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Measurement Reactivity in a Randomized Clinical Trial Using Self-Reported Data

Jahaira Capellan, MS, FNP-BC, RN¹ [Epsilon Xi, PhD Candidate], Mary H. Wilde, PhD, RN² [Epsilon Xi, Professor], and Feng Zhang, MS, ANP, RN³

¹University of Rochester, School of Nursing, Rochester, NY, USA

²University of Rochester, School of Nursing, Rochester, NY, USA

³University of Rochester, School of Nursing, Rochester, NY, USA

Abstract

Purpose—The objective of this article is to describe how self-monitoring contributed to measurement reactivity in a randomized clinical trial (RCT). The implications of measurement reactivity on self-monitoring and suggestions for minimizing its effect will be discussed.

Design—The study involved a secondary data analysis of responses from 145 participants who completed a 12-month long RCT. The original sample consisted of 202 community-living adults with long-term indwelling urinary catheters.

Methods—The data analyzed were from the participants' brief responses to the final study question concerning their perceived study participation value. The data were discussed and coded iteratively until three researchers reached consensus. At the end, each item was recoded into eight categories and minor codes.

Findings—Our belief that the calendar was the probable cause of reactivity was not fully supported as the control group also learned about paying attention to urinary catheter problems by the questions asked through the seven bimonthly interviews.

Conclusions—The calendar and interview questions were reactive by increasing participants' self-monitoring of catheter problems. Specifically, the frequent interviews exposed participants to catheter-related concerns and provided them with ideas as to how to better manage them.

Clinical Relevance—This article provides insight related to the internal validity threat of measurement reactivity in RCTs and gives suggestions to reduce its effects.

Keywords

Measurement reactivity; secondary data analysis; self-management self-monitoring; self-reported data

Self-reported measures, such as diaries, checklists, interviews, or surveys, are common in behavioral interventions. In randomized clinical trials (RCTs), the use of these measures can

lead to internal validity concerns due to the testing effects (i.e., Hawthorne effect or measurement reactivity) that these measures may elicit. McCambridge, Witton, and Elbourne (2014) operationalized the Hawthorne effect by describing it as the testing effect that occurs when participants are assessed by being directly observed, made aware of being studied, or asked to report on their behavior by answering questions. Measurement reactivity is a special case of the Hawthorne effect that specially focuses on the processes by which repeated measurement leads to changes in the participants being measured (French & Sutton, 2010; Shadish, Cook, & Campbell, 2002). Specifically, the measures themselves may inform the study participants of the intended behaviors being evaluated and in turn influence the achieved results. This can create questions regarding whether or not the intervention was effective (Gravetter & Forzano, 2009).

In a 1-year randomized trial teaching self-management skills to 202 people with long-term indwelling urinary catheters, both groups appeared to have improved. The research team attributed this to an increase in self-monitoring (awareness and observations or recordings) caused by use of the catheter calendar, but this conclusion was not supported by data from the study. The improvements of decreasing symptomatic catheter-related urinary tract infection and catheter blockage over the 12-month study were clinically meaningful in both the control and intervention groups (Wilde et al., 2015). Importantly, similar improvements were not observed in a prospective observational study of 34 catheter users of the same population who were assessed bimonthly over a 6-month period (Wilde et al., 2010), causing the researchers to wonder what contributed to both groups' improvements in the 12-month RCT.

The unintended improvement in the control group compelled the researchers to try to determine its potential cause, specifically whether the calendar or other factors caused behavior changes in the participants. We believed that the catheter calendar, used to record catheter problems, could have contributed to self-monitoring and in turn measurement reactivity in the control group. The answers to the final open-ended interview question for both the experimental and control groups were analyzed. The question asked was,

Now that the study is over, what can you tell us about how it went? Please tell us whether it was worth it to you to be in the study and why? (Note to interviewers: Describe in participant's words as much as able.)

This is a discussion of the data analyzed from the responses to this question, the measurement issues in self-reported data, implications related to self-monitoring, and suggestions for minimizing this testing effect in repeated measures studies, particularly self-management RCTs.

