

Unsolicited Written Comments: An Untapped Data Source

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Purpose/Objectives: To explore methods for analysis of unsolicited comments written on forced-choice surveys related to health-related quality of life (HRQOL) among men treated for prostate cancer.

Data Sources: Unsolicited comments written on surveys administered as part of a study investigating HRQOL for men receiving surgery, external beam radiation therapy, or brachytherapy for prostate cancer were abstracted from the parent study database at baseline (pretreatment) and 1, 2, 4, 8, 12, 18, and 24 months after treatment.

Data Synthesis: Researchers read through all of the comments for each timepoint. They coded each comment for the main idea expressed by each statement in each written comment. They grouped codes into categories and counted the number of participants writing comments in each category at each timepoint. They were displayed graphically. Of 375 subjects completing surveys, 87% wrote unsolicited comments on at least one of the surveys. Thirty-four codes were derived from 3,175 comments. Grouping of the codes resulted in eight categories.

Conclusions: Analyzing unsolicited comments proved to be feasible and useful in revealing additional information about respondent concerns.

Implications for Nursing: This type of analysis has value in its ability to reveal patterns in previously unused data that then can be used to explain or deepen survey findings or suggest avenues for more in-depth qualitative or quantitative nursing investigation.

Key Points . . .

- Unsolicited comments on forced-choice surveys may provide deeper insights into data.
- Coding and theme identification proved useful to categorize and graphically display unsolicited comments.
- Unsolicited comments provided explanation, elaboration, and context for responses to survey items.

respondents' satisfaction by surveys, especially related to their treatment experiences and quality of life (QOL) across the illness-treatment trajectory.

Numerous surveys have been conducted to assess QOL among men who have been treated for prostate cancer (Arai et al., 1999; Bacon, Giovannucci, Testa, Glass, & Kawachi, 2002; Bacon, Giovannucci, Testa, & Kawachi, 2001; Brandeis, Litwin, Burnison, & Reiter, 2000; Clark, Rieker, Propert, & Talcott, 1999; Eton, Lepore, & Helgeson, 2001; Fowler et al., 1995; Krongrad, Litwin, Lai, & Lai, 1998; Litwin, 1994, 1995, 1999; Litwin et al., 1995; Litwin, McGuigan, Shpall, & Dhanani, 1999; Litwin, Melmed, & Nakazon, 2001; Litwin & Penson, 1998; Litwin, Shpall, Dorey, & Nguyen, 1998; Lubeck et al., 1999; Lubeck, Litwin, Henning, & Carroll, 1997; McCammon, Kolm, Main, & Schellhammer, 1999; Penson et al., 1998; Yarbrow & Ferrans, 1998). Studies have investigated general health-related QOL (HRQOL) and prostate cancer-specific HRQOL similar to the longitudinal study from which unsolicited comments were abstracted for this methodologic exploration. Findings of various studies have indicated that general HRQOL does not suffer greatly following treatment for prostate cancer, even in the presence of symptoms such as incontinence and erectile dysfunction, which men indicate to be bothersome on prostate cancer-specific HRQOL measures (van Andel et al., 2004). Only a few studies have explored HRQOL longitudinally (Eller et al., 2006), and few of those lasted longer

Unsolicited written comments on forced-choice surveys are a rich, untapped source of data. Often, participants write comments on surveys in the margins or at the end, perhaps because of a need to convey an experience, context, or feeling that is not captured by the survey items and their choices. This practice may be understood based on the assumption that individuals make sense of experiences by putting them into narrative form (Brunner, 1990; Gee, 1985; Mishler, 1986). Forced-choice surveys do not allow individuals to act on a tendency to create stories to make meaning out of situations (Reissman, 1993). Surveys, in essence, fracture the essential meaning-making structure of narratives (Reissman), perhaps compelling some individuals to add written comments to provide more complete pictures of their experiences. Thus, unsolicited writings may provide insight into issues of importance to their writers. In addition, identifying time points in the illness-treatment trajectory when more individuals are likely to write unsolicited comments may indicate times when the need to narrate in the process of making meaning is more intense or may contribute to understanding the time trajectory of the meaning-making process. However, unsolicited comments can be challenging to analyze, because they are not purposefully or systematically collected. Nevertheless, they may provide useful insights into aspects or details not covered to some

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than 12 months (Korfage et al., 2005; Miller et al., 2005). Also, no reports have been published regarding analysis of unsolicited written comments on HRQOL surveys using a systematic, analytic approach.

