

# IPA as a Method for Identifying Education and Training Needs of Informal Caregivers

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## Abstract

Interpretative phenomenological analysis (IPA) is a qualitative research method that focuses on understanding, in detail, a person's lived experience. Principles from phenomenology, hermeneutics, and idiography serve as IPA's theoretical foundation for understanding meaning within a specific context. In this paper we describe how we used IPA to investigate how informal caregivers perceive and use remote monitoring technologies (RMTs) to help monitor and care for their family members who have dementia and are living at home. We describe the study with a particular focus on how we used IPA to analyze interview transcripts of four informal caregivers and identified education and training needs relative to making informed decisions about RMT adoption and use. Implications for researchers and educators who are interested in conducting and teaching IPA are discussed.

**Keywords:** interpretative phenomenological analysis, remote monitoring technologies, informal caregivers, dementia, needs assessment

## Purpose

Interpretative phenomenological analysis (IPA) is a qualitative research method that focuses on understanding, in detail, a person's lived experience. It draws from three philosophical perspectives including phenomenology (examination of lived experience), hermeneutics (interpretation of lived experience), and idiography (attention to particulars of individual stories). IPA is useful when the goal is to understand the process and meaning within a specific context (Smith, Flowers, & Larkin, 2009). The purpose of this paper is to describe how we used IPA in a study about how informal caregivers perceive the use of remote monitoring technologies (RMTs) to help them care for family members who have dementia and live at home (also known as age in place). We also discuss implications for researchers and educators who are interested in conducting and teaching IPA. While IPA was initially introduced in Europe as a way to address problems in health psychology, this method is becoming more popular in the United States and in other disciplines (Pietkiewicz & Smith, 2014; Smith & Osborne, 2015). Providing exemplars of IPA is important among the qualitative community to guide researchers in IPA selection and practice.

## Significance

While there are many descriptions of IPA and how to do an IPA study (e.g., Alase, 2017; Pietkiewicz & Smith, 2014), there are fewer exemplars of how it is actually conducted within

context and what decisions are made along the way. Jeong and Othman (2016) describe their IPA study exploring how international students in a doctoral program acquired second language academic literacy skills. In addition to describing the rationale for using IPA, they also offer insight into the methodological guidelines used to conduct the study. Wagstaff et al. (2014) describe how eight individual researchers used IPA ranging from topics of workplace commitment, living with spinal cord injury, working in higher education, and issues related to health and body image. By sharing their experiences, they offer insight into the strengths and weaknesses of IPA in various contexts.

Descriptions of how IPA is applied from the researcher's perspective are useful because they provide insight into how IPA can be interpreted and applied in creative and flexible ways to address important questions across disciplines and in various contexts. The corpus of literature about how IPA is conducted can also help those who are mentoring novice researchers and enable them to identify the necessary skills in their apprentice and guide them in conducting richer, more in depth, and meaningful studies.

### **Background of the IPA Study**

Informal caregivers are family members and close friends who are typically unpaid to provide support ranging from regular phone calls to check in on their loved ones to a more hands-on role of providing assistance with activities of daily living. Examples of activities of daily living include bathing, dressing, shopping, managing money, providing transportation, and administering medication. Informal caregivers often play an integral role in helping their loved ones live at home and "age in place" (Jaschinski & Allouch, 2019). RMTs are technologies that can sense, record, and communicate various activities of older adults who are living in their homes. Examples include wearable sensors such as personal emergency response pendants or bracelets, smartphone apps that provide mobile emergency alerts, sensor-embedded furnishings such as floor mats, remote video monitoring devices, and telepresence robots. Use of RMTs can benefit informal caregivers and care recipients alike (Hwang, Truong, & Mihalidis, 2016). Education and training interventions could potentially help informal caregivers learn more about the types of RMTs available along with their advantages and disadvantages so that they can make informed decisions about adoption and use. Our research question was: How do family caregivers perceive RMTs and their use for monitoring and supporting their care recipients who are living at home?

