

COLLECTING INFORMATION ABOUT THE HEALTH CARE EXPERIENCES OF ADOLESCENTS

Patricia M. Gallagher, Floyd J. Fowler, Jr., Center for Survey Research, University of Massachusetts Boston
Patricia M. Gallagher, 100 Morrissey Boulevard, Boston, MA 02125

Key Words: Mail Survey, Telephone Survey, Adolescents, Health Survey Methods, CAHPS

Researchers collecting information about patient experiences with health insurance plans will have to address the problem of how to collect information about the health care experiences of teenagers. We have spoken with both parents and teenagers separately in a focus group setting, and both groups agree that; 1) parents are not able to answer questions knowledgeably about their adolescents' interactions with health care providers and, 2) teenagers are not fully informed about their health plans. Two methodological experiments were conducted. The first to provide documentation for what we have learned anecdotally in focus groups and the second to test the feasibility of collecting information from teenagers about provider interactions and from their parents about interactions with health plans. This research was performed as part of the ongoing work to develop methods for the Consumer Assessment of Health Plans (CAHPS) project.

The goal of CAHPS is to develop survey instruments for members of health plans to reliably report their experiences with health professionals and plans. The project is sponsored by the Agency for Health Care Policy and Research (AHCPR) and is being carried out by a consortia led by Harvard Medical School, RAND, and the Research Triangle Institute. The Center for Survey Research is working with Harvard to, among other things, develop protocols for learning about the health care experiences of children.

Focus Groups with Parents and Teens

During focus groups with parents aimed at improving CAHPS instruments for children, we learned about parents' difficulties in reporting adolescent children's experiences with doctors. After a certain age, parents do not routinely accompany their teenaged children into the examining room or, for many, even to the doctor's office. Many expressed the concern that they did not have enough information to accurately answer questions about their children's interactions with providers. To confirm these observations, we held focus groups with two groups of adolescents.

One group was primarily composed of white suburbanites while the other was teenagers of color from Boston. The adolescents uniformly reported that their parents would not be able to describe the teens' doctors office visits because they were not there to witness them.

In addition, these teenagers were not very knowledgeable about the workings of their health plans.

Two experiments were designed. The first had two goals; 1) to assess parents' willingness to give permission for their minor child to be interviewed by telephone and the teenagers' acceptance of the process, and 2) to compare parents' and teens' responses to essentially identical questions about the adolescents' health care. The second experiment centered on evaluating the feasibility of using a mail protocol to collect some information directly from teenagers and the balance from parents.

Sample and Methods

Telephone Study

The particular complexity of gathering information about enrollees' experiences with their health insurance plans is that it requires collecting two distinct types of information. Questions have to be asked about both enrollees' interactions with the plan and their experiences with providers and office staff. In this first experiment one goal was to assess the comparability of parent and adolescent child responses to items querying each of these domains, we sampled from a list of employees of the State of Washington 200 subscribers who had a covered adolescent child.

The parents were first sent an advance letter to inform them of the sponsor and purpose of the study and to let them know that an interviewer would be calling. Using a computer-assisted telephone interview, professional interviewers asked parents about their teenagers' health care experiences. At the end of the interview, parents were asked to consent to having the adolescent child interviewed directly — an interview in which the same questions asked of the parent about the plan and the child's health care were asked of the child. The answers obtained from the child are compared with those obtained from the parent using Pearson Product Moment Correlations to assess inter-rater reliability.

Mail Study

The second experiment involved a probability sample of 150 adolescent children and their parents from the same sampling frame. A packet addressed to the parent containing two questionnaires, one targeted to the parent, the other to the teenager, was sent to each sampled household. The instrument for parents centered on questions about interactions with the health plan, while the questionnaire targeted to the adolescent is primarily composed of provider interaction items.

Parents were instructed to complete the parent instrument, ask the selected adolescent to complete the teen instrument, and return both questionnaires together in the postage paid envelope provided. The goal here was to test the feasibility of using a mail protocol to obtain responses about each of the domains of interest from the persons most likely to be knowledgeable.