Therefore, the researchers chose to undertake an exploratory analysis of unsolicited comments written on a forced-choice survey containing multiple instruments from a narrative perspective with symbolic interactionism underpinnings. The premise was that men wrote unsolicited comments on the surveys when they felt a need to provide context for or explanation of responses made to survey items as they made meaning of the experience for themselves and attempted to communicate that meaning to the researchers. The approach to the investigation was to uncover the parts of the story that men felt were left untold by the survey items. The survey was part of a study examining QOL longitudinally among men who were treated for prostate cancer. The goal of the project was to develop and apply an analytic methodology that would enable researchers to examine the type of data collected in the current study so that additional insights into QOL issues might be gained.

Analysis Procedures

Data collection for the primary study proceeded after institutional review board approval. HRQOL surveys were administered to 375 men at baseline (pretreatment) and 1, 2, 4, 8, 12, 18, and 24 months following treatment for prostate cancer with surgery, external beam radiation therapy, or brachytherapy. Participants had the option of receiving the surveys by mail and returning them in the provided postage-paid, addressed envelope or completing the surveys on a secure Web-based system. Unsolicited comments were written in the margins as well as in the comment section at the end of the paper-and-pencil surveys and in the comment section at the end of the Web-based surveys. The Web-based system restricted where comments could be written, whereas paper-and-pencil questionnaires did not restrict possible locations of comments. All comments were entered into a text field in the study database without any identifying information. Those from the paper-and-pencil questionnaires were entered manually into the database from handwritten materials. Comments from the Web-based system were entered directly into the database.

In preparation for analysis, all of the comments were copied into a new file grouped by study participant identification number under each time point. Initially, all comments were read to obtain an overall sense of the content at each time point. Then, each phrase of each comment was placed on its own line for detailed coding. Next, each phrase was coded to represent the main idea that was expressed. Codes then were clustered into broader representative thematic categories for each time point, which allowed the researchers to see which categories appeared at each time point across the illness-treatment trajectory. The number of participants making comments in each category also was identified and provided insight into the breadth of concern among patients regarding each category at each time point. Finally, participants and their comments were grouped over time by treatment type, permitting comparison of patterns of categories over time by treatment.

The number of subjects writing unsolicited comments at each time point varied. Therefore, the number and percentage of subjects with comment codes falling in each category at

each time point were calculated. The percentages were used to enable comparison across time points and by treatment type despite differing numbers of participants writing comments at each time point.

Graphs and tables displaying patterns over time were created for the most frequent issues related to prostate cancer treatment according to participants' comments (i.e., urinary, bowel, and sexual effects) and for comments related to patients' overall sense of progress following treatment, which was the fourth most commonly noted category. Graphs were created for the total group as well as by treatment. Doing so showed the patterns of percentages of participants commenting in specific categories across time and by treatment.

The process developed to analyze unsolicited written comments facilitated the discernment of patterns over time in the categories of respondents' comments and in changes in the frequency of comments that fell into the various categories overall and by treatment. Using coding techniques based on qualitative methods, the researchers identified categories that then could be quantified by the percentages of respondents addressing the categories with unsolicited comments at each time point. In addition, descriptive statistics were used to reveal the respondents' demographics and to identify important differences by treatment type.

Analysis Results

Of the 375 participants completing surveys, 87% wrote unsolicited comments on at least one of the surveys. Figure 1 shows the distribution of the number of comments written and the number of participants writing comments at each time point. As noted previously, the number of participants writing comments and the number of comments made at each time point varied. This finding also was true within each treatment. Overall, the number of respondents writing unsolicited comments rose sharply from baseline to one month. The number fell slightly at two and four months, with a further drop at eight months and slight rise at one year. After one year, the number of men writing comments fell more steeply, although the drop was more prominent in the surgery group than in the other treatment groups.