Background

Self-management clinical trials often use self-reported data for health status, health indicators, and healthcare utilization outcomes. Several recent Cochrane reports on self-management show low to moderate benefit in outcomes for conditions like osteoarthritis (Kroon et al., 2014), asthma (Peytremann-Bridevaux, Ardit, Gex, Bridevaux, & Burnand, 2015), and type 2 diabetes (Pal et al., 2013). In a meta-analysis of outcomes related to

behavior, physical and psychological health, and healthcare utilization, based on the Stanford Chronic Disease Self-Management Program (CDSMP) literature from 1999 to 2009, researchers suggested small to moderate effects in studies measured at baseline and at 6 and 12 months (Brady et al., 2013). In this review of the 23 studies, 9 were RCTs and the rest were longitudinal pre- and post-research. The CDSMP has been tested in multiple studies, including clinical trials for specific conditions like arthritis using peer leaders (Lorig, Ritter, Laurent, & Fries, 2004), for varying chronic conditions in online programs (Lorig et al., 2008) or for evaluating healthcare utilization (Ahn et al., 2013). Recently, significant improvements were found in health indicators and healthcare utilization in a study of people with different chronic conditions using mailed materials in a pre-post design (Lorig, Ritter, Moreland, & Laurent, 2015).

Self-reported data, such as those used in self-management research, may be particularly vulnerable to measurement reactivity. This is particularly true when the methods or repeated assessments used to measure a certain phenomenon promotes unexpected self-monitoring, which in turn culminates in changes in the behaviors of the individuals being measured (Darwin, McGowan, & Edozien, 2013; French & Sutton, 2010). For example, asking participants about catheter-related issues might cause them to pay more attention to their catheters, which they otherwise might not have done.

Self-monitoring is defined as an iterative process of increased “(1) awareness of bodily symptoms, sensations, daily activities, and cognitive processes and (2) measurements, recordings and observations that inform cognition or provide information for independent action or consultation with care providers” (Wilde & Garvin, 2007, p. XX). Self-monitoring is believed to contribute to better self-management of chronic conditions (Riegel, Jaarsma, & Stromberg, 2012). Therefore, intervention research in self-management often uses strategies to measure participant behavior that may increase self-monitoring and in this way become reactive. For example, the use of a recording device in measuring self-regulation may alter the study participant's behaviors or thought process by causing him or her to consider issues he or she may have previously neglected to examine (French & Sutton, 2010). Reactivity occurs through the mechanisms of self-appraisal, validation, and seeking support (Darwin et al., 2013). Self-appraisal involves self-assessment behavior (increased ongoing awareness) and can thereby impact study outcomes. Validation of participants' feelings, struggles, and experiences also can cause measurement reactivity by helping participants to realize that they are not alone in what they are going through. Lastly, measurement tools may influence participants to seek support from healthcare providers or family members.

In assessing measurement reactivity, it is important to determine if the noted reactivity solely adds “noise” to the gathered results or if it adds bias to them (French & Sutton, 2010). If a measure causes the scores in both control and experimental groups to consistently increase, this may only represent a source of variance, which may not be problematic to the interpretation of the results. However, result bias may occur if “(a) measurement is confounded (mingled together) with intervention/treatment; (b) the measurement otherwise interacts with intervention/treatment; (c) there is neither confounding nor interaction with intervention, but there is shifting of the absolute level of measurement gathered” (French & Sutton, 2010, p. 462). Information on the prevalence and magnitude of measurement

reactivity has been found to be inconsistent, given that some trials have not found any effects on outcome data, while others report small effects (McCambridge, Butor-Bhavsar, Witton, & Elbourne, 2011).

