ABSTRACT
Participant reactivity – a phenomenon in which the responses and/or behaviors of study participants are affected by their awareness that they are part of a study – is often deemed to be a potential threat to the research validity of a study’s findings. However, a growing number of studies report that research processes that engender participant reactivity may actually lead to important benefits both for participants (e.g., therapeutic benefits) and researchers (e.g., deeper understandings and more relevant and actionable findings). This mutually beneficial situation can help to maximize a different type of validity termed “street validity” by Greenwood (as cited in Boudah & Lenz, 2000; 2003), which directly relates to research impact.

This paper reports findings from a longitudinal mixed-method investigation of the information behavior of people with type 2 diabetes, focusing on participants’ self-reports regarding whether/how they felt that participating in the study had influenced (or will influence) their behavior. Many participants described specific ways in which they found their participation helpful. For example, they reported that it led to decreased denial, increased self-awareness, and improved motivation to look for and make use of diabetes-related information. This paper explores the potential trade-off between research validity and street validity within a qualitative study and posits that, as was the case with this study, important lessons can be learned as a result of directly questioning participants about whether/how their participation in the study influenced them and that these lessons can perhaps be implemented within the context of applying the research findings in assisting other people from the study population.

INTRODUCTION
Participant reactivity is often characterized as one of the major problems that can plague researchers, casting doubt on both the validity and reliability of their findings. In fact, Krathwohl (2004) lists reactivity as one of the types of threats to external validity that can result from obtrusive data collection methods, such as participant observation, interviews, and experiments. Krathwohl further describes the potential effects of obtrusiveness and the resultant participant reactivity, including the “I’m special!” or the Hawthorne effect, the hypothesis effect, the guinea pig effect, and the novelty effect. The Hawthorne effect, in particular, has “long been regarded as the ‘Achilles heel’ of participatory-based research” (Coombs & Smith, 2003, p. 97).

However, some recent studies have suggested that research processes that engender participant reactivity may actually lead to important benefits both for study participants and researchers – therapeutic benefits for study participants and deeper understandings and more relevant, useful findings for researchers. These benefits have been mentioned within the context of several different disciplines and in association with several different data collection methods. For example, several researchers (Aldridge & Stevenson, 2001; Beck, 2005; Hutchinson, Wilson, & Wilson, 1994; Morecroft, Cantrill, & Tully, 2004; Ortiz, 2001) have found that the interviewing process can lead to deeper understandings for the interviewer, while simultaneously resulting in therapeutic benefits for interviewees. Similarly, another group of researchers (Birch & Miller, 2000; Clarke, 2006; Colbourne & Sque, 2005; Gale, 1992; Harper & Cole, 2012; Shamai, 2003) have found that the process of member checking (in which a researcher consults with their participants in order to confirm his/her understanding) not only helps to improve the validity of the findings of a study, but also can result in therapeutic benefits for the research participants. Family therapy researchers Harper and Cole (2012) indicate that they found
the member checking process “to be beneficial to all parties involved in ways that proved to be far beyond the promise of methodological quality control” (p. 515). Learning disabilities researchers Boudah and Lenz (2000) similarly posit that the research process is often an “unregarded intervention” and emphasize, “By acknowledging, explaining, and capitalizing on research processes, researchers can facilitate more relevant and useable outcomes” (p. 149).

This paper describes a longitudinal mixed-method study of the information behavior of people with type 2 diabetes that resulted in the related discovery that many of the study participants reported that they found the very act of participating in the study to be useful for them. While this finding could be, at least in part, due to participant reactivity and therefore be suspect, the fact that such a large proportion of the participants expressed this sentiment and so many of these participants were able to provide specific descriptions of the ways in which they found their participation helpful suggests it may be possible to derive some lessons from their descriptions of their experiences that could have important practical implications for assisting this population with their health-related information needs.

The initial goal of the study was to investigate the information needs and information seeking and use practices of people with type 2 diabetes and how these change across time as their experience with the disease changes and as their health-related information behavior evolves. The original research questions motivating this study were: (1) What are the factors that motivate or impede information seeking and information use by people diagnosed with type 2 diabetes?; (2) What are people’s information needs and information seeking and use practices in relation to diabetes?; (3) What sources and types of information do people with type 2 diabetes find useful?; and (4) How do the answers to these questions transform over time, as people’s experience with, and knowledge about, diabetes undergo important changes?