### **Data Source (Population, Sample, Setting) for the IPA Study**

Participants included informal caregivers (e.g., adult children, spouses, partners, and siblings) of one or more older adults who live at home. Approval from our university's Institutional Review Board (IRB) and informed consent from participants were obtained prior to data collection. We administered a short survey via email and social media to gather preliminary data regarding the population of family caregivers and their current perceptions and use of RMTs. We used snowball sampling (Gay, Mills, & Airasian, 2009) and recruited participants by first sending email requests for participation to acquaintances. To increase the number of survey responses, we followed up by sending requests for participation through our personal networks on LinkedIn and Facebook. We received 38 survey responses. The results of the survey were used to get a sense of the current context, recruit those who were interested in participating in a follow up interview, and develop an interview guide that was used for an in-depth analysis of this target group's lived experiences.

Seven semi-structured interviews were conducted in person, by phone, and via Skype, a web conferencing tool. Prior to the interview, participants were asked to complete a verbal informed

consent. Each interview ran approximately 45 minutes to one hour. We used an interview guide (Appendix A) that consisted of a series of open-ended questions to learn about the interviewees' unique caregiving experiences. We also sought to learn more about their perceived use of existing RMTs, including perceived benefits and risks, and their concerns about adoption and use.

Each interview was audio recorded and transcribed into word-processed text by Rev.com a transcription service. Pietkiewicz and Smith (2014) recommend "In IPA it is necessary to audio record the interview and produce a verbatim transcript of it" (p. 11). To protect participant anonymity and personal information, informed consent that included the participant's full name was audio recorded separately from the interview. Only the recording of the interview was sent to the transcription service. Also, codes were assigned to audio recordings prior to transcriptions and pseudonyms were used in the reporting to protect the participants' identities. All audio files and transcriptions were securely stored in a password-protected folder in the first author's Microsoft OneDrive.

Four of the seven participant transcripts were selected purposefully for data analysis because each of these four participants was caring for a loved one who had some degree of cognitive decline. Smith et al. (2009) recommend using a small, homogeneous sample for IPA in order to examine a phenomenon in depth. Therefore, the other three transcripts were excluded from the analysis.

## Researcher Backgrounds

The first author, Martha Snyder, has 25+ years combined experience in learning technologies, user-centered design, and project management. Her interest in technology and design solutions for the aging population started in 2002 with her doctoral dissertation, which focused on the design of online learning communities for older adults. Since 2005, she has cared for multiple adult family members in her home. These experiences, in particular, inspired this research, and taking an interpretive stance (afforded through IPA) toward understanding the caregivers' lived experience appealed to her as a qualitative researcher.

The second author, Laurie Dringus, has 25+ years in research, teaching, and practice in human-computer interaction (HCI). Her background in information systems (IS) and psychology enable her to study the impacts of the use of technology in various contexts. Her research blends HCI, IS, and computer-mediated communication (CMC), focusing on understanding the complex nature of human interaction in technology. Her interest in this study focuses on usability and human-centered design of RMTs.

Both Martha and Laurie have applied IPA within the contexts of education, information systems, and human-computer interaction in their own and their students' research. They continue to learn and develop their IPA skills through their reflection in and on practice (Schön, 1983).

## Conducting IPA

IPA was used to analyze the interview data. Smith, et al. (2009) stated, "IPA is concerned with the detailed examination of human lived experience" (p. 32). IPA is useful when the goal is to understand the process and the meaning within a specific context as opposed to specific or concrete outcomes, causes, and consequences. For example, Osborne and Smith (1998) conducted a study with persons who have chronic back pain. IPA enabled a deeper account of the participant's experience. Hunt and Smith (2004) explored the personal experiences of four caregivers of stroke survivors to capture and report a rich and detailed representation of their experiences. Here the purpose was to explore informal caregivers' experiences and understand how they perceive RMTs and their use for monitoring and supporting their care recipients.