Measurement confounding occurs when measurement reactivity functions in the same manner as the intervention (French & Sutton, 2010). For example, the use of self-recording devices like pedometers or calendars to record behaviors may lead to increased self-monitoring (French & Sutton, 2010; Nelson, Boykin, & Hayes, 1982). This in turn can inhibit the ability of the intervention to cause observable changes in behaviors in comparison to the controls. When measurement effects are as large as the intervention effects, it is important to assess and learn which underlying mechanisms are causing these effects.

The interaction of measurement with intervention can occur when there is a limit to the amount of behavior a person is willing to carry out. Thus, if both the intervention and control groups increase in a specific behavior, then the intervention may be unable to cause any more increase in that behavior. In other words, the measurement effect may inhibit an additional intervention effect (French & Sutton, 2010). Lastly, if measurement reactivity causes a specified behavior increase, it can cause a ceiling effect, which will reduce the possibility of an intervention effect being elicited.

Keeping in mind the different ways that measurement reactivity can affect study results, the aim of this article is to determine the contributing factors of measurement reactivity in an RCT teaching self-management skills to persons with long-term indwelling urinary catheters. In discussing measurement reactivity, we will also address ways to determine what is causing both the control and experimental groups to improve or change. Furthermore, we will consider what steps could be taken to reduce reactivity.

Parent Study Description

The purpose of the parent RCT was to test whether a self-management intervention could decrease catheter problems and whether these changes were mediated by self-efficacy or self-management behaviors. The study was conducted from 2008 to 2012, with data collection from June 2009 until August 2012. The sample, all with long-term indwelling urinary catheters, included 51% men who were diverse in age (19–96 years old) and race (57% White, 30% Black, 2% American Indian or Alaskan Native, 2% biracial, and 9% not known). Eleven percent were of Hispanic ethnicity. The sample was composed of 56% with urethral and 44% with suprapubic catheters. The participants were highly disabled, with 60% of them needing help in completing activities of daily living such as dressing, bathing, toileting, and getting out of bed; 19% also needed help with eating. Attrition was similar in both the intervention and control groups, and 74% completed the full 12 months of the study. Several publications provide additional information about the study related to the main findings (Wilde et al., 2015), the study sample at baseline (Wilde, McDonald, et al., 2013), and a description of the intervention (Wilde, Zhang, et al., 2013).

There were two study sites: one was a large home care agency (with an active research branch) in a large metropolitan area in a northeastern state of the United States and the other

was a university site in the same state composed of urban, suburban, and rural regions. Human subjects' approval was obtained at both sites' institutional review boards in a synchronous approach. Participants gave informed written consent prior to participating.

The primary RCT study outcomes were reports of (a) treatment of catheter-associated urinary tract infection (CAUTI), (b) blockage of the catheter defined as a lack of urine flow within the catheter lumen, and (c) accidental catheter dislodgement or its falling out. Several follow-up questions were asked about these outcomes, including the presence or absence of 16 possible CAUTI symptoms and whether the participant was hospitalized or went to rehabilitation after being hospitalized for CAUTI. Secondary outcomes included having sediment in the urine, leakage of urine around the catheter (bypassing of urine), bladder spasms, catheter pain, and catheter-related care practices, such as irrigation of the catheter (Wilde, McDonald, et al., 2013).

The blinded data collectors (different people from the study nurses) were trained together, monitored for quality, and met with one another and the research team through regular monthly conference calls. A written script was used for each question. For both intervention and control groups, data were collected through a home visit at the beginning of the study (prior to the randomization) and through six bimonthly phone interviews, lasting about 30 to 45 min. Explanation of the data collection process was provided to participants, including the use of “show cards” (with a list of several possible answers). A 1-year catheter calendar and a simple code for problems and treatments were used in both groups to aid in recall and facilitate phone interviews. Problem codes were: U for urinary tract infection, D for accidental dislodgement of the catheter, and B for blockage (meaning urine not flowing within the catheter lumen). Treatment codes were: A for antibiotic, O for extra office visit, HV for extra home visit, ER for emergency room visit, H for hospitalization, and R for rehabilitation stay (related to residual effects from the CAUTI). Data collected at baseline involved the use of questionnaires related to demographics, catheter self-efficacy and self-management, quality of life, and catheter problems. At months 2, 4, 6, 8, 10, and 12, our catheter problems questionnaire (Wilde, McDonald, et al., 2013) was administered, and at 6 and 12 months, the catheter self-efficacy and self-management questionnaires (Wilde et al., 2015) were used.