The goal of this paper, however, is to discuss the findings that pertain specifically to the reasons that participants found it useful to participate in the study. Thus, the research questions addressed by this paper, which were formulated post hoc based on my experience collecting the data for this study and subsequently analyzing the data gathered, are:

1. What kinds of benefits did study participants report garnering from their participation in this study?
2. How might our knowledge of these benefits be used to improve our ability to help people with type 2 diabetes with their needs for information?

The next section of this paper provides a three-pronged literature review. The first prong briefly defines and describes consumer health information behavior and the important role it can play in enabling people to cope with and manage a serious illness. The second describes some of the various forms of participant reactivity that may occur when a researcher is using more obtrusive forms of data collection, such as interviews. The final prong describes some studies that have found that research processes that may engender participant reactivity may actually lead to very important benefits for both researcher and participant.

Following the literature review, the research design for the study is described. Next, the findings that pertain to participants’ perceptions regarding the influence of their participation in this study on their affect, cognition, and behavior are presented. Then the potential implications of these findings for the ways in which we might best help people with type 2 diabetes with their information needs are discussed. In conclusion, it is suggested that although reactivity is often unavoidable and may impact the research validity of a study’s findings, directly asking participants at the close of a study about any reactivity that may have occurred throughout the course of the study may actually help to improve street validity by yielding valuable information that can be used to inform and improve practice, and thus, the impact of our research.

LITERATURE REVIEW

Consumer Health Information Behavior

Consumer health information behavior (CHIB) encompasses people’s needs for health-related information, as well as the ways in which they look for, manage, share, and make use of this information. CHIB can play a significant role in influencing the trajectory and ultimate outcome of a person’s illness. The ways in which a person interacts (or fails to interact) with information throughout the course of an illness impacts the amount and quality of information they have available to them when they need to make health-related decisions, and thus, influences the quality of these decisions. In turn, the many health-related decisions a person makes and the actions they do or do not take throughout their journey with an illness impact how their trajectory unfolds and their ultimate health outcome.

Many empirical studies of CHIB have confirmed the crucial role that information seeking and acquisition play in helping people to cope with being diagnosed with and managing a life-threatening illness (e.g., Ankem, 2006; Clark, 2005; Hack et al., 1994; Lazarus & Folkman, 1984; Mills & Davidson, 2002; Wong et al., 2000). However, people’s perceptions regarding how active they wish to be about information seeking and about participating in making health-related decisions vary not only across individuals, but also across time and situation for any one individual (Butow et al., 1997; Degner et al., 1997; Eheman et al., 2009; Hack et al., 1994). Similarly, the types of information people need (Clark, 2005; Degner et al., 1997), as well as the types of sources they consult (Ankem, 2006; Chesser & Anderson, 1975; Gollop, 1997; Harris & Dewdney, 1994; Luker et al., 1996; Mills & Davidson, 2002; Wathen, 2006), also tend to change across time. Furthermore, people’s perceptions of the usefulness of
information change as their concerns change (Wilson, 1973), as their problem (or how they define their problem) changes (MacMullin & Taylor, 1984), as their situation (or how they perceive their situation) changes (Dunne, 2002; Schamber, 2000), as different stimuli in their environments become relatively more salient (Johnson, 1997), and as their beliefs and attitudes change (Barry, 1994).

The findings from this study suggest that, for many participants, participating in this study was a form of CHIB and these participants found the very act of participating in this study to be useful to them in a variety of ways. This paper discusses whether we can learn valuable lessons by investigating why participants found their participation in the study to be useful, despite the fact that the research validity of the study’s findings (including those pertaining to participant reactivity) may be diminished due to the potential influence of participant reactivity.

**Participant Reactivity: What is it?**

In studies which employ obtrusive data collection methods, such as interviews, focus groups, and experiments, various forms of reactivity may occur among participants as a result of their awareness that they are being studied. This section describes some of the most commonly discussed forms.