Smith et al. (2009) propose the following general steps for data analysis:

1. immersion in the data by reading and re-reading the transcripts,
2. initial noting,
3. development of emergent themes,
4. searching for connections across themes,
5. moving to the next case and repeating steps 1 through 4, and
6. looking at patterns across cases.

Analysis of data was a recursive process involving a transition of focus from “the particular to shared and from the descriptive to interpretative” (Smith et al., p. 78). The data analysis process entailed reading and analyzing the transcripts in an iterative way to identify themes that were unique to each participant and themes that were shared by all participants. We went back and forth within and across cases making descriptive comments and interpreting what was described—moving “between the emic and etic perspectives” (Pietkiewicz & Smith, 2014, p. 11).

Given the exploratory nature, we maintained an open stance throughout the research study. Chenail (2011) describes how qualitative researchers are like journalists. Both aim to have “open-ended inquisitiveness” (p. 1717). For example, we were open to how our interpretations of the data might shift as we listened to the audio recordings, re-read the transcripts and became more familiar with the informal caregivers’ stories. That is, we were open to what we might find in the data through our descriptions and interpretations of the interview transcripts. Smith et al. (2009) also recommend keeping an open mind when making initial notes. They suggest making notes about “anything of interest within the transcript” (p. 83).

### Initial Noting

Smith et al. (2009) distinguish between three types of initial noting or exploratory commenting including descriptive (noting keywords and phrases), linguistic (use of pronouns, pauses, metaphors, repetitive use of words, etc.), and conceptual comments (parts of the participant’s account that may prompt further questions). Figure 1 is an example of our initial noting of Cara’s (pseudonym) transcript using Microsoft Word. As we read and made our initial notes, we also developed coding conventions. For example, CR=care recipient and CG=caregiver. Descriptive comments were in normal text, linguistic comments were noted in italics, and conceptual comments were underlined. In addition to making notes in Word, we also made notes by hand. Figure 2 is an example. The purpose of showing both examples is to emphasize the iterative nature of analysis. Even after we made our initial notes in the Word document, we continued to go back to the original transcript to understand and interpret what was said. Both types of notes were used to develop emergent themes.

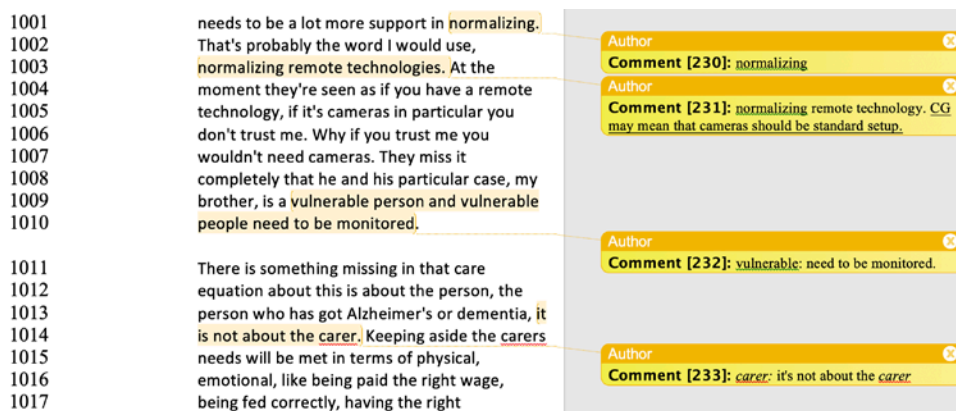


Figure 1. Example of initial noting from Cara’s transcript in Microsoft Word.