Thirty-four codes were derived from 3,175 comments. Grouping of the codes resulted in eight categories, as displayed

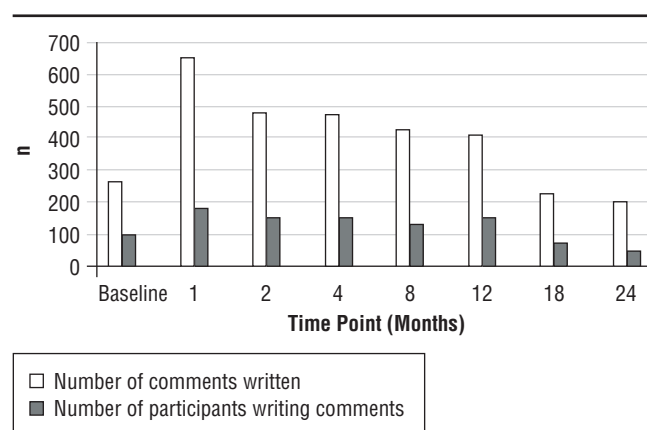


Figure 1. Number of Comments and Participants Writing Unsolicited Comments at Each Time Point

in Table 1. The distribution of percentages of participants writing comments in each category varied over time and by treatment. This article focuses on the four most common categories based on overall percentages of respondents writing comments within each category.

Sexuality

The most comments at all time points were regarding sexuality. The pattern of the percentage of participants by treatment type writing comments in this category over time can be seen in Figure 2. The range of expression can be seen in the following exemplars. “No desire. No erections. But hope it is temporary so not worrying about it.”

My sexual capacity has been permanently altered and may indeed be nonexistent. Only time will tell, but my desire still remains. My wife and I have had many discussions about this, and we know the consequences, but the facts remain. There will be changes, and there will be two victims, not one.

Table 1. Categories and Underlying Codes Identified From the Unsolicited Comments

Category	Codes
Sexual function	Pretreatment sexual function
	Impotence
	Effect on relationship
	Current sexual function
	Masculine identity
Urinary function	Coping
	Incontinence
	Expectations
	Activity modifications
Bowel function	Change in function
	Incontinence
	Discomfort
	Activity modifications
Overall progress or decline related to treatment	Getting better
	Not doing well
	Expectations
	Evaluation of treatment choice
	Effect on lifestyle
Context of treatment	Other illnesses
	Lifestyle pretreatment
Emotional response	Anger
	Outlook
	Desire to help others
	Depression
Complications and side effects	Symptoms other than incontinence and impotence
	What went wrong
	Coping
	Surprises
	Fatigue
Information	Inadequate preparation
	Unanswered questions
	Incomplete information
	Good information
	Self-education

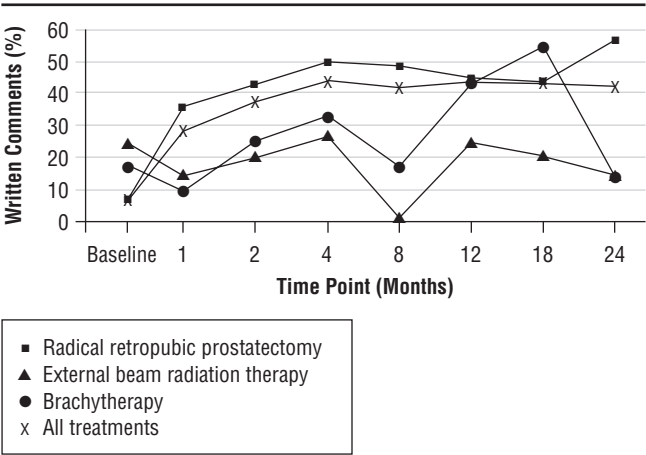


Figure 2. Written Comments Related to Sexual Function by Treatment

The percentage of participants writing comments related to sexuality peaked at four months, with 45% writing comments such as, “The loss of sexual function is a great disappointment, but the choice between life or sex is not a difficult one to make,” “Impotence is no fun, but I expected it. Patiently awaiting return of sexual function,” and “Now I use Viagra® (Pfizer Inc., New York, NY) and get good erections and have a good climax, but not as natural as before. It takes some planning.” The percentage of participants writing comments in this category remained above 40% through the last time point at 24 months after treatment with the following types of comments. Eight months: “I am disappointed Viagra has not worked, but considering the alternative, I’m fine” and “At about the eighth month point, Viagra began to work perfectly.” Twelve months: “I am pleased that my erection function is almost back to pretreatment status, although ejaculation is not,” “I am sexually active with Viagra. My erections are strong with medication,” and “My wife and I cuddle affectionately in the morning when we awaken. A firm erection is rare, especially after treatment.” Eighteen months: “I am now reconciled to not having an erection, again.” Twenty-four months: “Two years post–radical prostatectomy, and I am still impotent and incontinent. Sexual activity is very unsatisfactory. Viagra combined with the vacuum device moderately or barely successful in producing partial erection” and “After two years, my sexual function has reawakened somewhat.”