One of the most famous forms of reactivity is what has come to be known as the “Hawthorne effect”. From 1924 to 1932, a series of experiments was carried out at Western Electric’s Hawthorne plant to find out if improving the lighting at the plant resulted in improved worker productivity. While the researchers found a great deal of evidence for this finding, they also found that the reverse was true – decreasing the lighting also resulted in improved worker productivity. Researchers from Harvard University were brought in to supervise a second set of experiments in order to investigate what the original researchers deemed to be a problem with the reliability of their methods of measurement. They recruited a small sample of workers and reached the same finding – no matter what types of changes they made to the work environment of these workers, their productivity improved. It was concluded that workers’ improved productivity was actually due to a feeling of “I’m special!” that developed among workers simply because they were being given special attention. This phenomenon has been dubbed the “Hawthorne Effect.” (Beins, 2004; Gobo, 2008; Krathwohl, 2004)

Another form of reactivity known as “hypothesis guessing” or the “deference effect” relates to the demand characteristics of a study. In this form of reactivity, participants attempt to ascertain what the researcher is trying to find and then adjust their responses in an attempt to be helpful to the researcher. For example, subjects participating in an experiment investigating the efficacy of a new drug may try to discern the expectations of the experimenter and then try to tailor their verbal responses to be consistent with these expectations. (Beins, 2004; Bernard, 2000; Krathwohl, 2004)

Two other types of participant reactivity – evaluation apprehension and the social desirability effect – are present when participants calculatedly respond or behave in ways that they believe will reflect well on them. Beins (2004) further points out that evaluation apprehension may result in study participants behaving in ways that are consistent with prevailing stereotypes. (Beins, 2004; Bernard, 2000)

Another form of reactivity is the novelty effect. Study participants may respond positively to an intervention simply because it’s novel. In contrast, however, some participants may respond negatively because they believe that the intervention may be harmful and they do not want to serve as a guinea pig (Krathwohl, 2004).

The problem with all of these forms of reactivity is that they can be difficult to completely prevent and their occurrence can threaten the research validity of a study’s findings and, thus, any conclusions drawn therefrom. Researchers who collect data via experiments can institute control groups to ascertain the impacts caused by these various forms of reactivity. Qualitative researchers, on the other hand, often have less ability to gauge reactivity and its impacts; however, they may actually be able to not only gauge reactivity and its impacts but also obtain valuable information by directly questioning study participants after the study about the occurrence and specific manifestations of these various forms of reactivity within their own participation experiences. In fact, it is proposed here that what researchers learn from such follow-up questioning may have much wider applicability and significance than just within the context of the study itself and may be used to help to inform and improve real-world practice.

**Participant Reactivity: Is it all bad?**

Recently, some studies have appeared within various disciplines that focus on the research process as an intervention that, while potentially leading to participant reactivity, may also lead to important benefits for study participants and deeper understandings for researchers. For example, Morecroft et al. (2004) conducted a follow-up questionnaire with 25 patients with hypertension several months after conducting in-home interviews with them. These researchers found that participating in the interviews had led participants to develop a broader understanding of the condition, including new understandings about how to manage it, even though no medical information had been provided by the interviewer. Furthermore, seven interviewees indicated that the interview had led them to consider changing their behaviors (e.g., exercising more) in order to improve their ability to manage the condition.

Nursing researchers Hutchinson et al. (1994) compiled an extensive list of benefits identified by people who had participated in in-depth interviews regarding their health. These included catharsis and a sense of relief, feeling validated, feeling a sense of purpose through being able to potentially help others facing a similar situation, becoming more self-aware, and feeling more empowered. Participants
in some situations, such as those who are dying or those who have experienced incest may feel that no one wants to hear their story; these individuals, in particular, may feel that the research interview has given them a voice — giving them an (perhaps their first) opportunity to tell their story and to be listened to with respect. Some participants in in-depth research interview studies have even reported feeling that the interview process itself was healing for them.

Similar findings regarding the benefits of participating in research interviews were obtained by Ortiz (2001) who conducted a series of interviews with the wives of professional athletes to learn about their marital and overall life experiences. Some of these interviewees “experienced a cathartic process of self-revelation and an introspective process of self-discovery” (p. 192). Ortiz emphasizes that he, in turn, learned much more than he had hoped to from these interviews and that information regarding his interviewees’ processes of self-revelation and self-discovery added another dimension to the data he gathered.

Such research participation benefits have been found even in studies that have been conducted completely online. For example, Beck (2005) found that her qualitative e-mail interviews with women who had experienced birth trauma led to important affective benefits for them, such as a feeling of being cared about, listened to, and empowered, as well as cognitive benefits, such as a clearer understanding of what they had experienced and an improved ability to make sense of their experience. Furthermore, they felt their participation had given them a voice and they highly valued the opportunity to help other women in the same situation.

