

UTILIZING FOCUS GROUPS IN THE FINAL STAGES OF QUESTIONNAIRE DESIGN

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Within the survey research domain, focus groups have become popular, serving as a tool to develop the conceptual framework, data specifications, or question wording of surveys. In questionnaire design, focus groups help to determine whether the proposed survey topic or data collection procedure is feasible. Therefore, they are especially useful in the early stages of question development (Bercini, 1992). Focus groups are seen as a useful starting point because they can provide a means for exploring the ways in which potential respondents think and talk about objects and events, for developing initial survey items, and for determining the best approaches to response or scale alternatives. Although the standard approach is to use focus groups in the first stage of design prior to question development, focus groups do not need to be limited to only this preliminary phase (DeMaio, 1991; Bercini, 1991; Stewart and Shamdasani, 1990).

This paper describes the use of a focus group to develop and test a questionnaire for polio survivors. In the sections below, the survey objectives and instrument are described. Results of cognitive laboratory testing of the proposed instrument are examined along with the decision to conduct the focus group. In particular, the focus group methodology, results, benefits, and implications for further use are discussed.

Survey objectives

During the first half of this century, poliomyelitis epidemics occurred unpredictably in the U.S., with incidence peaking in the early 1950's (Robbins and Nightingale, 1983). After the introduction of the Salk vaccine, the number of new cases declined rapidly. Polio is still widespread in many Third World countries, but it has been virtually eliminated within North American and Western Europe (Kaufert and Kaufert, 1984). However, many survivors of the earlier polio epidemics have reported new health problems to their physicians that they attribute to their earlier experience with polio (Raymond, 1986; Halstead and Wiechers, 1985). Studies conducted of these late effects of polio, also known as post-polio syndrome, suggest that as many as 25-30 percent of polio survivors are at risk for these new health problems, which may appear as many as 30 or 40 years after the onset of the original illness (Codd, Mulder, Kurland, Beard and O'Fallon, 1985; Halstead and Wiechers, 1985;

Ramlow, Alexander, La Porte, Kaufman, and Kuller, 1992).

In the mid-1980s, the National Center for Health Statistics (NCHS) sought to measure the prevalence of polio survivors in the U.S. by adding some questions onto the National Health Interview Survey (NHIS). NHIS is a continuously conducted household survey of a nationally representative sample of the U.S. civilian noninstitutionalized population. National estimates are produced on illness and disability, use of health services, and other health-related topics. Each year, new sets of questions on health topics of special interest are added as supplements to the core instrument.

In 1987, the NHIS included three questions designed to identify polio survivors. The NHIS sample yielded a national estimate of about 640,000 U.S. paralytic polio survivors, much larger than previous record-based estimates which ranged from 250,000-500,000 (Halstead and Wiechers, 1985; Munsat, 1991). This finding suggests that there are many more polio survivors who may be at risk for post-polio syndrome than earlier estimates would have predicted (Parsons, 1991).

Because of the level of interest among the statistical and medical research communities to further the study of this unique population, a decision was made to collect more detailed data on polio survivors beginning in 1994. Of central concern to the sponsors was the history of the respondent's experience with polio. This meant that respondents would need to answer questions about the onset of the polio, severity of the initial impairment, the rehabilitation period, level of maximum recovery or "physical best", any new health problems associated with polio, and current level of impairment.

The instrument

The study plan was for polio survivors to first be identified through screening questions on the NHIS at the time of the initial household interview. A follow-up interview would be conducted in person within two months. The questionnaire administered in the follow-up interview would ask a wide variety of general disability questions as well as specific questions designed to verify the polio diagnosis, to trace the natural history of the disease, and to determine the existence of post-polio syndrome symptoms.

Construction of the 1994 NHIS polio supplement actually began with an instrument first developed by researchers at the University of Michigan under a cooperative agreement with the Centers for Disease

Control and Prevention. This prototype questionnaire was used in a study of polio survivors experiencing the late effects of polio (Maynard, 1991). The Michigan study was designed to develop a set of methods for assessment and identification of preventable secondary disabilities among populations of people with chronic motor impairments. Data collection included a self-administered home survey and a follow-up clinical examination by medical personnel to validate the self-reports.

The 1994 NHIS polio supplement was intentionally drafted to closely resemble the instrument used in the Michigan study. The questionnaire relied heavily on a medical conceptualization of the polio illness which identified distinct phases of the disease. This framework was utilized because subjects with a history of paralytic polio in the prior clinical study were reported to have answered the questions with relative ease (Maynard, 1991). The sponsoring epidemiologists took the Michigan instrument, modified it for face-to-face interview use, and developed some new questions designed to obtain more detailed information wanted by the survey sponsors.