Besides data collection, the control group only received their routine catheter-related care through their regular providers, for example, nurses from a home care agency, physician or nurse practitioner office visits, or both. The experimental group received, in addition to data collection, three home visits by a trained study nurse. These visits included two visits in the first month a week apart, followed by a phone call 2 weeks later and a “booster” home visit at 4 months. Each visit lasted about an hour. The aim of the first visit was to teach participants on the use of (a) the 3-day urinary diary, which included measuring fluid intake and urine output and noting urine color and character; and (b) the journal for the recording of self-monitoring observations and catheter-related problems. The second home visit, which took place 1 week later, included a discussion about the information recorded and suggestions for improvement or action. A 20-page educational booklet was reviewed in depth, with emphasis on maintaining optimal fluid intake and preventing catheter dislodgement. The educational booklet included an overview of basic catheter self-

management, tips from catheter users (quotes collected from catheter users from other studies), 11 chapters of strategies to prevent or resolve common catheter problems, a urine color chart, and a “sources of caffeine” sheet. All areas of the booklet were reviewed, but the emphasis was on a discussion of the participant's problems and suggested strategies and goals. Progress toward goals was acknowledged and reinforced to develop self-efficacy (i.e., confidence in participant's catheter management).

Group differences through general estimating equation analysis were found only in the first 6 months of the study for blockage favoring the experimental group (Wilde et al., 2015). Rates of primary outcomes per 1,000 catheter days, however, showed that both groups improved from baseline over the 12 months of the study for CAUTI, blockage, and dislodgement. For instance, CAUTI decreased in the experimental group from 6.93/1,000 catheter days to 4.89 (or a decrease of 29%) and the control group went from 5.5/1,000 catheter days to 4.12 (which was a 25% decrease). For blockage, both groups improved from baseline: the experimental group from 9.26 to 4.76/1,000 catheter days and the control group 11.05 to 6.04/1,000 catheter days. Dislodgement decreased in the experimental group from 2.8 to 2.06/1,000 catheter days and the control group went from 4.3 to 2.6/1,000 catheter days (Wilde et al., 2015).

Methods for the Current Analysis

In this secondary analysis, the principal investigator (PI) and students brainstormed about possible threats to internal validity that may have caused the control group to have significant improvements in the measured catheter outcomes. As reported in the main findings publication, we concluded that power was adequate to determine group differences, group differences were found for blockage in the first 6 months, attrition was similar by group over time, and both groups had clinically significant improvements as reported in rates from baseline through the 12-month study (Wilde et al., 2015). To determine what else might have contributed to reactivity, if it occurred, we analyzed: (a) whether the calendar was used differently by the experimental and control groups; and (b) whether other factors might have influenced outcomes, such as the occurrence of history or contamination effects of the intervention into the control group. Because participants were asked whether they had a catheter problem (i.e., blockage, CAUTI), we used the dates of their occurrence to determine whether the calendar was used. The PI of the RCT and two doctoral students analyzed the qualitative data acquired from the responses to the final study question about the value of their participation in the research: “Now that the study is over, what can you tell us about how it went? Please tell us whether it was worth it to you to be in the study and why.” There were 145 entries, 71 from the experimental group and 74 from the control group. Data were entered into SPSS version 19 software (IBM Corp., Armonk, NY, USA), verified by the study coordinators and data analyst, and downloaded into a table format for coding. The PI identified 14 initial codes and then trained the students on how to complete the coding on all responses. Based on several iterations of discussions and further coding between PI and students, the larger categories of codes were reduced to eight, with several minor codes identifying content further. The coding team then met four times during meetings lasting an hour or two to thoughtfully recode each of the items into these eight categories, and separating the codes into each of the two treatment groups (i.e., intervention

and control groups). Delineation of final code assignment for each comment was determined by reaching consensus during these discussions. Many comments included content that fit into several codes. In a few instances, individuals made contradictory statements, showing that there were parts of the study that were perceived as positive and other parts that were negative. The group evaluated such comments to discern their meaning as best as possible. Interpretation of the differences and similarities in treatment group responses were drafted and agreed upon by all authors. Key quotes were identified to illustrate the findings. The final manuscript included input from all authors.