Consulting study participants to find out about the types of benefits they feel resulted from their participation in a study can yield important discoveries for the researcher that can potentially be used to inform practice-based decisions. As Ortiz (2001) states, “We can learn a great deal more about those we are studying from the ways in which they define their participation in our qualitative studies and from how they describe what they personally gain from the process. Their insights are worthy of our attention, and we should give them greater consideration” (p. 214). Such information can improve our ability to ultimately make a meaningful difference in the lives of, if not our direct study participants, at least other members of the populations from which they were drawn. And while this information may be deemed evidence of the decreased research validity of our findings, it can simultaneously (and arguably, more importantly) serve to increase the “street validity” (Greenwood (as cited in Boudah & Lenz, 2000)) of our findings and the ultimate impact of our research. Using this information in this way can help to improve the state of affairs described by Greenwood (2003): “Too often, researchers have asked and answered questions with little practical value. Too often, solutions developed by researchers have been unwieldy and unsustainable” (p. 468).

The possible tension between research validity and street validity is directly addressed by nursing researcher Munhall (2010), who writes: “The therapeutic imperative of nursing (advocacy) takes precedence over the research imperative (advancing knowledge) if conflict develops” (p. 492). However, research and street validity are not necessarily mutually exclusive. In fact, researchers can seek to maximize both types of validity by: (1) paying attention to research validity, especially while designing their study and collecting data from participants; (2) assessing the research validity of their findings through direct inquiry of their study participants (among other methods); and (3) capitalizing on what they learn from their participants in such a way as to also maximize the street validity of their findings, and thus, the ultimate impact of their research.

METHODS

Recruitment
Participants were recruited using three different methods, including an online ad posted on a clinical health studies Website, flyers posted in a local hospital and associated clinics throughout the county, and flyers handed out at in-person diabetes-related support group meetings. In order to participate, people had to be at least 18 years old, currently residing in Southeast Michigan, and have been recently diagnosed with type 2 diabetes, started on insulin for this condition, and/or developed a diabetes-related complication. The latter requirement regarding either a recent diagnosis or a recent exacerbation was instituted to ensure the salience of the topic in participants’ minds.

Data Collection
A series of two interview sessions were held with each participant between July 2010 and April 2011. Thirty-four people participated in initial sessions. At the initial session, a background questionnaire was administered to collect demographic information from participants, as well as information about their experience with computers and the Internet and about their experience with type 2 diabetes. Following the background questionnaire, a semi-structured interview was conducted. The protocol for this interview was developed, in part, based on Dervin’s (2003) Micro-Moment Timeline Interviewing Technique. During this interview, participants were asked to talk about their experiences with type 2 diabetes before they were diagnosed, during the diagnosis process itself, and after the diagnosis. Questions focused mainly on participants’ information needs, seeking, and use; however, questions pertaining to related physical, cognitive, affective, and social factors were also included in order to get a more contextualized picture of each participant’s diabetes-related information behavior. After the interview, participants were asked to think aloud as they completed a health condition questionnaire, which used 5-point Likert-type scales in order to gather participants’ ratings of their health, their feelings about their health, and their relevant information behavior. Lastly, five card-sorting exercises were conducted with participants in order to get their assessments of how
useful various sources and types of information had been to them in helping them to learn about diabetes, as well as how often various motivations had spurred on their diabetes-related information seeking. An “Other” card was provided for each exercise so participants could write in and rate sources/types of information and/or motivations not already included in the decks of cards.

Approximately four months following the initial interview session, all 34 participants were contacted to set up a follow-up session. Thirty-two (94%) agreed to participate; one participant had since passed away and one had become too ill to participate. The follow-up session began with a semi-structured interview which included some repeat questions (in order to permit cross-time comparisons), as well as some novel questions that mainly focused on getting an updated picture of the participant’s experience with type 2 diabetes and gaining a more complete understanding of how the participant was defining usefulness and what sources and types of information they had found particularly valuable. Following the interview, participants were asked to think aloud as they constructed a timeline depicting any important points that had occurred along their journeys with diabetes. Although a list describing the types of things they might like to include was provided, it was emphasized that they should include whatever they felt had been an important part of their journey. The follow-up session concluded with a re-administration of the same health condition questionnaire and card-sorting exercises.

Data Analysis
Interview sessions were audio-taped in their entirety and then transcribed. Transcripts were imported into NVivo 9 for qualitative data analysis. Three codebooks were developed, including two structural codebooks and one thematic codebook. The thematic codebook was developed deductively based on a literature review focused on empirical studies of CHIB, as well as inductively based on all of the data gathered as part of this study. The thematic codebook was developed and iteratively revised as data collection and data analysis progressed.