Cognitive laboratory testing

Prior to field pretesting, the NCHS Questionnaire Design Research Laboratory was asked to test the draft questionnaire by conducting face-to-face cognitive interviews with polio survivors. The sponsors considered the instrument to be in a final draft stage because the prototype had been used successfully in the prior clinical study. Thus, the cognitive interviews were expected to test mostly for comprehension problems associated with use of medical terminology and for retrieval and decision-making problems associated with the recall burden.

For the cognitive laboratory interviews, polio survivors were recruited from an advertisement placed in the *Washington Post Weekly Health Magazine*. Approximately 50 people responded to the advertisement and 10 were scheduled. The interviews lasted one hour and subjects were paid \$30.

Intensive probing and retrospective think-aloud techniques were used in the interviews (e.g., Tourangeau, 1984; Lessler, Salter, and Tourangeau, 1989; Willis, Royston, and Bercini, 1991). Terminology problems were quickly detected in questions that contained unfamiliar, vague, or ambiguous terms and concepts. For example, one question asked, "*What type of polio did you have? Bulbar, spinal or both?*" Very few subjects knew what the term bulbar meant, so the question was dropped. A more difficult type of cognitive problem was posed by

the question, "*After the onset of polio, what was the farthest you could walk without stopping? Less than 100 feet; 100 feet to 1,000 feet; 1,000 feet to 1 mile; more than a mile?*" In cognitive probing, it became evident that although subjects quickly chose a response category, they could not relate how they knew their answer was accurate. Subjects could not describe how far 100 feet was or what the interval 100 feet to 1,000 feet represented. Responses reflected subjects' best guess or estimate. The proposed change after testing was, "*After the onset of polio, what was the farthest you could walk without stopping? Could walk across a room; could walk up and down the street; could walk around the block; could walk a mile or more?*" This solved the cognitive problem and while the sponsor sacrificed a level of precision, the potential for response error was reduced.

Of greater concern, however, was the detection of more serious cognitive issues concerning the subjects' conceptualization of their illness history. After several revisions based on intensive laboratory interviews, subjects still had problems relating to questions about the rehabilitation and physical-best phases. This was a result of the wide variation of the rehabilitation experience and the dramatic changes in levels of impairment over a span of years. Furthermore, there were subjects who had contracted polio but experienced full recovery, and thus could not respond to questions measuring level of impairment. This group posed an unexpected problem as the questionnaire was designed to capture information from those who had suffered from paralytic polio and had not been designed to study a non-disabled population.

The sponsors recognized that changes to the questionnaire needed to be made, but were reluctant to make major modifications. This reluctance was mostly because of the success of the prototype questionnaire and the desire to use a medical model that would be comparable to other studies. Further, there was some concern that the problems detected in the laboratory were, perhaps, idiosyncratic and not thought to be valid for the majority of polio survivors. The benefits of continuing more cognitive interviews were discussed, and although there was acknowledgment that further laboratory interviewing would eventually confirm suspected problems and lead to resolutions, this was not seen as the most efficient questionnaire design method, particularly in light of the time constraints. Thus, a decision was made to discontinue individual cognitive interviews and instead, to conduct an intensive focus group interview.

The focus group

Subjects and materials

Participants for the focus group were selected from those people who had responded to the advertisement but who had not been previously selected for a cognitive interview. Nine focus group subjects were recruited, 6 females and 3 males, ranging in age from their 30s to their 70s. Most were well-educated and had worked full-time during at least some part of their adult life. All participants had experienced some paralysis when first contracting polio. Subjects were paid \$30 and the session lasted 90 minutes.

In conducting the focus group, a variety of techniques were employed to identify how subjects conceptualized the phases of the illness and to identify cognitive issues associated with the recall burden. First, each subject was given a timeline which instructed them to chart the course of their illness. The primary purpose of the timeline was to enhance recall; a secondary purpose was to obtain an unbiased self-report of the polio history. In order to provide anchors for recall, the timeline instructions also encouraged the charting of significant life events such as year of marriage and birth of children (e.g., Loftus and Marburger, 1983). Second, a structured discussion guide was used to facilitate the subjects' ability to articulate details about their illness. The session was structured to target certain problems under investigation and to reduce the likelihood of a more general discussion (Stewart and Shamdasani, 1990). And third, intensive cognitive probing techniques were used by the focus group moderator to identify comprehension and recall problems, and estimation and judgment strategies (e.g., Tourangeau, 1984; Lessler, Salter, and Tourangeau, 1989; Willis, Royston, and Bercini, 1991).

Procedure

When subjects arrived, they were greeted by the moderator and given the timeline to complete. Instructions were written on the timeline and no explanation from the moderator was provided.