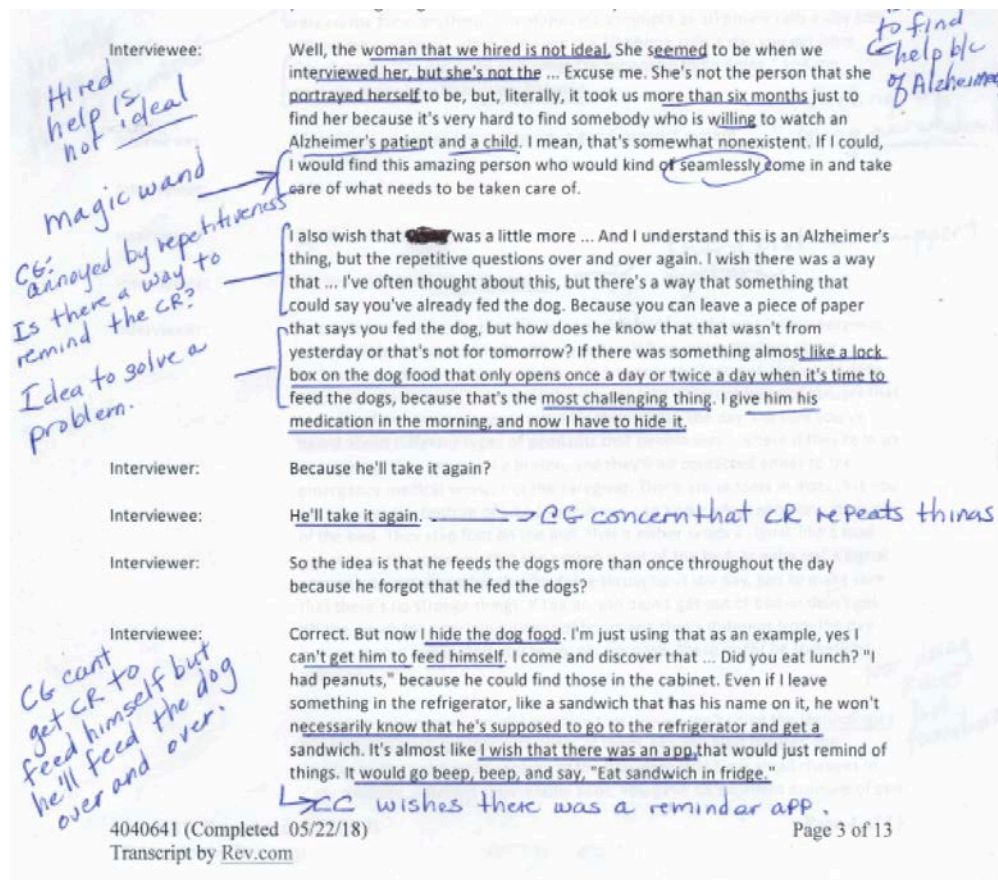


Figure 2. Example of initial noting by hand from Lucy's (pseudonym) transcript.

## Developing Emergent Themes

The process of developing emergent themes involved looking through the transcripts again paying attention to the exploratory comments, as well as what was learned through the process of reading, re-reading, and making initial notes. Smith et al. (2009) describe this process as taking more charge of the data by organizing and interpreting it. They warn that the researcher might feel awkward about this process since the initial noting was driven more by what was presented in the transcript or more “participant-led” (p. 91). However, an important tenet of IPA is the double hermeneutic loop or “dual interpretation process” (Pietkiewicz & Smith, 2014, p. 8). While participants aim to make meaning of their experiences, we attempt to translate or interpret that meaning so that we can share it with others. Table 1 is an example of how we developed emergent themes based on our initial noting.

## Searching for Connections Across Emergent Themes

The process of searching for connections across emergent themes involved looking at themes across cases, determining which themes stood out so as to produce a more organized format for presenting the salient parts of participants' accounts (Smith et al., 2009). This process enabled us to identify key themes within each transcript.