A standard mail survey protocol was followed. First, an advance letter on letterhead from the State of Washington was sent to each sampled household. About a week later instruments with cover letters were mailed; seven to ten days later a thank you/reminder postcard was sent to the entire sample; seven to ten days after the postcard mailing, replacement questionnaires with cover letters were sent to all nonrespondents. A month after the replacement mailing, reminder phone calls were placed by trained interviewers to all nonrespondents.

Results

Telephone Study Results

Parents report that teenagers often go to the doctor's office unaccompanied. For over 40% of those teens who had appointments within the reference period, parents indicated that they did not always go with the adolescent. The response rate for the telephone study was 50.0%. Not included as completions are the two cases where it was not possible to complete the interview with the adolescent after parental consent was obtained (one teen refused to be interviewed, for the other it proved impossible to find a mutually convenient time to schedule an interview).

Analyses of the telephone study data are based on the 81 completed pairs of telephone interviews. Items with fewer than 25 responses (because of skip patterns or missing answers) were excluded from these analyses. In the remaining pool of 32 items; 13 describe interactions with providers; 7 with plans; 7 are contingency questions that function as gatekeepers to other items; and 5 query demographic information. To test the inter-rater reliability of the teens and their parents, a correlation was calculated for each pair of responses to the telephone survey.

With samples this small, question pairs with correlation coefficients above 0.25 tend to be significantly related so it is more informative to concentrate on the level of correlation. Responses to the 32 survey items were not very highly correlated (see Table 1). Nearly 60% of the item pairs had correlations lower than 0.3 (see Table 2 for the text of these items) while only 7 items (about 22%) demonstrated correlations above 0.5. Not surprisingly, parent and teen reports about the child's demographic characteristics were most consistent; 4 of the 5 most highly correlated items ($r > 0.7$) were demographic items. Questions about adolescents interactions with doctors were least

consistent demonstrating the weakest correlations. In fact, the items asking how well providers explained things to the teenager and whether the doctor had discussed how the child was feeling, growing, or behaving were negatively correlated. Furthermore, correlations for questions about the health plan were generally low — none were above 0.5.

Items where teens answered "Don't Know" or answers were not ascertained provide additional evidence of the adolescents' inability to answer certain questions. Overall, about 3% of the teens' answers fall into these two categories. Stratifying by question type highlights adolescents particular lack of knowledge about their health plans: Teens were not able to answer about 10% of the plan interaction questions while the rate for other question categories hovered at less than 2%.

Mail Study Results

The primary interest in the mail study was rate of return. About half of all eligible or assumed eligible cases returned completed questionnaires for a response rate of 49.0%. The case where only the parent half of the parent/teen pair of questionnaires was received by mail is not included as a completion in the calculation of this rate.

It is worth noting that good contact information was not available for 17% of the mail sample and 20% of the telephone sample. Another way to think about outcome rates is to calculate the rate of cooperation. This is the proportion of all eligible units ever contacted who responded. The cooperation rate was 82.4% for the mail study and 72.9% for the telephone study. Looking at the study outcomes in this way allows an estimation of respondents' willingness to participate that is independent of the quality of contact information provided.

Conclusions

It is clear from the analysis of inter-rater reliability that there is not a great degree of concordance between parent and adolescent reports. For more than three quarters of the items analyzed, parents and teens answers to questions about the child's health care experiences are correlated below 0.5. As expected from focus group reports, the greatest number of differences appear on items asking about interactions with doctors.

This study is limited by low statistical power. It also is not certain which estimate is best when parents and teens differ. In the absence of a gold standard identifying which set of responses best reflects reality, it is reasonable to assume the teens' reports of their own experiences are better than those of parents, who often must rely on the second-hand reports of the adolescents. Parents are more likely to have encounters with health

insurance plans and their answers can be assumed to be more reliable.