FINDINGS
This section provides a description of participants and reports findings related to participants’ perceptions as to whether and how participating in this study had influenced (or will influence) them. For complete findings from this study, please see my dissertation (St. Jean, 2012).

Participants
The 34 people who participated in the initial interview session were quite diverse in a number of respects. For example, 41% (n=14) were men and 59% (n=20) were women. They ranged in age from 32 to 81, with a mean of 53.4 (SD=10.6) and a median of 52. Regarding educational attainment, participants were evenly divided as to whether they had some college or less versus an associate’s degree or higher. Approximately one-third (n=12; 35%) of the participants were employed, four (12%) were unemployed, ten (29%) were disabled, and eight (24%) were retired. Participants held a wide variety of occupations, including cashier, construction laborer, housekeeper, juvenile detention parole officer, pediatric surgeon, and secretary. More than three-quarters (n=26) of the participants had a computer and Internet access from home. Only five (15%) said they did not use the Internet at all, from any location.

Participants were initially diagnosed with type 2 diabetes between 1980 and 2010, with the majority (n = 19; 56%) diagnosed in 2009 or 2010. Participants were asked to report the result from their most recent A1C test (a blood test that yields a three-month average blood glucose level) at both their initial and follow-up interview sessions. At the time of the initial interview sessions, participants’ most recent A1C test results ranged from 5.6 (considered good blood glucose control) to 14.0 (considered an unhealthily high level of blood glucose) (Healthy-ajoas.com), with a mean of 7.8 (SD = 2.0). By the time of the follow-up sessions, the range remained stable (5.5 to 14.0), but the mean decreased to 7.3 (SD = 2.0). To illuminate the importance of this one-half point drop in the average, a one-point drop can decrease a person’s risk of experiencing microvascular complications (i.e., complications having to do with the eyes, kidneys, and nerves) by 40% (National Center for Chronic Disease Prevention and Health Promotion, 2011, p. 10). While just one participant reported an A1C of less than 6.0 at the initial interview sessions, five did so by the time of their follow-up sessions. Although two participants experienced a dramatic increase in their A1C’s (I04’s A1C increased from 6.2 to 13.8 and I20’s increased from 11.5 to 14.0), several participants experienced dramatic decreases (e.g., I09’s A1C decreased from 14.0 to 8.2, I33’s decreased from 11.7 to 6.7, I32’s decreased from 11.3 to 8.0, and I19’s decreased from 7.5 to 5.8).

Influence of Participating in this Study
At the close of their follow-up interview, participants were asked whether they felt that participating in this study had influenced (or will influence) their behavior in any way. Although the way in which the question was phrased emphasized changes in participants’ behavior, this (luckily) did not impede them from mentioning any ways in which they felt the study had influenced them. Of the 32 participants who completed both interview sessions, 25 (78%) reported that their participation in the study had influenced them in some way. Nearly all of these participants indicated that they had found participating in the interview sessions to be helpful and provided concrete information about what they found helpful and why. The benefits that participants described can be roughly grouped into cognitive and affective, although some of the benefits they described (such as helping to decrease their denial) more accurately span both categories.

Cognitive Benefits
Many participants described cognitive benefits they felt they had derived from participating in this study. For some,
this pertained to bringing them out of their denial about having diabetes. I15, for example, stated, “[The denial] went all the way until like right after we had our first meeting… That’s when I kind of realized… When we first met… Because you was asking me all them questions, [it] kind of made me aware of everything that I’m not thinking about it.” Other participants felt that it helped them to become aware of topics they hadn’t yet thought of. I34 described, “I think it helps because… you ask a lot of questions… So it makes me think more about different things that I might not think of ever… subjects that I wouldn’t come up with on my own.” This participant went on to explain, “Nobody else really asks questions so much as they tell you, ‘This is what you need to do’… Maybe just the questions, like I said, just opening up doors that maybe weren’t opened by anybody else’s questions.”

For some participants, the cognitive benefits stemmed from having the opportunity to learn and become more self-aware by listening to themselves. I17, for example, stated, “I’ve said things that maybe I didn’t even know… There’s something being drawn out of me that helps me know myself… This has been a discovery for me… I’m learning something from this.” I31 similarly described, “[Participating is] making me be more aware of myself and circumstances and knowing that I can help somebody, make a difference in someone else’s life.” I09 emphasized, “I feel like these interviews have made me a little more… aware of my attitudes and my journey.” Speaking specifically about the timeline exercise, I20 stated, “You made me think. You made me sort out some issues, organize my thinking… And… whenever you flesh things out with somebody else, it helps you to focus. And it just helps you to articulate really what’s going on inside.” I21 described the impact of participating in this way: “Basically, it just let me see what I’m thinking a little bit… now that it’s on paper. Kind of like doing a journal except what you’re doing is writing in it first instead of after you get done.”