Table 1. *Developing Emergent Themes*

<b>Theme</b>	<b>Key Words</b>
Caregiver Concerns	isolation/no help (feelings of frustration and being overwhelmed); finding good help (concerns relating to willingness to care, competence, potential mental abuse); maintaining dignity and respect (feeling useful, feeling independent, dignity through appearance-second-hand perceptions); technical ability (lack of technical knowledge/skills; declining cognitive function); acceptance of wearables
Remote Monitoring Technology (RMT) Benefits	Peace of mind (facilitates communication, help/support, and observation); self-efficacy as a caregiver; feelings of independence (both caregiver and care recipient)
Remote Monitoring Technology (RMT) Risks	Invasion of privacy (intrusion on care recipient's personal space, access to personal information/data, intrusion on caregivers' personal space); security of information; false sense of security (RMT features, technology confusion/misuse/non-use); confusion with technology; distraction (time-consuming, value uncertainty)
Adoption and Use Needs	Access to information (information access, difficulty finding needed information, format preference, website usability); cognitive decline, cost, training on the technology, normalizing RMT use, the caregiver as the educator

### ***Looking for Patterns Across Cases***

Once key themes were identified in each case, the next step was to look for patterns across cases (Smith et al., 2009). Wagstaff et al. (2014) point out the challenges with this step noting it felt like it drew researchers away from the idiographic underpinning of IPA. They suggest a resolution to this dilemma might be to identify a “super-ordinate theme for each participant in addition to common, group themes” (p. 6). In Table 2, we provide an example of our approach to this step. We chose to identify the group themes (column 1) and if there were unique qualities within the themes, we would find exemplary quotes that represented those qualities (column 2). In column 3, we presented our interpretation of the theme given the unique qualities that were identified.

### ***Researcher Bias and Reflexive Journaling***

Because phenomenology is a key underpinning of IPA, we must be concerned with researcher bias. Phenomenology is an eidetic method that requires the researcher to describe a phenomenon how it appears rather than how it fits into a particular framework or body of knowledge. The researcher, as an active participant who is trying to understand an experience from the participant's perspective, must bracket his or her perceptions and pre-conceived notions (Pietkiewicz & Smith, 2014). Maintaining a reflexive journal is one way a researcher can be mindful of his or her biases (Orange, 2016). Figure 3 is an excerpt from Martha's journal, which reflects her feelings and apprehensions about analyzing the transcription data. Writing these feelings on paper helped her to be more cognizant about the times she chose to immerse herself in the data and analyze the transcripts.

Table 2. *Looking for Patterns Across Cases*

<b>Theme</b> (Qualitative Distinction)	<b>Events</b> (Exemplary Quotes)	<b>Meanings</b> (Interpretations)
Family Caregiver Connection	<p>“I think what’s challenging is the frustration of just being the only one of my family that does this, or supports this. There isn’t someone to relieve me as much.” (frustration)</p> <p>“Sometimes it’s as simple as 10 phone calls a day just asking me questions, which between the 10 phone calls you get from my husband going, ‘I’m not quite sure what I’m supposed to do...’” (overwhelmed)</p> <p>...</p>	<p>Caregivers can become frustrated and overwhelmed in their roles because oftentimes, all the work falls on them. They love and care so much for the family member that they want to help but this connection can stress them out even more.</p> <p>...</p>

### ***Reporting the Findings in an IPA Study***

There are many ways to write up an IPA study and Smith et al. (2009) offer guidelines for this process. Just as data analysis is an iterative process, so is the writing process in IPA. That is, analysis of the data continues as the researcher is writing the report. There is fluidity in the data analysis and reporting. Smith et al. (2009) remind researchers that in writing the report, they should represent “both the I and the P of IPA; IPA is a joint product of researcher and researched” (p. 110). This means that it is important to capture the individual voices of the participants while at the same time interpreting what they mean within the broader context of what’s being studied. We provide an example of how we plan to report the final findings for one of the themes, *tailored solutions*, in Appendix B.