The 90-minute session was essentially divided into three segments: memories about the onset of polio; memories about rehabilitation; and memories about the period from physical best to reports of any new weaknesses, pains, or problems. Each subject was asked to describe the acute phase of their illness to the group. In the two remaining segments, subjects were encouraged to relate specific memories about later phases of their illness. Participation was voluntary for these last two segments.

Subjects were prompted by the moderator to provide specific information so that, for a given phase, they were asked to describe the extent of impairment and

mobility, the surgeries and therapies experienced, and the different assistive devices used. The moderator often probed subjects to describe the basis of their response and their method of recall. Subjects were asked whether responses were based on actual memories or information told to them by others. Subjects were asked how sure they were of their recollections and how confident they were of their accuracy. Complex concepts were decomposed by the moderator to determine the level of subject understanding.

Results

In the focus group, we observed considerable variability among subjects in conceptualizing distinct phases of the illness according to a medical model. Providing details about the acute phase of the illness, period of rehabilitation, period of physical best, and current status (to include any recent decline) posed problems for most subjects. For example, one subject said that she contracted polio at age three, had therapy immediately following the acute stage, and experienced no further disability until adulthood. However, after hearing other discussions about surgery experiences, the subject then mentioned an operation she had at age seven to correct a serious polio-related problem with the muscles in her foot. She said, "*...the doctor did a tendon transplant on my left foot, so that I could raise the foot better...I was walking everywhere but I was, I supposed I must have had a dropped foot and not walking very well. But I mean I was walking well but I must have had a slight limp.*" At the beginning of the focus group discussion, she clearly did not perceive this surgery as part of her rehabilitation phase.

In another example, a subject spent considerable time talking about the therapies and surgeries used to increase the use of her legs during her rehabilitation period. When the moderator probed with, "*Did your therapy include any therapy for your arms as well as your walking?*" the subject revealed that her arms had been completely paralyzed and that much of her rehabilitation was designed to increase the use of her arms. Even though the moderator had opened the discussion with prompts for subjects to mention each part of their body affected, this subject related her disability as impairments to leg mobility and did not report on impairments to other parts of her body.

Results from the focus group demonstrated problems that were suspected but had not been confirmed in the laboratory interviews. For example, a measure of fatigue was very important to the sponsors as fatigue had been identified as a potentially strong indicator of post-polio syndrome (Codd, Mulder, Kurland, Beard,

and O'Fallon, 1985; Maynard, 1991). The question tested in the laboratory was, *"During the past few weeks, how easily would you tire while performing your usual daily activities? Tire very easily requiring frequent (five or more) rest periods; tire easily requiring occasional (two to four) rest periods;..."* and so forth. During laboratory interviews, subjects answered this question easily and while the interviewers had conveyed concern to the sponsor that rest periods might be too ambiguous a concept, subjects did not indicate any cognitive problems (even when probed). In the focus group, however, a subject who was a teacher initiated a discussion on fatigue that effectively demonstrated the problem of measuring fatigue by number of rest periods. She said, *"In 1985, ..I was walking fine. I'm active...and then I notice that in walking through the halls, I was holding onto the wall. And then I'm discovering that at the end of the day I'm just exhausted. And I can't walk from my room to the parking lot to the car. So I ended up staying at school until six and seven o'clock in the evening, because I had no energy to even get to my car."*

The substantial recall burden imposed by the concepts to be measured was clearly evident during the focus group discussion. In particular, identifying weakened body parts for each stage of the illness, which was an important measure to the sponsor, was either very difficult for subjects to remember, or not even represented in memory. For example, one subject knew he had experienced paralytic polio, but could not name specific body parts affected by the disease. He said, *"I'm told I was paralyzed from the neck down, that's what my mother said. I've often wondered what that means, since your heart works and everything. But basically it's the limbs I'm sure that were affected."* In another example, one subject said of his acute phase, *"...the rest is mixtures of my own memory and what I was told..."* After probing to determine actual memories versus information told by others, the subject said he remembered walking out of the hospital and described the casts and crutches that he used.