Some participants felt that the interview sessions were helpful because they were confirming of their knowledge and/or behavior. I28 described, “I think this was a very informative study. And it brought my attention to… Even though I didn’t know a lot about diabetes… through this study… I have been gathering [that] I’ve been pretty much doing the right things to learn about diabetes.” I22 similarly stated, “I think it’ll make me aware of that I give more information than I think I do, that I do more than I think I do. I think it did make me aware that I do have more purpose than I think I do.”

Some of the cognitive benefits that participants mentioned had to do with certain aspects of information behavior, such as an increased awareness of their information needs and information seeking practices and/or of the various types of information resources available. Several participants emphasized that their participation made them more aware of having diabetes and of their diabetes-related information needs. I14, for example, said that participating in the initial session was a turning point for him in his journey with diabetes: “[The initial interview session] raised my awareness of… my diabetes… I don’t think about getting questions answered or anything like that… I really never thought that way until the first interview when you were asking me these questions. They just made me think.” I03 described, “This was really helpful for me too in terms of kind of bringing up things that I hadn’t really thought of or put a finger on… It’s been useful to me… I kind of identified some things that I’d like to find out more about… so it’s been helpful.” I13 similarly stated, “You’ve added to my list of questions.” I30 indicated that participating in the study helped to raise their awareness of potential sources of diabetes-related information. I11, for example, said, “I think [participating] makes me more knowledgeable about some of the sources… It definitely made me think more about how do people get information about medical stuff.” I14 said of his initial interview session: “It was a turning point… It kind of opened my eyes… at anything in particular other than the fact that there are resources.”

Based on their experiences during their interview sessions, particularly during the card-sorting exercises, some participants concluded that they could be doing more about getting diabetes-related information. When I15 was rating the usefulness of various types of diabetes-related content, she exclaimed, “Wow! See, you’re just showing me what I need to do… I’m going to have to do some studying, ain’t I? This makes me feel bad to know I ain’t done none of this.” When working on the card-sorting exercise pertaining to the various types of motivations that may have driven them to look for diabetes-related information, I03 stated, “Deal with my emotions about diabetes… To get information about that… Never. I need to do. Some of my never’s are the things that I need to do.” I16 and I18 had similar reactions to particular cards in this card-sorting exercise. I16 stated, “Keep up to date on new discoveries, treatments… I should, but I really haven’t.” I18 similarly stated, “Learn what I can do to improve my health and/or prevent disease. You know what? I never even thought about that… Probably not… I should.”
**Affective Benefits**

Many participants found the interview sessions to be helpful emotionally. Some simply appreciated being able to talk about their experience with diabetes and having someone listen without telling them what to do. I01 described, “I appreciate [it]… because I can’t always tell my daughters things… And my sisters, they just don’t always want to hear it or they got their own problems or they may think that I’m not doing things right.” I17 similarly stated, “It was helpful, yeah. It feels like you listen to me. I think people want to preach at you and you’re supposed to take it all in… I find it satisfying to meet with you. It’s like a one-on-one thing and I like that… I don’t think you can get enough support.” This participant further stated, “It’s just been really nice to talk to somebody one-on-one. You don’t seem judgmental… And it feels good to air it, say things.” She also said that participating “builds my confidence as far as the diabetes is concerned.”

A handful of participants emphasized that their participation made them feel good because they felt that they were helping other people by sharing their experiences. Describing how participating in this study had influenced him, I23 stated, “I think I might talk a little more to other friends that I have that have diabetes and talk to them a little more about it… to learn from them, teach them… I’m going to talk to my sons that are overweight and say, ‘Hey, you got to do something about this weight situation or you’re going to catch it.” I28 said he would be more likely to participate in future studies, explaining “Hopefully, it will help somebody on down the line by… The information gathered about my experience can be passed on.” I35 described, “Someone… doing the actual research of it makes me feel… like I’m adding to help like children later on… It makes me feel like in a small way, I’m helping. But the research is not small, it’s huge.”