### **Assumptions and Limitations**

Smith et al. (2009) point out, “the effectiveness of the IPA study is judged by the light it sheds within the broader context” (p. 51). Achieving this outcome assumes that the researcher is able to capture, make sense of, and interpret a person’s lived experience and report it in such a way that it makes a contribution to the larger body of literature about the phenomenon. Thus, patterns within particular areas can be studied through a meta-analysis of multiple IPA studies (Chenail, 2009). The value of IPA research is that it documents the nuances within the spaces of other quantitative and qualitative accounts. This type of endeavor requires time, skill, and commitment.

#### ***Time***

Conducting IPA is a time and labor-intensive process. It is also a creative process (Smith, et al., 2009). It involves focused concentration, creativity, and mental energy to listen and read the transcripts, make interpretations from participants’ experiences, and present results in a way that captures the whole but preserves the parts. Our goal was to be able to understand, interpret, and report the perceptions of informal caregivers and their use of RMTs as a whole, while at the same time reflect the nuances of the individual experiences. Perhaps with more time, we might have been able to dig deeper into the analysis and thus, produce a deeper level of interpretation (Smith, et al., 2009).

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I've been putting this analysis off for the entire summer. I need to get down and immerse myself and this takes physical and mental strength!

As I analyze the transcripts I keep finding myself wanting to jump to conclusions and write overarching themes. I need to remind myself to stay in the moment and follow the IPA process.

It can get emotional reading these transcripts because the interviewees are describing real struggles and expressing real pain. I'm not a psychologist so I'm not trained in how to take this all in. At the same time, I can empathize because personally, I've been through the same/similar situation as a CG for my mom and then

Figure 3. Example of reflexive journal entry—August 3, 2018.

### **Skill**

In IPA, the researchers' and participants' interpretation of a phenomenon is represented. Therefore, the level of expertise and experience the researcher has with certain skills such as interviewing (including building rapport, questioning, and listening skills), and writing will impact the richness and quality of an IPA report (Pietkiewicz & Smith, 2014). Being able to bracket one's biases so as to step freely into another person's shoes to experience a phenomenon is also important. However, problems addressed through IPA are oftentimes laden with emotions, which not only can impact the participant during an interview but also the researcher. Pietkiewicz and Smith (2014) point out that, we must be aware of how the participant is feeling and know



how to handle potentially difficult situations, although such situations are uncommon. They suggest counseling skills could be useful here. With regard to how the interview may emotionally impact the researcher, it is helpful to be aware of this possibility and know what tools we can use to help us manage it, such as using a reflexive journal and sharing such experiences with others on the research team.

### ***Commitment***

In IPA, there is a continuum of researcher skill sets and Smith et al.'s (2009) clear guidelines offer a useful entry point for researchers at all levels to learn and develop their craft. To this end, a commitment to the philosophical underpinnings of IPA and continuous learning and development of important skillsets can strengthen the rigor of IPA studies and broaden its acceptance across multiple disciplines and contexts.

## **Implications for Education, Educators, and Researchers**

IPA could serve as a useful method for future research in education, perhaps addressing topics where there is less of a need for making broad generalizations and a desire to explore a particular research gap with depth and detail in order to make an idiographic contribution to the literature (Hunt & Smith, 2004). We hope that this account of how we applied IPA and our perspectives as researchers will help other researchers and practitioners who are interested in doing and teaching this method.

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## **Appendix A**

### ***Interview Guide and Questions***

#### ***Usable Remote Monitoring Technologies: Informal Caregivers' Perspectives***

Name participant:

Assigned code or pseudonym:

Referral source:

*[Script begins.]*

#### **Introduction**

Hello, my name is [name of IRB-approved investigator]. I am glad you've agreed to be interviewed and I thank you in advance for your time. I want to explain how this will work. We'll do about a 45-minute interview that will be tape recorded and transcribed. Once transcribed, I will send you the transcription for your review to make sure that everything was captured accurately.

There are two parts of the interview.