Among those who had surgery and wrote comments, sexuality was the category with the highest percentage of comments. A lower percentage of men who had external beam radiation therapy and brachytherapy wrote comments related to sexuality at all time points, except for the 18-month point, when the percentage writing comments about sexuality in the brachytherapy group rose above the surgery group.

In general in this category, men described their sexual functioning, how it affected their relationships with their partners, how it affected their feelings about themselves and their masculinity, how sex and sexuality were different since treatment for prostate cancer, and their ways of adjusting to the changes. The responses provided context and explanation of responses to items on the survey.

Urinary Issues

Comments about urinary issues related specifically to changes in urinary function and the impact of the changes, including incontinence, expectations of post-treatment urinary function, modification of activities because of changes in urinary function, and changes in function. As seen in Figure 3, the percentage of written comments in this area was low (8%) at baseline. The only comment on urinary function at baseline was written by a man who was going to have radiation therapy. The percentage of respondents in all groups writing comments about urinary issues steadily increased, peaking at eight months and then generally trending down. Among those who had brachytherapy, the highest percentage who wrote comments about urinary symptoms did so at 12 months. A second lower peak occurred at four months. Among those who had radical prostatectomies, the highest percentage writing comments occurred at 24 months. However, among the radical prostatectomy group, an increase occurred in the percentage writing comments at month one that was relatively sustained through month eight, with a decline at month four before increasing again at month eight. A dropoff was noted in the percentage who wrote comments in the radical prostatectomy group at month 12, with an increase at month 18 before the peak at month 24.

Bowel-Related Comments

Bowel-related comments revolved around bowel incontinence, rectal discomfort, discomfort with bowel movements, diarrhea, constipation, and activity modifications made to accommodate bowel function. Bowel concerns were not commented on at baseline in any of the treatment groups. Among those who had surgery, the percentage writing comments about bowel concerns remained low throughout the time period. Among those who had radiation, comments about bowel concerns did not appear until month two and then peaked at month eight before falling back off to zero by month 24. Likewise, among those who had brachytherapy, comments about

bowel concerns did not appear until month two. The peak also occurred at month eight, followed by a decline. However, the percentage in this treatment group did not return to zero.

Bowel dysfunction is associated primarily with external beam radiation therapy and brachytherapy but not with radical prostatectomy, as demonstrated in Figure 4. This was reflected in the pattern of percentages of comments among those receiving external beam radiation and brachytherapy compared to those who received surgery. The percentage commenting on bowel function in the external beam radiation and brachytherapy groups peaked at month eight and then subsided. In both groups, comments on bowel function peaked after completion of treatment—almost eight months for brachytherapy and approximately six months after completion of external beam radiation. This finding is consistent with the expectation of the timing of symptom occurrence following treatment.

Feelings About Treatment and Its Effects

Written comments most common in this category reflected issues relating to satisfaction with care, regretting or being satisfied with treatment decisions, and perceptions of improvement or worsening of symptoms. The areas evidently were believed to be important but not adequately addressed by the survey items and responses. Comments in this category reflected perceived improvement or decline in overall health and recovery relative to expectations, such as, “I’ve seen a big improvement in my physical health since surgery” (one month) and “I feel that my recovery has gone well” (one month). At the first month after treatment, 42% of men writing comments in all treatment groups discussed getting better or worse. One month: “Directly after brachytherapy, it was a little uncomfortable, and the drugs made me feel a little sleepy. Over the month, this has improved” and “Severe pain during bowel movement. No sign of decrease in pain three to four weeks following completion of radiation.”

The percentage writing comments varied from 24% at month four to 39% at month 24, with the percentages at the other time points near 30%. Comments in this category often discussed time frames or described change over time, possibly because men wanted to provide a sense of progress, not just a snapshot of the point in time requested by the survey items.