Some participants even found participating to be therapeutic. I01, for example, stated “It’s therapeutic… I think it helps me out, especially lately when I’ve been so kind of upset with my doctor and just things aren’t going… I think it was a little therapeutic for me.” I34 stated, “I found… that actually just talking to somebody about stuff [helps]… As far as putting it on an emotional level… how it is affecting me, how do I feel about it, I probably talk to you more than anyone… I have my own little therapy.”

Another way in which participating was perceived to be helpful was that it motivated some participants to look for and/or make use of diabetes-related information. I29 described the influence of participating in this way: “I think I will be a… probably more active searcher… Just the focus and attention on information and how I use it and what I value in the information that I seek… I think it will enhance my information collection behavior.” I14 similarly described: “I think I’m more compelled to get information, raise questions to the practitioners… I think some of that I had thought about from time to time, but not always. But I think from this point on, I’ll definitely be seeking more information… Be a little more conscientious.”

Participating in this study motivated some participants not only to seek more information, but also to use this information to better manage their diabetes. I03 stated, “When you talked about these things, I think I was a little bit more motivated to get information [and]… to follow that information.” I18 described, “After… our interview, I started looking up more information… Changed my diet just after that, too… I became more carb-conscious, staying out of sugar, lowering my A1C, keeping my diet right… It made me put more thought and effort into it.” I17 felt that participating in the study helped her to rededicate herself to trying to manage her diabetes: “I think I need a renewal. Probably this conversation has prompted me to renew… I think with diabetes, you can level up and then you need to get excited about it again.” Referring to the longitudinal nature of this study, I33 stated, “It has motivated… The next time I have this interview… there will be progress and there will be more changes… ‘cause you hate to be doing interviews and interviews and we’re still stuck in the same, doing the same thing. It’s like what’s the sense of doing these interviews if you’re not going to change?”

**DISCUSSION**

The specific benefits that participants felt they derived from participating in this study echo many of those identified by the researchers mentioned above. Like Morecroft et al.’s (2004) participants, the participants in this study described developing new understandings about the disease and considering (and, in the case of this study, even verbally committing to) changing their behaviors so they could better manage the disease. Many of the benefits mentioned by Hutchinson et al. (1994) were also identified by the participants in this study, such as appreciating the opportunity to share their story, becoming more self-aware, feeling more empowered, and finding the interview process therapeutic. Also, like Ortiz’s (2001) participants, many of the people who participated in this study reported feeling that the process of participating was one of self-discovery for them. And similar with Hutchinson et al.’s (1994) and Beck’s (2005) participants, participants in this study also mentioned that they valued this opportunity to help other people facing a similar situation.

Some of the novel benefits identified by participants in this study concerned their information behavior in particular, such as increased awareness of their information needs, information seeking processes, and the diabetes-related information resources available to them, as well as increased motivation to look for and/or use information in order to better manage their disease. These benefits, and the implications of these benefits, will be explored further in the remainder of this paper.

Participants’ comments regarding the ways in which they felt that their participation in this study had influenced them (or would influence them in the future) may result, at least
in part, from various forms of participant reactivity (such as the Hawthorne effect, hypothesis guessing, or the novelty effect). Furthermore, this reactivity may threaten the research validity of these (and other) findings. However, the thesis of this paper is that there are some potentially useful lessons we can glean from participants’ responses and perhaps implement within the context of helping this population with their information needs. Analyzing what it was about the interview sessions that participants found helpful and why suggests ways in which healthcare providers, information professionals, and family members and friends can better assist members of this population.

One of the central findings yielded by this study was that participants may, at times, be what I term here “incognizant”; that is, they may be unaware of their information needs and thus unable to recognize the potential relevance and usefulness of information. Over time, the presence, extent, and nature of incognizance changed. As a result, participants sometimes did not have, or were unable or unwilling to make use of, information at the time when it could be of the most use to them. For some participants, their incognizance only began to fade as they developed new physical symptoms or after they had experienced a very severe diabetes-related complication, such as having a stroke or going into a diabetic coma. In retrospect, these participants were able to see that they had had information needs of which they had been unaware and even though they sometimes had relevant information earlier in time, they had been either unable or unwilling to perceive its relevance and to act on it at that time.