In the first part, we will talk about your role as an informal caregiver and what that entails. Perhaps we can talk about for whom you provide care and how that came to be. You might describe a day-in-the-life as a caregiver in terms of what you do on a daily basis, how you interact with your care recipient, and what types of care and assistance you provide, etc.

The second part of the interview will focus on different types of technologies and how they might be used to help in the caregiving process. As technology continues to improve, new devices are entering the marketplace that can sense, record, and communicate various activities remotely. Caregivers are using these devices to help them monitor and support their care recipients.

When we scheduled the interview, you completed a verbal consent to participate in the study and you were sent a list of general interview questions. Do you have any questions about the verbal consent or the interview questions? *(Answer questions. If participants did not get a chance to review the questions, tell them that it's okay given this is a semi-structured interview and you will have specific questions based on their survey responses.)*

Okay, let's get started.

## **Appendix A**

### ***Interview Guide and Questions (cont'd)***

#### **Interview Questions**

The following questions are provided as a guide. Additional questions might come to mind during the interview process. At the same time, some of these questions might not be relevant in a given situation.

#### **Part 1: Life as an Informal Caregiver**

1. Tell me about your caregiving situation (e.g., for whom you care, how did the caregiving relationship come to be, etc.).
2. Regarding your caregiving relationship, what is a typical *day-in-the-life* like? What happens? How do you assist your care recipient? What kinds of tasks do you perform? Perhaps there is a specific day that you can walk me through.
3. What do you like best about being a caregiver?
4. What do you like least about being a caregiver?
5. If you had a magic wand, what would you change about your caregiving experience?

#### **Part 2: Perceptions and Use of Remote Monitoring Technologies**

##### ***Participants who are unfamiliar with RMTs***

1. In your questionnaire you mentioned that you were (unfamiliar) with various types of remote monitoring technologies. What interest (if any) do you have in learning how various technologies such as in-home medical/emergency devices, wrist-worn sensors or bracelets, etc. can be used to help informal caregivers monitor their care recipient(s)?
2. [If interest is expressed] What are you most interested in learning about these types of technologies? How do you envision using technology to help you with caregiving?
3. What do you perceive as benefits and risks of using RMTs in your particular situation?
4. What difficulties might you have helping your care recipient adopt and use RMTs?

## Appendix B

### ***Example of Final Findings for One of the Four Themes***

#### **Tailored Solutions**

While there were some commonalities in experiences among the cases, each family caregiving situation was unique. When considering how we can facilitate caregivers' ability to make decisions about adoption and use about RMTs, there are issues pertaining to availability and format of information, privacy and security, cost, and the progressive nature of dementia.

With regard to availability and format, Samantha expressed a preference for brochures in doctors' offices stating, *"So probably for me, the easiest place to receive information would be from, for example, if we had an emergency room visit, and someone would have given me a resource, or a tool, and said, 'Here are some things that are available. Here are some things that we participate in.' That might have been helpful. Maybe the doctor's office having brochures."*

Privacy and security concerns were also mentioned. When discussing potential use of remote cameras, Samantha stated, *"I think from her perspective, she more recently, over the past year or so, has been much more into a sense of 'I want my privacy,' and I think that she might have trouble with the idea of someone watching, to the extent that she would remember that it was in place."* Regarding security, Devon mentioned privacy and security are important to his wife and did not think she would accept any technology tied to the Internet because *"...she understands just how easily those systems can be hacked."*

Cost is another factor that concerns participants as it relates to RMT adoption and use. Samantha asked, *"Are any of them [RMTs] supported or sponsored? Or is there a testing? You know how sometimes you could go to, I don't know, a hairdresser in training, and it's cheaper?"*

Finally, there is a need for progressive education to follow a progressive condition such as dementia. Devon stated, *"I wish that some of the technology companies did the exact same thing so that when you get your diagnosis of Alzheimer's or you go back a year later and there's been a decline, such as our situation, they can hand you a packet."*