Findings

Analysis of Group Differences

Missing dates for blockage or CAUTI occurrence was an indication that the calendar was not used in these instances, despite the participants' report of the occurrence and frequency of these catheter-related problems. Details on blockage, including dates of the events, were asked only on the first four blockages per participant (131 events), and a few individuals had blockage as often as 20 times in 2 months. Recorded dates were missing for 1.8% of the reports of the first four blockages in nine individuals, six in the experimental group and three in the control group. These included 19 blockage events recorded as “don't know” (15 events in experimental, 4 in the control group) and 5 events recorded as “refused to answer” (all in control group). Only three dates for CAUTI were missing as “don't know” in three individuals, one in the experimental group and two in the control group. Therefore, we believe that the groups were similar in their use of their calendars for reporting blockage and CAUTI events.

Analysis of Final Study Question From Both Groups

The final seven codes are represented in Table 1. While not very different, the control group's comments included a few more responses about paying attention, a key concept of the intervention (13 responses in intervention vs. 16 in control). For example, a participant from the control group stated: “the things in the study that I was not paying attention to, now I'm good paying attention to it. I'm paying attention to what's going on more, like kinks.” From an intervention participant, the following comment was received: “It helped me to stay ‘on point’ and to pay close attention to my catheter. I now know more about my catheter. Things that I did not imagine I have control of [e.g., urinary tract infection, blockage].” The next statement, from an individual in the control group, showed the value of the calendar in self-monitoring and for interacting with the physician: “It helped me to see the benefit of writing things down. It was helpful when I met with my doctor to know the dates of problems and possible reasons why.” A participant in the intervention group shared a similar sentiment: “The calendar was helpful in showing the MD the patterns of infections. It enabled the urologist to see a unique pattern of organisms and infections.”

One striking difference was in how many more people in the control group commented specifically about the interviews (i.e., 6% intervention and 23% control). There were only three comments from the experimental group about the questions from the interviews needing refinements or being a burden, whereas eight participants in the control group

provided this type of feedback. Six comments from the control group were about the questions “making you think.” Some of the participants in the control group identified that they had learned about or to pay attention to the catheter in general “from the questions” asked by the interviewers. One person in the control group talked about this in relation to increased awareness, which is a key component of self-monitoring, by saying: “Just the questions in the interviews helped [me] to be alert to many things in how to look at my day-to-day activities ... [and] helped me to be aware.”

As seen above, it was not unusual for people from the control group to reflect our theoretical language about “paying attention” (i.e., increasing awareness). Some also seemed to know about the content of the intervention, possibly based on the questions we asked. The following comment illustrates key components of what was taught in the intervention about monitoring fluid intake and assuring the correct catheter position. We heard this comment from a person in the control group: “I learned to pay close attention to my catheter. I learned how to monitor the intake of fluids and the position that my catheter is supposed to be.”

Whereas the control group talked about how the interview questions helped them learn, the experimental group talked about their confidence or reassurance, using study information for daily catheter care and communicating with healthcare providers. Both groups made comments about valuing the research in general, feeling valued through talking about the catheter, and perceiving that the researchers appreciated them and that they were not alone in dealing with catheter problems.

Discussion

As an alternative to our belief that self-monitoring reactivity might have occurred in the control group, we considered whether history (changes in practice) or contamination of the control group occurred. This study is believed to be the only one like it on self-management, and providers would not have had access to the intervention information except as nurses at the Visiting Nurse Service of New York. These nurses might have seen the educational booklet and diary used in the experimental group. However, given the nurses' familiarity with blinded study protocols, it is unlikely that they breached the RCT guidelines.