Among those who had surgery, the highest percentages of comments in this category were at month one (55%) and month 24 (44%). The percentages varied from a low of 16% at month 18 to a high of 33% across the other time points. The highest percentage of decline or progress comments among those who had radiation therapy occurred at 24 months (72%), followed by 18 months (40%), and one month (36%). Figure 5 displays the patterns of comments for each treatment group.

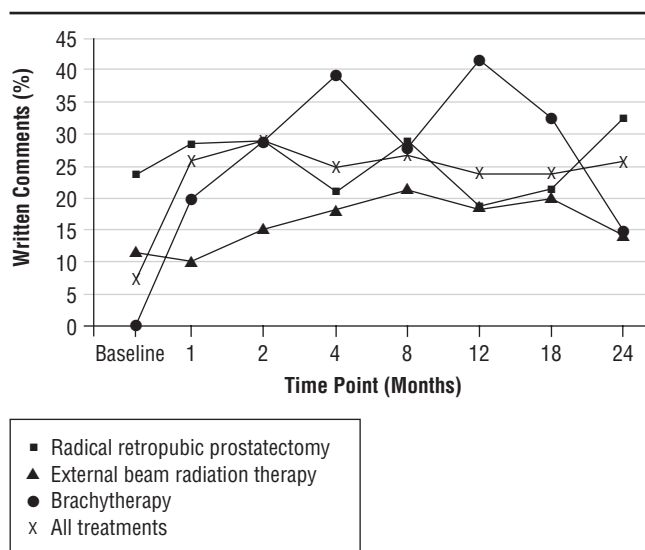


Figure 3. Written Comments Related to Urinary Function by Treatment

Discussion

The approach used to analyze the unsolicited comments proved to be feasible and useful in revealing additional information about respondents' concerns. Although the abstraction and coding of comments were laborious, they provided for the organization of the unsolicited information so that it was able to be analyzed further. By categorizing the codes and determining the frequency of the categories, the researchers could discern shifts in patterns over time and by treatment. Even though not all men wrote comments at all time points,

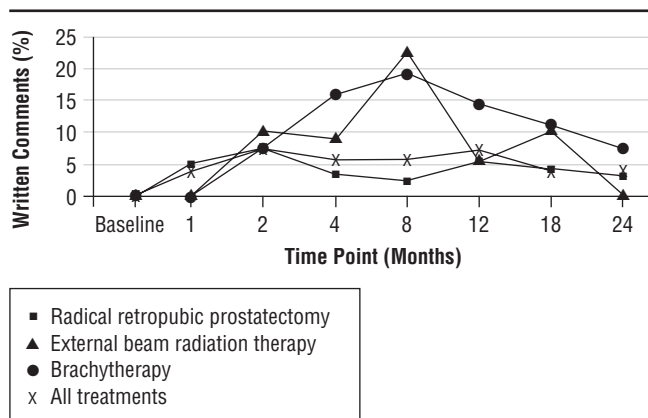


Figure 4. Written Comments Related to Bowel Function by Treatment

using percentages of men writing comments for each time point allowed analysis that provided a window into issues that concern men enough to prompt them to write unsolicited comments on HRQOL surveys. Comments provided explanation, elaboration, and contextualization of responses to survey items. All of those functions are consistent with the narrative theory of using storytelling to make meaning of events. Clearly, the forced-choice surveys did not permit satisfactory elaboration of events at critical points in time, when symptoms such as erectile dysfunction and incontinence were being experienced. One explanation may be that, during times when the meaning of symptoms had not yet been discerned in the context of their own lives, men needed to explain and contextualize their symptoms as part of the process of making them meaningful. Writing comments to expand or explain choices made on surveys may be an expression of this action.

Three of the comment categories were related directly to the primary side effects associated with treatments, whereas the other indicated concern for gauging overall status progress in recovery. All of the prostate cancer treatments included in the current study have been associated to some degree with erectile dysfunction and urinary incontinence. Although the prostate cancer-specific QOL instrument asked for rating of function and bother related to sexuality, incontinence, and bowel dysfunction, men writing comments must have felt that the items needed further explanation and expansion.

The pattern of comments over time may have been reflective of men's sense that the items or the response choices of the questionnaires did not fully capture what they wished to convey about their experiences. Based on the pattern of comments, the desire to make thoughts known beyond the contents of the survey appeared to drop off after one year. Several explanations are possible. For instance, the symptoms of concern may have resolved by the one-year time point, timeline expectations for the symptoms may have been met, or men may have adapted to uncertainty regarding symptoms' persistence beyond their expectations. The decrease in written comments also may indicate that meaning had been attributed to the treatment experience and associated symptoms so that the need to narrate to make meaning had diminished.

