with respect to "dietary modification, necessary health education material needed prompts. Field staff and patients showed good comprehension in the finalised instrument of PASS with 40 questions.

Ease of response and use

Participants felt that by easing out the response the PASS instrument as well as items needed to be made easier to understand and some of the items needed to be combined. One of the important issues observed with various items used for "social functions" and it was decided to include examples like weddings, visiting temples etc.

The original items were as follows

Due you think due to disease you are not able to participate in family activities.

Due you think due to disease you are not able to participate in functions of relatives.

Due you think due to disease you are not able to participate in functions of friends.

The revised simplified item was as follows

Do you think that your current disease status has affected your participation in social functions (wedding, visiting temples etc.) and prompts may be used if required.

Decision making process: The participants felt that the decision making process was easy when the items are simple and short. Longer items were taking longer time for decision making for the appropriate response. Many participants felt that the item

"Do you think that you are at risk for developing kidney disease since you have diabetes/hypertension" and while participants felt that the item

"I always try to get more information about kidney disease to reduce chances of developing severe kidney disease." was difficult for the decision making process.

Improper or incomplete questions

Many participants felt that some of the items are improper or incomplete and need to be deleted from the PASS instrument. Those items were as follows:

I feel I have to do more regular check ups if I get kidney disease.

I am satisfied with the amount of time spending on the regular treatment.

I need to spend more time on regular treatment if I get kidney disease.

Response scale, preference of scale and its modifications

There was a lot of discussion to use type to response scale to be used for the items. Items assessing abstract concepts needed to have likert scale and there was discussion with experts and all participants about the use of 7-point or 5-point or 3 point likert scale. It was finally decided to use the 5-point likert scale as "strongly agree, agree, neutral, disagree, and strongly disagree".

Missing questions

All participants felt that all important items required are included.

Sensitive questions

Participants felt that there are few sensitive items and also felt that are required in the PASS instrument. Some of the identified examples of the sensitive questions by the participants were as follows:

Do you think that getting kidney disease is as per God' will and you do not have any role in preventing it.

Do you think that your family members support you in undergoing assessment for complications?

Do you think that your family members support you in following dietary modifications?

Do you think that discussing your health problems with your family members reduces your worries?

Are you satisfied with the support provided by your family members?

Formatting instrument, response format, Editing

Participants felt that formatting is required in the original instrument with respect to design of appearance of instrument and tabular form needed for easy ticking of responses. Sequences of items to be arranged properly are in coherence for ease of filling properly.

Overall feedback, overall rating of the instrument, applicability and acceptance

Participants felt that the original PASS instrument was very long. Some items were ambiguous and had medical related terms or jargon. Using the think-aloud method was good for easy understanding and comprehension. Overall the revised final instrument was found to be useful and appropriate for the purpose by all participants. Participants felt that it is very well applicable and acceptable. All items were important, non-ambiguous, and similar to everyday questions in clinical practice in a more structured way. Participants felt that item related discussion of the disease and its important aspects with relatives and friends were very useful. Participants felt that some questions are sensitive and still need to be asked.

Added value of cognitive interviewing for this instrument

The cognitive interview helped researchers to adopt the changes as suggested by the field staff and patients and it has overall improved the quality of the instrument. It gave an idea of practicability of the instrument in clinical practice and understanding the field staff and patient's perspective for the items of instrument. In addition to academic and research components of the instrument development, cognitive interview added the subjective component with respect to comprehension, judgment, recall and understanding while answering those items of PASS instrument.

4. DISCUSSION

There is limited literature about the assessment of perception, awareness and social support of high risk patients with diabetes and hypertension (Abdel-Kader et al., 2009; Barnes et al,. 2004; Chen et al., 2009; Chilcot et al., 2011; Clarke et al., 2016; Pagels et al., 2012; Sawicki et al., 2011; Searle et al., 2007; Tan et al., 2010; Watkins et al., 2000). There is a need to develop an Instrument About Measurement of Perception, Awareness, Social Support (I am PASS) scale developed for high risk patients with diabetes and hypertension for Chronic Kidney diseases as part of CKD PREPARE project. The PASS instrument had earlier more than 101 items and the final instrument is with 40 items after cognitive interview. The PASS instrument is a multidimensional instrument which is based on a health belief model and it comprises all the aspects of the model. The health belief model is one of the most accepted models for developing health related instruments. The think-aloud method of cognitive method was predominantly used while few items needed verbal probes. Cognitive interview should become a mandatory phase of any instrument development process as it involves both academic as well as subjective aspects of the issue. It helps research to design and develop better instruments so that participants can understand the items in a simplified better way to appropriately respond. Thus the instrument will guide clinicians for better management of the patients.

PASS instrument comprises items related perception, awareness related to various aspects of chronic kidney diseases and its risk factors. Social support plays an important role in most diseases but in chronic conditions like diabetes, hypertension, Chronic kidney Disease (CKD), it is of significantly important as targeting those important aspects during holistic management during the patient care. This will evolve the era of personalised care in chronic diseases which is the need of the hour. Revised version of PASS instrument was found to be a simple, user friendly, easily comprehensive version compared to its earlier version before cognitive interview. The instrument reduced to a 40 item instrument with 5-point likert scale. It takes about 30-40 minutes for an individual to respond. During the patient waiting time before meeting the doctor, this can become an easy tool to be filled up and the important aspects can be better discussed and managed during the consultation process with the clinicians. Also this instrument with important aspects of various issues related social support, perception, awareness can also act as eye opener for those practices to be followed by the patients and their families for early diagnosis, treatment and prevention for complications of diabetes and hypertension and emergence of chronic kidney diseases (Abdel-Kader et al., 2009; Chen et al., 2009; Chilcot et al., 2011; Clarke et al., 2016; Covic et al., 2004; Fowler & Bass, 2006; Griva et al., 2009; Jansen et al., 2013; Klang & Clyne, 1997; Klang et al., 2014; O'Connor et al., 2008; Searle et al., 2007; Tan et al., 2010; Watkins et al., 2010). As overall prevalence of various risk factors of diabetes, hypertension and chronic kidney diseases are increasing, there is a need to have this kind of instrument for easy sensitization of the community at large as being available in the local language.

Study limitation

There are few limitations of the cognitive interview and the most important being creating an artificial environment for doing the whole process. But that kind of artificial environment is necessary for understanding the complete process of answering those items of the instrument. Since there is no similar suitable instrument available for this aspect, there was no comparison made during the cognitive interview process for PASS with another instrument. Despite these limitations, the observations during the whole process had led to an improvised version of the PASS instrument.

5. CONCLUSION

PASS instrument has passed through the rigorous process of consultation with experts and cognitive interview with field staff and patients with diabetes and hypertension for the next step of instrument validation process.

Abbreviations

PASS: Perception, Awareness, Social Support
CKD: Chronic kidney Disease

CKD PREPARE study: Chronic Kidney Disease PREdiction, Perception, Awareness Role of social support, Experiences study

Conflict of interest
The authors declare that there are no conflicts of interests

Informed consent
Informed consent was obtained from all individual participants included in the study.

Ethical approval
The study was approved by the Institutional Ethics Committee of SRIHER (IEC-NI-12/AUG/29/40).

Data and materials availability
All data associated with this study are present in the paper.

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