Recognizing our goal in this study of analyzing responses to the final question in the RCT, we discovered that it was not just the calendar that contributed to the changed behavior in the control group, but also it is likely that the repeated (seven) interviews in 12 months had an impact on thinking and behavior on many participants. Thus, our belief that it was the calendar that caused increased self-monitoring (awareness and observations or recordings) and interfered with group outcome differences was not fully supported. Based on the comments, we now believe that the seven interviews over 12 months also contributed to the increased self-monitoring and resulting reactivity. The persons in the study might have changed their behavior because they heard information repeatedly about catheter self-care during these interviews.

Although the groups did not differ much in their responses to the last question about the study, many comments seemed to reflect their group assignment and how they interacted

with study personnel, either with interviewers for data collection or with both interviewers and study nurses. For example, it seems logical that participants in the control group made more comments about the interviews because the interviews were the only contact they had with the study personnel. But we were surprised that some people in the control group used the theoretical language of the study (e.g., self-monitoring). The instruments on self-efficacy and self-monitoring were administered only three times, at baseline and at 6 and 12 months. However, there were many items on these questionnaires and perhaps some participants recalled the language.

Comments related to the bimonthly interviews that were “making you think” most likely reflected the self-monitoring that occurred in relation to the participant's awareness of what to notice based on the question content as this type of comment was received six times in the control group and only once in the experimental group. We noted that there were slightly more comments in the experimental group (see Table 1) related to study concepts of confidence, using the information for daily catheter care, and communication with healthcare providers. Thus, the experimental group responded to our final question with more details about increased awareness of what to notice (self-monitoring) and self-management activities.

In this RCT, the calendar and bimonthly interviews were considered confounding variables, as they seemed to lead to an increase in self-monitoring behavior in the control group, thus threatening the researcher's ability to find observable differences in the treatment group (French & Sutton, 2010). As in other research (Barta, Tennen, & Litt, 2012), the participants' access to calendar recordings may have raised awareness of their individualized catheter-related concerns and motivated them to not only seek additional advice or help from their healthcare providers, but also start taking better care of their catheters.

Suggestions to Decrease Reactivity in Intervention Research

Because only a 3-day urinary diary of fluid intake and urinary output and journal notations was used in our single group pilot study ($N = 11$; Wilde & Brasch, 2008), we were not aware of the calendar's potential to impact outcomes through measurement reactivity; hence, we did not consider asking the participants about what they learned from the calendar or interviews. In hindsight, we acknowledge that our design was possibly affected by use of a calendar, which was meant only to improve recall for the interviews. When researchers plan studies using potentially reactive measures, such as those in self-reported data collection, they should acknowledge this potential issue and take steps to minimize it (French & Sutton, 2010). One way to reduce measurement reactivity is to do pilot testing and eliminate instruments that may have ceiling or floor effects (Becker, Roberts, & Voelmeck, 2003). Another commonly used method to minimize measurement reactivity is concealing the purpose of the study. However, this method could be difficult to implement in studies with self-reported measures. Such measures require participants to understand the questions and then engage the self to respond to them (Knowles & Byers, 1996). To prevent some level of reactivity, the interviewer should avoid providing any feedback related to the nature of the study that could be revealed in the questions.

Measurement reactivity can be examined by conducting a Solomon four-group design, which allows the researcher to estimate a wide range of effects on the intervention (Barta et al., 2012; French & Sutton, 2010) and test the study's internal validity (McCambridge et al., 2011). In this type of design, study participants are randomly assigned to four groups: experimental and control groups that are assessed and experimental and control groups that are not assessed (McCambridge et al., 2011). A caveat to this type of design is that it can be a costly one, given its need for a larger sample size to achieve statistical power (French & Sutton, 2010; McCambridge et al., 2011). If this type of design is not feasible, then in order to prevent indeterminate results, it is essential to certify that the expected effect size for the intervention is more than the mean effect size correlated with measurement alone (Godin, Sheeran, Conner, & Germain, 2008).