Perhaps those who wrote unsolicited comments after one year still were experiencing symptoms and felt the need to

expand on their experiences because of the long-term duration or later appearance of symptoms. This finding was consistent with the sharper drop-off in the number of comments written by those who had had radical prostatectomy compared to those who had had radiation therapy or brachytherapy, both of which may have later side effects.

Also, the course of symptom resolution may not have followed the pattern expected by the men, creating a continued need to make meaning of an experience that did not meet expectations. This possibility was demonstrated by the fact that even at 18 and 24 months, a number of men felt that their thoughts needed to be expressed beyond the constraints of the forced-choice questionnaire. In particular, comments at later time points most frequently were related to sexual and urinary function among those who had had radical prostatectomy, bowel function among the brachytherapy group, and overall progress or decline among the radiation therapy group. Expectations of symptom resolution by later points in time may have motivated the continued writing of comments. When expectations are not met, making meaning of symptoms and the treatment experience may become more difficult and cause the need to narrate to be ongoing.

Limitations

Conclusions cannot be drawn from the current analyses with the same kind of certainty as with data that have been collected systematically based on qualitative or quantitative study design. Of note is that statistical comparisons were not made, only visual, qualitative comparisons at a level appropriate to the available data. Web-based restriction to writing in margins may have altered or limited comments, because they could not be made during completion of individual items but had to be held until the end of survey. In addition, comments were only portions of stories. The narration of complete stories that would be needed for full qualitative analysis was not available. Although the comments did provide some additional insights, they were fragmented.

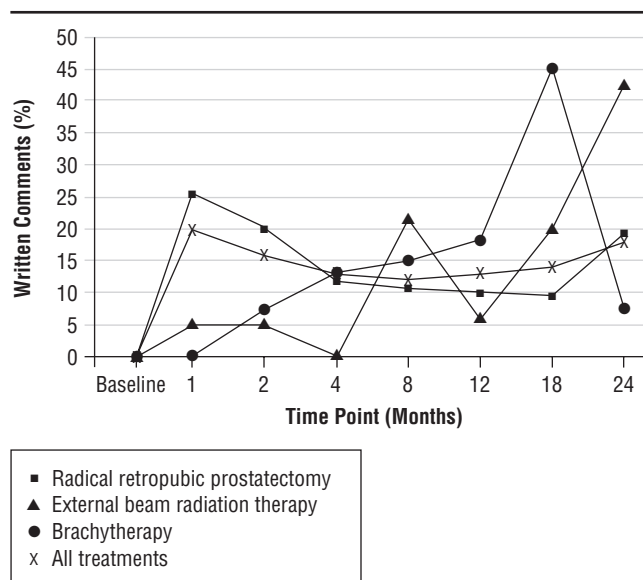


Figure 5. Written Comments Related to Feelings About Treatment and Its Effects

Implications

Despite limitations, the type of analysis used in the current study has value in its ability to reveal patterns in previously unused data that can explain or deepen survey findings or suggest avenues for more in-depth qualitative or quantitative investigation. For instance, the researchers would want to explore the reasons that men wrote unsolicited comments or whether the continued writing of comments after one year is reflective of perceived status relative to expected outcomes. Further exploration would aid in the interpretation of the current findings. Also, the findings suggest that men's concerns related to sexual function, urinary function, and overall progress or decline beyond a year after treatment should be explored, because a number of men in the present study still wrote about their concerns after one year. Further study could add to the knowledge base on survivorship and chronic treat-

ment-related symptoms. In addition, use of other techniques, such as discourse analysis, might provide perspective on the analysis of this type of data.

The results suggest that adding a planned qualitative component to forced-choice surveys might enhance understanding of findings and provide respondents the opportunity to contextualize their responses. Also, knowing at which points along the treatment trajectory men completing HRQOL surveys tend to write unsolicited comments can provide guidance on timing of qualitative interviews to maximize capturing issues at the height of their concern to participants. Finally, the findings demonstrate very clearly the human tendency to create stories to make meaning of life events, as described by Reissman (1993), even on forced-choice surveys.

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