If researchers decide to collect information from both parents and adolescents, our experience demonstrates that it is feasible to gather this information using either an interviewer administered or a self administered interview. The response rates for the two modes were virtually identical, but the telephone response was lower than expected from previous experience with CAHPS telephone studies. This project required extra effort from phone room staff both to enlist parental consent for the interview with the adolescent and to schedule (and successfully complete) interviews with busy teenagers. A dual mode strategy of a mail survey followed by telephone interviews with nonresponders would almost certainly increase the rate of response. However, using an all telephone protocol eliminates

issues about confidentiality that may arise in a mail study where the parent must collect the questionnaire from the child and mail it back. While this is not a particularly sensitive instrument, issues of the social desirability of responses can arise when teens know their parents will have access to their answers.

In conclusion, this study, despite its limited sample size, clearly demonstrates that parents and teens often give different answers about the adolescents' health care experiences. Our next step will be to do a larger study to obtain better information on the data consequences of the decision about whether parents or teens are asked to report on teens' health care experiences. We will also be examining alternative protocols for collecting data from parents and their teen-aged children.

Table 1. Inter-Rater Reliability of parents' and adolescents' ratings of adolescents' medical care and health insurance plan.

Question Type	Pearson Correlation				
	<.3 % (# of items)	.3 - .5 % (# of items)	.5 - .7 % (# of items)	.7 and above % (# of items)	Total % (# of items)
Provider Interaction	69% (9)	15% (2)	8% (1)	8% (1)	100% (13)
Plan Interaction	43% (3)	57% (4)	—	—	100% (7)
Screening	86% (6)	—	14% (1)	—	100% (7)
Covariate	20% (1)	—	—	80% (4)	100% (5)
Total	59% (19)	19% (6)	6% (2)	16% (5)	100% (32)

Table 2. Text of Items Demonstrating Correlation Coefficients < 0.3

Item	r (n)
Provider Interactions:	
When you went to your personal doctor or nurse's office or clinic, how often did the doctor or nurse talk with you about how you are feeling, growing, or behaving?	-.012 (54)
How would you rate your personal doctor or nurse now? (0-10 scale)	.263* (62)
How often did doctors or other health providers listen carefully to you?	.277* (63)
How often did doctors or other health providers explain things in a way you could understand?	-.151 (58)
How often did doctors or other health professionals spend enough time with you?	.118 (59)
How would you rate all your health care?	.229 (62)
In the last 12 months, when you needed regular or routine health care, how often did you get an appointment as soon as you wanted?	.109 (47)
How often did office staff at a doctor's office treat you with courtesy and respect?	.256* (63)
How often were staff at a doctor's office as helpful as you thought they should be?	.085 (63)
Plan Interactions:	
How much of a problem did you have in receiving care you and your doctor believed necessary.	.101 (76)
How would you rate your health plan?	.199 (65)
How much of a problem was filling out forms for your child's health plan?	.281* (77)
Contingency Questions:	
Do you have one person you think of as your personal doctor or nurse?	.137 (80)
Did you phone a doctor's office or clinic during regular office hours to get help or advice for yourself?	.274* (81)
Did you have an illness or injury where you needed to see a doctor or other health provider right away?	.284* (81)
Did you make any appointments with a doctor or other health provider for regular or routine health care?	.261* (81)
Did you need information from your health plan about covered services or administrative issues?	.171 (77)
Did you call your health plan's customer service to get information or help?	.141 (80)
Covariate:	
In general, how would you rate your overall health now?	.297** (81)

* p< 0.05; **p<0.001

Notes: 1 - Items are shown in the text intended for the adolescent respondent.

2 - The reference period for all but the covariate item is 12 months.

3 - CAHPS version β 2.0 item wording.

Acknowledgments

This article relies on data collected from employees of the State of Washington. We thank them for their time and kind cooperation. We are also grateful to the administrators at the State of Washington Health Care Authority, particularly Mary Uyeda and Vicki Wilson, for their invaluable help with this project.

References

Fowler FJ Jr., Gallagher PM, Nederend S. Comparing telephone and mail responses to the CAHPS survey instrument. *Medical Care*, (in press) 1998.