Limitations

The limitations of this study in evaluating measurement reactivity include that we did not systematically assess the frequency of calendar use by the participants and we did not consider pilot testing it. Also, because we expected a short response in this final question, we did not capture a full description of how people viewed their participation. We believe that (a priori) we should have included a number of randomly selected persons from each treatment group to be interviewed at the end of the study as a component of our evaluation of the RCT. In-depth qualitative analysis might have helped us better understand the mechanism by which our measures (bimonthly interviews and calendar) might have contributed to self-monitoring reactivity.

Summary and Conclusions

We believe that measurement reactivity occurred and that both groups were affected not only by use of our calendar (to improve interview accuracy), but also from the content in the seven bimonthly interviews. While RCTs often are considered the gold standard for intervention research, there are limits in self-reported data often used in self-management research because self-reports inherently involve self-monitoring, which can affect measurement results. We offer several suggestions to minimize this threat to validity, particularly in RCTs in which both groups must by design receive identical measures, often through questionnaires and interviews.

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Clinical Resources

- International Continence Society Nurses' Committee.
<http://www.ics.org/committees/nursing>
- Wiki. [https://en.wikipedia.org/wiki/Reactivity_\(psychology\)](https://en.wikipedia.org/wiki/Reactivity_(psychology))

Table 1

Responses to Question at the End of the Study

		Intervention group (<i>n</i> = 71)	% of <i>n</i>	Control group (<i>n</i> = 74)	% of <i>n</i>
1. Overall value	Worth it—beneficial/helpful	58	61/71 = 86%	61	62/74 = 84%
	Interesting	5 ^a		5 ^a	
	Helped aides/family	1		1 ^a	
	Neutral—not bad, ok	2	9/71 = 13%	8	16/74 = 22%
	Did not learn anything new/no catheter problem	4		2	
	Did it for the money/incentive	3		3 ^a	
	Aides/family do catheter care	0		3	
	Not knowing results	0		2 ^a	
	Not worth it	1	6/71 = 8%	5	6/74 = 8%
	Differing expectation/disappointment	6 ^a		1	
2. Paying attention	Paying attention to catheter, awareness, monitoring intake of fluid and position or self (independence)	11	13/71 = 18%	12	16/74 = 22%
	Through question	0		2	
	Keep track of catheter and problems/use of calendar	2		2	
3. Learning	Learned about catheters or body	3	27/71 = 38%	17	23/74 = 31%
	Learned through question	0		4	
	More information or educational	18		0	
	Confidence/reassured/validated	5 ^a		3 ^a	
	Use information towards the daily care of my catheter	3 ^a		1 ^a	
	Improvement	1		1 ^a	
	Helped me to communicate with doctors and nurses	3	7/71 = 10%	3	4/74 = 5%
4. Communication	Have a good relationship with doctors and nurses	1		0	
	Learned to be more proactive and prepared	3		1	
	Voice/talking about catheter	4	9/71 = 13%	4	11/74 = 15%
5. Feeling valued	Appreciate researchers caring about them/helping to find solutions	5		7	

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	Intervention group (<i>n</i> = 71)	% of <i>n</i>	Control group (<i>n</i> = 74)	% of <i>n</i>
6. Sharing information	Sharing information about self and catheter	1	3	29/74 = 39%
	Others with catheters dealing with similar problems	1	1	
	Helping others—recognize research benefits others with catheters	24	25	
7. Interviews	Needs refinement/repetitive	2	5	17/74 = 23%
	Burden/not comfortable	1	3 ^a	
	Questions relevant, make you think	1	6	
	Interviewers professional	0	4	

^aThe responses provided by a particular participant fit into one or more subcategories within a category. Thus, the final cumulative number in the percentage column may not equal the sum of each subcategory.