One way in which participants perceived their participation in this study to be helpful to them pertained directly to incognizance. For some, taking part in the study helped them to decrease their level of denial about having diabetes. It also helped them to focus, to organize their thoughts, to realize that they have (or should have) questions, and to identify what the questions are – what it is that they don’t know, but need to know. It introduced them to topics that they hadn’t known about or thought about previously. In this way, it helped to increase their ability to perceive the relevance of information on these topics. Furthermore, participating in the interview sessions increased some participants’ motivation to seek out diabetes-related information, as well as to make use of this information and to more actively work on managing their diabetes.

Many participants indicated that participating in the interview sessions helped to increase their awareness of their diabetes-related information needs, the ways in which they seek out diabetes-related information, and the different types of information resources on this topic available to them. The card-sorting exercises, in particular, led some participants to conclude that there was more they needed to do to get diabetes-related information. On the other hand, some participants felt that the interviews helped to confirm that they are already doing the right things in terms of how they go about gathering diabetes-related information.

Another way in which participation proved helpful to participants was that participants benefited from the opportunity to talk about their experiences with diabetes and were able to learn from themselves and increase their self-awareness by listening to themselves speak. As pointed out by several participants, being asked how they are doing and being attentively and non-judgmentally listened to presented rare opportunities for them, as most of the people they encountered tended to tell them what to do and had little interest in, or patience for, listening to them talk about their experiences. Participants found the interview sessions to be therapeutic and felt they provided them with a form of support and helped to increase their confidence.

Directly asking participants about their perceptions regarding the ways in which their participation in this study influenced them yielded important information. As Ortiz (2001) found, this type of information adds another dimension to what you can learn from participants. For example, all of the different ways in which participants found the interview sessions helpful suggest a few guidelines for how we might help this population with their information needs. Ideally, information should be provided in a somewhat structured manner to ensure that people get introduced to key topics with which they are not yet familiar, thus helping to reduce their level of incognizance. It also needs to be provided in an ongoing manner, particularly in light of the fact that participants’ incognizance, along with their willingness and ability to perceive the relevance of information and to act on it, change across time. However, the just-in-time approach to information provision should be avoided due to the potential danger it can present. The potential usefulness of information changes over time – in order to ensure that a person has access to the information they need at the point in time when it can be of the most use to him/her, it is better to follow a much more proactive model. Current and likely future areas of incognizance need to be sensitively elicited or inferred and proactively addressed, to the best of the information provider’s ability.

Information provision also needs to incorporate interactivity. Purely one-way information dissemination robs people of the important benefits that can be derived from more interactive forms of information provision, such as the opportunity to learn from listening to oneself speak, the sense that one is being listened to, cared about, and taken into consideration, and increased motivation to look for and make use of information in order to better manage one’s disease. Information that fails to take the intended individual information recipient into account, that is not tailored to the individual and where he/she is at in the current moment cognitively, physically, socially, and emotionally, is more likely to be perceived as unwelcome, irrelevant, and/or unactionable, and simply discarded.

However, these findings also suggest that information provision alone is insufficient when helping this population with their information needs. Many participants needed
help with a wide range of information-related activities, including identifying their information needs, developing an awareness of where they can turn when they need information and of how to go about pursuing information, processing and understanding information, evaluating and verifying information, assessing the personal relevance of information, adapting information to increase its personal relevance for them, and enacting it in their own lives.

CONCLUSION
Participant reactivity often cannot be completely avoided when conducting research, particularly when using more obtrusive types of data collection methods, such as participant observation, interviews, focus groups, and experiments. However, research processes which engender reactivity may lead to important benefits for both study participants and researchers. Participants may find their participation to be cognitively and/or affectively helpful. Researchers may find that they can achieve deeper understandings and obtain findings that are more relevant and more readily translated into practice. Directly asking participants at the close of a study about their experiences in the study may lead to the discovery of important information that can help to inform and improve practice.

Although it is impossible to infer causation as many other things that were happening in participants’ lives may have contributed to both the overall decrease in their A1C’s and to the many benefits they attributed to their participation in the study, the proportion of participants that reported finding their participation helpful and the detailed nature of their descriptions of what they found helpful and why suggest that we may be able to derive useful information from their responses that we can use to improve our ability to assist them with their needs for personally relevant, actionable, and timely health-related information.

Research validity is often one of the primary criteria used in evaluating the quality of research. While research validity is extremely important in ensuring the truthfulness and believability of our findings, it is not always a sufficient criterion for ensuring our ability to translate our findings into relevant and helpful interventions for the people whom we hope will benefit from our research. Thus, the ultimate impact of our research may depend upon achieving a balance between research validity and street validity.

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