Discussion

The development and testing of questionnaires are the least scientifically rigorous components of the survey design process (Oksenberg, Cannell, and Kalton, 1991). It has long been held that poorly designed questions can result in poor data quality (Payne, 1951). Particularly in household or population surveys, field interviewers do not have the medical background, the training, or the time to probe responses for medical or technical accuracy. This is why questions that appear to work well in clinical settings can sometimes fail in

survey settings. Respondents may misinterpret questions, fail to recall the information requested, or give answers that present them in a better light (Jobe and Mingay, 1989). Traditional field testing can certainly identify many questionnaire flaws such as problems with skip patterns, inconsistencies across questions and response alternatives and other overt questionnaire flaws (Royston and Bercini, 1987). Techniques from cognitive psychology complement, rather than replace these traditional methods, and often result in significant improvements to questionnaires (Royston and Bercini, 1987). Laboratory testing allows us to learn about the response process in an effective, efficient, and flexible manner where feedback is quickly shared with sponsors, questions are revised and retested in a short amount of time and the interviewing cycle continues only until we are satisfied that the questions work as well as possible (Sirken, Bercini and Jobe, 1990). This method extends to the focus group, where much of the benefits of individual cognitive interviews can be realized in an intensive group discussion.

In this study, the cognitive laboratory first became involved in the latter phase of questionnaire development and was not involved in basic question design. The sponsors who constructed the draft questionnaire were reasonably confident that a modification of the prototype instrument would work well in laboratory testing. They did not expect the laboratory interviews to reveal serious cognitive or structural problems. This was the basis for the lab staff's decision to conduct individual cognitive interviews rather than consider a focus group when work was initiated.

There is little doubt that continued laboratory testing of the polio questionnaire could have identified findings similar to those of the focus group. It is not that one method is superior to the other but rather, that questionnaire designers should consider use of focus groups at late or final stages of design and testing when confronted with fundamental question design problems. Further work should examine the questionnaire design process in greater detail to better understand how different cognitive science techniques could be utilized in the laboratory environment.

Along the same lines, using the timeline served several important purposes and its application in focus groups should be explored further, especially when long-term recall is a significant factor. The timeline was an excellent method for obtaining a relatively "pure" sense of how the subjects conceptualized the phases of their illness without influence of other participants, the moderator, or even the structure of a survey instrument. It also was a positive warm-up exercise that gave the subjects something to do while

waiting for the session to begin. And perhaps most importantly, it cued subjects to remember details about their illness and prepared them to participate. Before deciding to use a timeline, we had considered use of a short self-administered questionnaire which might have accomplished the same objectives. Self-completion tools such as timelines and questionnaires clearly have a place for use in focus groups.

Social dynamics of group discussion

The focus group experience provided a forum for participants to discuss personal experiences in a non-threatening way and allowed for spontaneous interaction among participants. There was a strong sense of comradery among the focus group members which reinforced participation and actually served to jog and clarify memories. Each participant was eager to share his or her story and actually became more stimulated and attentive as they listened to others. This resulted in an abundance of qualitative information which would have been more difficult to obtain in individual cognitive interviews. This is because the individual interview technique does not enable the moderator to leverage the benefits of peer interaction that exists in focus groups (Greenbaum, 1992).

Guidelines for using focus groups in questionnaire design

Focus groups in the final stages of questionnaire design can, in some cases, have substantial benefits over further laboratory testing. When the conceptual basis of the questionnaire is suspect, use of focus groups allows one to depart from the structure imposed by the questionnaire. Interview situations by definition require a formal exchange of questions and answers which do not lend themselves to interactive and spontaneous communication. The standardization inherent in questionnaire administration imposes constraints on the survey interview that make it significantly different from ordinary conversation (e.g., Suchman and Jordan, 1990; Means, Swan, Jobe, and Esposito, 1991). Our observation is that even in intensive cognitive interviews, subjects will make every attempt to answer questions and adapt to the survey structure imposed. Even when subjects are encouraged to depart from the questionnaire in order to relate misunderstanding or confusion of meaning, the typical subject does not do this well until probing or other cognitive interviewing techniques are used.

However, this does not mean that the objective of a focus group should be to generate general discussion with little or no imposed structure. Rather, the very structure seen as a constraint in the one-on-one interview should be positively adapted to focus group

planning so that the likelihood of obtaining a significant amount of relevant qualitative data is increased. It is, thus, crucial that questionnaire designers treat focus groups as sophisticated research tools, and that they choose to use them at the right points in time.

Conclusions

Focus groups can provide a rich source of qualitative information that may not be easily collected through individual cognitive interviews. We have seen that through the synergism of group dynamics, a significant amount of information is obtained as participant discussion serves to cue recall of past events. In this study, results of the focus group led to a better understanding of the concepts to be measured, and ultimately, to an improved questionnaire. Focus groups can also serve as a practical demonstration to clients or sponsors of serious remaining problems, and solutions can be formulated and tested spontaneously. Focus groups conducted in the final stages of questionnaire design can be extremely effective and efficient in identifying and solving problems with concepts and questions and can lead to improvements that reduce response error. We are hopeful that the results of this project will assist other researchers in identifying various methods for studying cognitive issues in the response process.

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